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1. 2006

1.1 February

The Beginning (2006-02-04 22:46)

In April of 2004, I had no idea what was ahead for me relative to my health. I had a routine physical at my local clinic with no problems. In May, I noticed that I had bad canker sores that seemed to replace the previous ones as they healed. In August, I had phlebitis, first undiagnosed in my left leg and then within a week more in my right leg. The second case was diagnosed as superficial phlebitis and treated with heating pad.

During all this period, I noticed that I was getting breathless, even after minor exertion such as climbing a flight of stairs. In October while raking leaves, I noticed being more tired and then that my right knee really hurt afterwards. I have had arthritis problems for many years and had arthroscopic surgery on my left knee twice, latest in 2002. My orthopedist recommended knee replacement surgery, which was scheduled for November 10.

The mystery begins (2006-02-05 19:34)

In my pre-op physical on November 5, my hemoglobin was first noticed as low and my breathing had become more labored. My doctor prescribed an Advair inhaler, thinking maybe I was getting asthma. During the week, I also developed lump in my lower abdomen. On Friday, November 12, the lump coupled with even more labored breathing resulted in my admittance to the hospital for tests.

That evening in the hospital, I was given a complete torso CT scan plus blood tests. The CT scan was difficult because I could not hold my breath long enough. Initial feedback was a spot on my lung, which later was determined from a second CT scan to be a blood clot (pulmonary embolism). The lump was just an ingrown hair (pseudofolliculitis), which was lanced and cleared up quickly. I went through EKGs, echocardiograms, ultrasound on legs and many blood tests. Blood tests finally discovered a lupus anticoagulant inhibitor and diagnosis of antiphospholipid syndrome (APS), also known as Hughes Syndrome. I was treated with heparin in the hospital from the first day and went home on the November 19th with a Lovenox heparin injection and a Coumadin blood thinner prescription. I also had oxygen at home for couple of weeks, but started work half time on December 1 and full-time on December 13th. My hemoglobin level was about 10.5 and platelets about 600 during this time.

Follow-up and referral (2006-02-05 21:50)

After several follow-up appointments while monitoring my Coumadin and INR levels, my hemoglobin was dropping further towards 10, but my platelet count improved to below 500. I was referred to a faculty hematologist at the University of Minnesota with appointment on January 18th. Another CT scan showed additional pulmonary embolism so I spent three days in the Fairview University hospital for additional heparin treatment and tests. I was switched to Lovenox heparin blood thinner and scheduled for a bone marrow biopsy (BMB) and colonoscopy in mid-February. During this time, an abscess was discovered on a front tooth and an old root canal was redone. During these days as the Lovenox was discontinued temporarily, I experienced another blood clot found by CT scan on February 28th.

The results of the BMB showed 95 % hypercellular activity in the bone marrow, which was producing maximum red blood cells, a sign of myeloproliferative disease (MPD). Problem was that these blood cells did not survive in the blood stream resulting in the anemia. It was a double-whammy with my oxygen intake affected by both the low hemoglobin (9 to 10) in my blood and the reduced blood flow through my lungs due to the multiple clots.

Mayo Consultation (2006-02-08 22:13)

Being from Minnesota and with strong encouragement from my family, I arranged for a consultation with Mayo Clinic in Rochester. I was there twice in May of 2004; first to get the general blood, lung and heart tests. My hemoglobin (Hb) level was down to 8.8 on the first visit and 8.4 two weeks later. A lung function test indicated operation at only 53 % due to both clots and anemia. An echocardiogram showed no evidence of pulmonary hypertension. I had a bone marrow biopsy and CT scan that confirmed the previous U of MN tests and my MPD unclassified diagnosis. The Mayo hematologist advised me to have my siblings tested for possible BMT. He also advised me to get my Hb tested the next week at my local clinic and also get my vaccinations updated. After comparing BMT programs between Mayo and the U of MN, I decided to stick with the U for further monitoring of my condition. Any BMT match was delayed in the meantime.

First transfusion (2006-02-09 20:43)

As a follow-up to my Mayo visit, I had my Hb checked at my local clinic and got my vaccination for tetanus and pneumovox. Hb was 9.2 and white cell count was 5300. The next day I got an infection in my upper right arm, a fever of 102 degrees and WC of 33,500. I was admitted to the hospital and treated with Zosyn IV antibiotics. My Hb went from 8.6 to 7.2 in one day at which point I had my first 2 units of blood transfused. My Hb only increased to 7.6 so the next day I received another 2 units of blood. I was discharged after 3 days in the hospital with an Hb of 9.5. Three days later my Hb was 11.5 when checked at the U clinic, but then down to 9.7 two weeks later.

Travel and clotting (2006-02-09 21:00)

On July 4th, I flew out to Boston and helped my daughter drive a Honda Civic with two cats back to MN. While we took three days, there were periods when I must have been too stationary, probably during a three-hour stretch through Chicago area in rush hour traffic. The day after I sensed increased shortness of breath. I went in for a CT scan and routine blood test. My Hb was 8.8 and my platelets had increased to a high of 690. Dr prescribed Hydroxyurea, 500mg per day, to reduce the platelets. The CT scan showed another blood clot in my left lung and I was admitted to the U hospital. Clot probably developed in my leg at moved up to the lung. My Hb had dropped to 7.7 after just 2 days on HU so I received another 2 units of blood. While in the hospital for 2 days, I also had an echocardiogram and ultrasound on my abdomen. My spleen, liver, kidneys and gallbladder all checked out OK. A few days later my INR had increased from an average of 3 to 6.7 and we started to measure Factor II, which was 15 %. My coumadin prescription was increased twice a week to 7.5 mg per day with 5 mg for other 5 days. Target Factor II is now 20 %.

Hydroxyurea effects (2006-02-09 21:24)

Over the next two months, the HU did reduce my platelet count from a high of 719 to 440. Unfortunately, it also affected my RBC and Hb, requiring another 2 unit transfusion on August 18th. Dr then prescribed Procrit (20,000 units once per week) to counter the HU and stimulate RBC generation. By Sept 7th, my Hb had dropped to a new low of 7.0. I got another 2 units of blood and was switched from the HU to Anagrelide (.5 mg twice a day).

Anagrelide, Blood changed (2006-02-09 21:46)

After switching to the AG, I experienced headaches, pulse pounding and even vision pulsing. The AG dose was reduced to just one .5mg per day and became tolerable. Unfortunately, the effects of the HU must have hung on while the Procrit had not kicked in. My Hb dropped further to 6.4 and my platelets reached a low of 331. I required 3 units of blood this time, less than two weeks after the last transfusion of 2 units.

Whereas the blood was matched previously in a few hours, it took 8 hours to match and the transfusion had to be continued the following day. Since the last transfusion, the blood bank reported that my blood type had changed from A+ to A- and that I now had antigens D & E as well. Later the blood bank reported antigen C as well.

Canker sores and heart OK (2006-02-10 23:53)

As I mentioned before, I had experienced canker sores in my mouth since May 2004. Shortly after I started on Procrit, I also read about a link between dry mouth, SLS based toothpaste and canker sores. I switched to Biotene toothpaste and my canker sores cleared up. Maybe this was also connected to the Procrit as well.

Anyway after the blood transfusions in September, I also had over 3 months being transfusion free. During this time, my reticulocytes increased from 4 % to over 12 % indicating the Procrit was working. My Hb actually increased to almost 10 though my platelets crept up to 529. Unfortunately, the canker sores came back in December.

I also switched hematologists since my original one moved out east. The new Dr had me checked out completely by a cardiologist since the Anagrelide is known to cause heart problems as a side effect. My heart checked out fine.

Not so good new year (2006-02-11 00:20)

I started out the 2006 New Year with a hemoglobin level of 8.6, platelet up to 529, Factor II down to 14 % and ferritin and blood pressure up as well. Within a week after feeling weaker, my Hb was down to 7.2 and I was admitted to the hospital for CT scan, another bone marrow biopsy and two more units of blood. This was my first transfusion in over 3 1/2 months and it took the blood bank 18 hours to match my blood type and acquired antigens. The CT scan showed no more clots and the BMB essentially was the same as last time in May 2004. Good news, bad news.

Two weeks later, I was back in for another blood transfusion when my Hb was 7.8. This time, somewhat due to confusion between the clinic and blood bank, I did not get blood for 34 hours and spent a day resting at home in between. Due to this change in transfusion dependence, I went through an orientation with the U of MN BMT Center and had my bone marrow typed. Also received instructions to get my two sisters and brother tested as well.

Prednisone – good and bad (2006-02-11 00:35)

Since my BMB still showed 95 % hypercellular activity and my reticulocytes were over 10 %, my hematologist decided it was time to try another tack and prescribed prednisone. The thought is that my autoimmune system is killing off my red blood cells and prednisone would test the theory. I started with three 40 mg doses per day and have felt great at first. I was all fired up the next day, but had problems getting to sleep.

The second day, I experienced severe pains in my legs and suspected blood clots. Actually, some of the pain was like a sharp knife stuck right into my thighbone. I had ultrasound on my legs, but found no clots. The prednisone was then reduced to one dose of 60 mg and I have only experienced one minor episode of pain since and that was handled with some Tylenol.

Good news is that my Hb is back up to 9.0 and has actually been steady for the last two weeks. Platelets are also down to 333 and my Factor II is right on target at 20 %. White cell count though is up to 13.2. I feel great and even worked extra hours this week.

Bone marrow match results (2006-02-11 00:51)

I learned yesterday that neither of my two sisters' bone marrow matches mine. Also, my brother's blood sample was not tested since his clinic forgot to label the vial that they sent FedEx from Missouri. I thought my best bet was with my younger sister, since my brother is 68 years old. It is important that he is in good health and I await the results, probably in about ten days.

Body, Blood & Breath (2006-02-11 16:49)

Over the past week, I have created this blog and recollected my health experiences over the past couple of years. I have documented the facts as best that I know them, but with little emotion. Looking back, it may seem depressing to you, as it has been to me a few times. Why has this happened to me? What is in store for me? Why do bad things happen to good people?

I believe there is a purpose in all of this and that I have been uniquely prepared for this purpose. This blog is a continuation of that purpose which I first recognized over 20 years ago. Earlier chapters of "My Story" are documented in a web site named "Story2tell". Follow the link in the right column to read more.

In summary, the problems with my body, blood and breath are infinitely overcome by the body and blood shed for me by Jesus Christ and the breath and power given to me through the Holy Spirit. I pray that through this blog, this power and strength will be shown to you and that through your prayers, God's power can be directed back to me.

Please come back and comment if you wish. Your experienced feedback on health or faith will be appreciated.

Anonymous (2006-02-12 10:29:00)
Thanks for sharing your story with us!

Anonymous (2006-02-13 09:07:00)
very good site

Anonymous (2006-02-13 21:16:00)
This is really a good blog site. Our prayers are with you.

No transfusion needed (2006-02-14 18:36)

When I got up this morning, I thought I needed another blood transfusion. I have said in the past that I can tell when I do and have been right the last five times. Today was different.

I have been sleeping pretty well at night over the past week, but noticed I was somewhat tired at work on Friday and over the weekend. I also noticed that I had less endurance before getting short of breath. Last night I got about six hours sleep before getting up about 6 am. I worked about an hour at home before going into work about 8:15 am. When I got to work, I called the triage center and arranged for a blood test around 10 am. My hemoglobin level was at 8.8, essentially unchanged over the past two weeks. White cell count was up a little to 17,200. I felt encouraged after talking briefly with Dr who reduced Prednisone to 40mg per day. I went back to work and then came home early to rest.

Seems like the effect of the Prednisone interferes with my sense of hemoglobin level. I am scheduled for the next blood test in one week.

Anna (2006-02-15 16:50:00)
Dad, sorry it took me so long to find read your blog. I'm glad you didn't need a blood transfusion yesterday.

Bone marrow match made! (2006-02-17 20:11)

I got great news today from the U of MN BMT clinic. They got my brother's sample in from Missouri and it is a match! I was not even expecting results this week so had not thought about it. I have been feeling pretty good the last three days, working over 9 hours per day and making up the time I was out on Tuesday. A BMT is still not a certainty, but it is great to have the match and option if I need it. Praise God!

Son Shine (2006-02-19 11:24)

While I didn't sleep real well last night and woke up last at 8:30 am, I was greeted by the sun shining brightly through the bedroom window. It reminded me of the many times that my father had said to me "The sun is always shining". "It is just that sometimes the clouds get in the way". The weather here has been very cold with morning temperatures of about 13 degrees below zero yesterday. But then the thermometer outside my bedroom window is on the south side

of the house in the sunshine. As the sun came up yesterday, I noticed the temperature rose rapidly as the sun struck the thermometer. I have also noticed how the interior of my car will be toasty warm in the winter even though the air temperature outside is freezing. It is the same with God's son. He is always there ready to support and sustain us through the Holy Spirit. It is just sometimes our other troubles get in the way.

As I started writing this morning, I was watching the "Hour of Power" which I have recorded on my computer earlier in the morning. Robert Schuller, Jr., was preaching about David and Goliath. In his final wrap-up of the sermon, he said "Remember that it is not how we die, because every single one of us will die. It is how we live that counts and it is what happens in us that is far more important than what happens to us. God has given us the will and power to overcome any Goliath that we face in our life today. You can do it with God."

Let the son shine in your life!

Hemoglobin returns (2006-02-21 14:54)

Yes, that's not a misprint. The ornery Hemoglobin has returned. My blood test this morning showed that my hemoglobin level is down to 7.5 g/dL. It was 8.8 a week ago. I suspected as much today but thought the same last week and was wrong. My platelets are also up some from 338 to 397, but my white cells are down a bit from 17.2 to 15. Anyway, I am now scheduled for a transfusion on Thursday afternoon. This should give the blood bank adequate time to find blood for me. Last time, they could not assure 24 hrs turn-around so we had delayed for 34 hours. Then, I just stayed home in between. I have a full day of meetings tomorrow and then more on Thursday morning, depending on my strength to even get to work. By Friday, I should be refilled to attend a scheduled offsite seminar.

More on the good news. I reported Friday that my brother was a bone marrow match, but then had more questions about the details. I checked back with the BMT clinic yesterday and found out that he actually matches 8 of the HLA factors. Typically, it is considered a match with the main 6 factors that we inherit from our parents. The Dr even feels the match might be better yet as they look at an additional 4 factors. This all plays importantly into how my body reacts to the donor blood stem cells after the transplant. I am sure to learn more about this since the prednisone does not seem to be helping the hemoglobin.

Anonymous (2006-02-21 20:42:00)

Thank you for the update. Hope the transfusion goes well. Thank you, also, for the wonderful Christian witness in your previous blog entry. It was beautifully written and genuinely inspirational. We continue to remember you in our thoughts and prayers.

Anonymous (2006-02-21 20:46:00)

This is a test message. I am trying to figure out how to comment as I am not very computer oriented. Thanks.

Anonymous (2006-02-21 20:51:00)

Hi, I just sent a test message and noticed the message that "Your comment has been saved and will be visible...etc.," so I will try to leave a "real" message. I hope your blood transfusion goes well. Also appreciated your previous entry about the Son Shining. That was a wonderful Christian witness and is also helpful to me in my own life. We continue to remember you in our thoughts and prayers.

Myelo (2006-02-21 20:56:00)

Thanks for the comments. You can always use Anonymous or Other as an identity. If you also have a blog on Blogspot, you can use your Blogger identity. I am currently moderating comments so I get an email message that you left a comment which I then approve. I have not figured out how to delete comments afterwards, but once I have, I may just let them be posted and clean up later if needed.

Blood & Oxygen (2006-02-23 21:37)

Well, I had a blood transfusion today and feel somewhat better. When I got to the hospital at 11:30 am, they said they were not expecting me until tomorrow, but they did have the blood and worked me into their schedule. Another mix-up between the clinic on the first floor and the transfusion unit on the third floor, complicated by the blood bank being somewhere else. Seems like 48 hours should be plenty of time to get everything together. They started the transfusion about 1pm and I was home by 5:30 pm.

Yesterday, though I worked about 9 1/2 hours, I still realized that my hemoglobin was at one of its lowest levels ever. I knew it was below 7.5 from the day before. My wife asked me later whether having an oxygen tank would have helped. Possibly, but there are a number of factors involved and in my case, the low red blood cell count and low hemoglobin level is the driving factor. I am still affected by the blood clots in my lungs that reduce the blood flow. When I first experienced breathing problems back in November 2004, my local doctor thought it might be asthma, which would have affected the airflow. My hemoglobin was higher (11) at the time and oxygen helped overcome the reduced blood flow. They ruled out the asthma factor once the blood clots were discovered.

Another big factor is the level of oxygen in the air, typically about 21 percent. But that is not a pure number since it is affected by other air gases such as nitrogen and carbon dioxide and the humidity. For example, by the end of the church service last Sunday, I was short of breath and eager to get outside for some good air. (It may not be the sermon that puts the congregation to sleep! Just kidding, Pastor, but some more oxygen would help.) Also, this morning when taking a shower, I had problems breathing because of the humidity of the air. Check out the [1]Occupational Hazards web site article, paragraph on the Respiratory System, for more details.

1. http://www.occupationalhazards.com/safety_zones/31/article.php?id=1502

Charlotte (2006-02-24 19:59:00)

What good news that Jim matches on 8 of the HLA factors. Bob Lee knows Phil Dyrud who had a BMT at the U. He is out of the hospital now and doing well. The funny thing is that the DNA in the saliva of one who has had BMT is that of the donor. The DNA in the blood remains that of the one who received the BMT. So if you commit a crime, (HA) be sure to leave blood and not saliva behind. (Just a warning.)

You continue in my prayers that the Lord would heal you if He so wills, but especially that He would grant you His grace and strength for these trying days. I can tell from your writing how the Lord has sustained you and given you hope and joy. Keep looking up.

Love,

Myelo (2006-02-24 20:35:00)

You may have the saliva/marrow DNA reversed, but definitely appears to be possible according to the following:

From - <http://www.thenakedscientists.com/HTML/shows/2005.12.04.htm>

Question: Ethe in Suffolk - I've heard that bone marrow transplants can cause havoc with DNA testing. Is this the case, and if so, how can the problem be resolved?

Answer: You're right. A bone marrow transplant can cause a problem because what you essentially become is a mixture of two people. Someone takes away your normal bone marrow and replaces it with the bone marrow of somebody else in order to make up for the damage caused by your own bone marrow. This means that you potentially leave behind two DNA fingerprints at a crime scene and could even implicate your donor.

Also from

<http://www.thenakedscientists.com/HTML/shows/2005.03.13.htm>

Question: If you had a stem cell transplant, would your DNA change?

Answer: fantastic question! It's not just stem cells you need to consider, but indeed any type of organ transplant or tissue donation. Another person, unless they are your identical twin, will have DNA different from your own. The reason lung transplants or bone marrow transplants actually work is because you are substituting dodgy tissue for healthy tissue. At the same time, you are replacing a gene that has gone wrong by putting in a healthy copy of the gene. That means the DNA in the tissue you've replaced will be different. The rest of your body won't change. If you do a bone marrow stem cell transplant for someone with leukaemia, the cells that you will have inside your bone marrow will come from your donor. Therefore, they will also be genetically identical to the donor. This means that a man who receives a bone marrow transplant from a lady will have bone marrow cells that have two X chromosomes. Sometimes people can even see a change in their blood group.

Myelo (2006-02-24 20:42:00)

Note in the last comment, the final parts of the urls should be:

2005.12.04.htm and 2005.03.13.htm

Somehow blogger cut off the ends.

Anna (2006-02-26 11:23:00)

all of this is interesting. I'm glad you are feeling better dad.

1.2 March

Lesson in this (2006-03-05 07:41)

The last ten days, since my last transfusion, have been pretty good. Last weekend, I went shopping at Home Depot, Sam's and the Northtown Mall, walking all around these large stores. I also ushered at church on Ash Wednesday and worked 42.5 hours. Friday, I even applied for a higher level manager job at work. Yesterday, after visiting my sister, I cleaned a portion of the basement, sorting through some of my old computer stuff, even carrying old computers and heavy monitors around. But then, I am pushing myself, trying to be positive about my situation.

During all of this, I can sense my blood hemoglobin dropping. I can do less and less before breathing hard and having to take a short break. My blood pressure and heart rate are also increasing again. Another blood transfusion may be necessary in the next week. I have my next doctor appointment on Wednesday when hopefully we will determine whether a BMT is the next step.

Everyday, I read the "[1]Our Daily Bread" devotional through the internet. It always has something that seems to speak to my situation. Recently, it has had a link to a Discovery Series titled: [2]"Joseph: Overcoming Life's Challenges". One section titled [3]"The lessons of life" starts out:

"On the old Happy Days television show, Richie Cunningham had just been "grounded for life" by his father, Howard, for misbehavior. As they talked about it, Howard asked his son, "Did you know that there is a lesson in this for you?" Richie's response was priceless: "I figured anything with this much pain had to have a lesson in it somewhere." That is real life! We do not learn character in times of ease and prosperity but in times of difficulty. The greatest lessons of life are often the product of our most serious heartaches."

Later on, the author states "Everything happens in our lives for a reason, and a great part of that reason is to help us grow in our faith." My trials over the past several years have certainly strengthened mine.

Isaiah 40:31 but those who hope in the LORD
will renew their strength.

They will soar on wings like eagles;
they will run and not grow weary,
they will walk and not be faint.

1. <http://www.rbc.org/odb/odb.shtml>
2. <http://www.rbc.org/ds/q0715/>
3. <http://www.rbc.org/ds/q0715/page1.html>

Anonymous (2006-03-05 21:21:00)

Thanks for sharing this information with us, Joel. It is helpful to know exactly what to pray for.

Blessings, Pastor Sean

Anonymous (2006-03-05 21:42:00)

That is really a good thought about the greatest heartaches in life teaching us the greatest lessons. As I think about it, this has certainly been true and continues to be true in my own life. Appreciate the insight as it helps me put my own problems and issues in perspective. Love and prayers, Marge

Jim (2006-03-06 23:24:00)

To add to this, whenever Jesus met one-on-one with people, it was most often when they had a problem, like the man with leprosy, a man whose daughter had died, a man who was blind, man who is crippled, etc. He was more a Redeemer in these situations than when He was in the synagogue.

Reduce meds (2006-03-09 00:01)

I had my monthly appointment with hematologist today. My hemoglobin was 7.4 so I am scheduled for another blood transfusion on Friday. Since it seems like this may be a biweekly thing, we agreed that the threshold for

transfusions would be raised to 9 rather than 8. This in effect will keep my hgb between 8 and 10, rather than 7 and 9. Like it doesn't cost any more to keep your gas tank full rather than empty, except in this case I will have more power.

My platelets were down to 186 from 397 two weeks ago. Factor 2 relative to blood clotting was down to 13 from 17. My blood pressure was higher as well. Summary, we are making a change in medications, cutting AG in half (affects platelets and maybe hgb), reduce coumadin (just tonight, affects Factor 2), taper off Prednisone over next two weeks (which did not seem to reduce anemia and may be responsible for high blood pressure) and stop Procrit after 2 weeks. Procrit has not seemed to improve hgb. I will have a blood test in two weeks and check with Dr.

We discussed the possibility of a BMT further. Dr feels that it is still not warranted yet; the risk is too high versus complications of continued blood transfusions. My spleen seems to have increased in size from cleaning up RBCs and my ferritin (iron) levels are going up as well. I may need some iron chelation treatment which is now available as another pill instead of a blood filtration process.

I am a little disappointed since I thought a BMT might be the magic pill to cure this, but with my age and blood clotting problems, the risk is elevated. There are also BMT complications of Graft versus Host Disease (GVHD) that could take several years to clear up. But it is certainly good to have an option if the blood counts drop even more.

Prayers are appreciated.

Emergency Room (2006-03-10 20:11)

Last night, I experienced some irregular and rapid heartbeats. Marilyn and Andrew took me to the emergency room at 12:30am where they wired me up and monitored me for a few hours. I witnessed an episode where my heartrate went from 88 beat per minute to 148 and back down in the space of a minute. I could sense it was happening and turned to see it on the monitor just in time.

My hemoglobin was also down to 5.9, the lowest that I have had. Since I was scheduled for a transfusion at 11:30am, they just checked me into the hospital and had blood flowing into me by 5:30am. After 2 units of blood, my hgb was up to 7.9. Since they had more blood typed for me, they gave me 2 more units which just finished. I expect my hgb will be up close to 10 which will be the highest in the past year. That will make it the lowest and highest all within the same day. They will monitor me over night and expect to let me go in the morning. No more rapid heartrate that I can sense, now that my hgb is back up. I should have all kinds of energy for the reat of the weekend, until the cycle starts all over.

This actually has been a blessing since it may get me on a cycle between 10 and 8 instead of between 9 and 7 (or even lower). If the cycle is faster than every two weeks, it may be a factor in whether the BMT is warranted.

Keep looking up!

Immunoglobulin G (2006-03-11 15:04)

Well, I am still at the hospital and will be at least one more day. After 4 units of blood yesterday, my hgb only made it to 9.2. Last night, I had a slight fever and head ache. I still have a fever of 101. Latest idea is to give me intravenous immunoglobulin G (**ivIgG**). IgG is supposed to act as a decoy so that the immune system attacks it instead of the red

blood cells. Will get some today and tomorrow and if I tolerate it ok, should get to go home tomorrow afternoon. I will need to get blood tests every week and then more blood and ivIgG probably in three weeks.

Anonymous (2006-03-11 22:39:00)

Thanks for the update; sounds as though you have had a very challenging week. It is good that things seem to have settled down. It must have been quite an experience to watch your heart rate rise and fall on the monitor. I used to have PAT attacks alot and know what it is like to have one's heart jumping around in one's chest. Not very pleasant! Am glad you got through it okay. M.

Ken Brandt (2006-03-12 06:39:00)

Hi Joel

I can see you are really "going through the wringer." Hope the new medication works.

Ken Brandt

Drip, drip... (2006-03-12 12:04)

Still writing this from the hospital on Sunday, but looking to go home this afternoon. My first bag of ivIgG took 10 hours to go in and finished at 5 am this morning. I petitioned the Dr to send me home and have me come back on out-patient for the rest. But they still want to monitor me while they see how I react. So they started a second bag of 1800 ml at 10am and thought they could speed it up to finish in about 6 hours. The nurse has been increasing the speed periodically and it is now up to 300ml per hour. So I have now been here for about 58 hours watching the IV drip, drip, drip...

Looks like I missed the nice weekend and it may be snowing when we drive home this evening . Depending on how I feel, may have to shovel snow tomorrow morning and go to work . I will be back in every week for a blood check and will get more ivIgG when necessary. Nurse thinks this stuff cost \$10,000 per bag so glad (hope) that the insurance is paying for it. At the current rate that is about 50 cents per drip.

Pastor Sean Kelly (2006-03-12 17:07:00)

Thanks for the continued updates, Joel! 50k a bag, huh? Jeez - I'm in the wrong business!!! Hope you feel better and blessings as you return home. We're also praying for you mother-in-law as well.

In Him, Pastor Sean and family

Anonymous (2006-03-12 18:54:00)

I wonder what makes it so expensive. Oh, well, I'm just glad that we have it. Glad your insurance is paying for it (if it is). M.

High Speed Internet (2006-03-12 16:39)

The drips continue, but I don't look at them as much. I got my laptop to work in high speed wireless mode through the University Hospital network. I had tried on Friday, failed and called the U help desk. Since it was late, they referred me to others twice and I never heard back.

This afternoon, I tried connecting to my office network and it worked for a while. The error message indicated they were working on some network stuff there, unless they thought I was a hacker and blocked me. Anyway, I then set the name server to the one that I use from home and everything worked. I ran my standard [1]speed test

and found that it was running at close to 10 Mbps, 2 to 3 times as fast as I get at home. I may have to come back here just for the fast internet. Really, it will make things much more tolerable when I come back for another transfusion.

The last bag of ivlgG (or IGIV) is just about through and then I can go home. I probably will take a few days vacation this week while both Marilyn and Andrew have spring break. Not sure when I will have a better time to use vacation later.

1. <http://myspeed.visualware.com/>

Anonymous (2006-03-12 19:01:00)

That is great that you were able to get connected so you can use your laptop during these transfusions. It can make a big difference if you have something interesting to read or do. I remember a few years back I was fortunate enough to have an absolutely riveting book with me when I went to the Mayo to have a colonoscopy. I was so absorbed in the book that I hardly noticed the grueling preparations for the procedure. If I only I could be so fortunate for every medical procedure in the future! Hope you will be so fortunate, too. M.

Anonymous (2006-03-12 19:46:00)

I really enjoyed lunch with Marilyn, Anna, and Andrew. Andrew did a great job in helping me understand your illness better. I believe he will make a great Doctor.

Ken Brandt

Northern Born Southerner (2006-03-13 14:07:00)

I hope that everything is going better for you today! Are you home?

Back from Hospital (2006-03-13 17:16)

I finished my ivlgG yesterday and drove home from the hospital. Marilyn drove to the hospital, but you know the "man" has to drive home. When I walked out to the car, it felt a little cold. I then remembered that I gave Andrew my jacket in the emergency room and he took it home.

Anyway, feeling much better today. Andrew and I shoveled about 10" of snow from the driveway. He did most of the heavy lifting, but I stayed with him shoveling the edges and cleaned off both cars. We then drove the van out the unplowed street and bought another shovel to replace one that disappeared this morning.

I changed my comments setup so that you should see any additions almost immediately. I had it set for my review and approval since Anna had received some nasty anti-Christian comments on hers. I need to have her show me how to delete comments if such occurs, though I may have a different setup with the special domain name.

Anna (2006-03-13 22:30:00)

Too bad you and Andrew didn't come over and shovel my car out. I got stuck for an hour and a half moving my car to the back alley. I helped one neighbor push her car out when she was stuck, thinking that then she would help me, and instead, when she was free, she drove away. I had to go and wake Sara up who was home sick to help me. then I decided to take the bus, which took an hour to come.

Anonymous (2006-03-14 14:24:00)

Dear Joel,

It was good to see you on Sunday. I know Mom was glad she could visit with you. Glad to hear you are doing better, even

clearing snow. As Mom and I were leaving the parking ramp on Sunday a woman backed into me with her 99 Jeep. She said, "Didn't you see me?" I had the right of way. I called her insurance company yesterday and tomorrow I will take the car in for an estimate. The rear door on the driver's side got scraped and dented in. Maybe I won't get anything for damages if they believe her story. Most of my fender benders take place in parking lots and ramps. At least no one was hurt. I didn't work yesterday. It was nice to have a whole day at home. I got a workout shoveling snow. I'm praying for you, for a miracle if the Lord wills.

Love,
Charlotte

Anonymous (2006-03-16 11:35:00)
Hope you continue to feel good.

Ken Brandt

IgG Works (2006-03-16 18:35)

I was in for a blood test early this morning and got great news. My hgb was 10.4, probably the highest that it has been in over a year and up from the last measurement after my blood transfusions on Friday. I will getting it checked again next Wednesday. I thought that maybe it was about the same since on Monday and yesterday, I shoveled snow with little problem. But I was surprised that it had actually increased. Hallelujah!!

From "[1]Our Daily Bread" for today:

The rarest [blood], AB-Negative, is found in only 1 in 167 people, or 0.6 % of the population. ... "The rarest blood type is the one that's not there when you need it." There is another supply of blood that is one of a kind and always available to those who ask for it. First John 1:7 states, "The blood of Jesus Christ His Son cleanses us from all sin."

My blood is A-Negative which is found in only 6.3 % of people. But then that number is reduced by the antigens C, D and E that I have in my blood. Thank God that Jesus' blood is available infinitely and to all. There is only one test for a match; just believe and accept the free gift.

1. <http://www.rbc.org/odb/odb-03-17-06.shtml>

Big Brother (2006-03-16 20:30:00)
That's great.
Let's pray your blood count stays up.

Northern Born Southerner (2006-03-17 10:01:00)
Praise the Lord! We will continue praying for you!

Sanyo (2006-03-17 20:51:00)
One family can have many miracles. I pray that the miracles will keep coming! All it takes is the faith of a mustard seed. JUST BELIEVE. PTL

Anonymous (2006-03-19 16:05:00)
Wow! That is really good news! Hope it continues to work.

Ken Brandt

Improvement Continues (2006-03-22 18:39)

I was in for a blood test this morning and found out that my Hgb is now up to 10.6 from 10.4 last week. This is not a significant change, but great since it did not drop. The true test is next week when it may drop due to the IgG getting depleted. If so, I may need some more IgG or another blood transfusion. I also see the Dr then and get his opinion on what happens next.

My platelet count was also up to about 600 from 187 two weeks ago when I reduced the Anagrelide to every other day. Dr wants to watch that for another week before deciding what to do. He also decided to keep me on the Procrit so I am getting another 4 weeks of injections to take at home. I took my last Prednisone today. Had tapered down to 10 mg per day in the last week from initial dosage of 120 mg two months ago.

I am feeling pretty good and can tell that my Hgb is above 10.

Anonymous (2006-03-23 10:44:00)

Is that platelet count of 600 bad?

Glsd the Hgb is good.

charlotte (2006-03-23 11:02:00)

Dear Joel,

It is encouraging to see that your hemoglobin hasn't dropped in the last week and actually went up a little. My platelets were 759 last week. I suppose with your high platelet count, you are susceptible to blood clots. I continue to pray for your health and well-being and that of your family also. I need to get in touch with Marilyn about birthdays. Today is Andrew's. I didn't get his card sent as I thought I would give it to him when we get together.

Steve comes on March 31 so I hope he can get to see the extended family while here.

Blessings on you.

Love,

Charlotte

Myelo (2006-03-23 21:38:00)

Normal platelet counts are between 150,000 and 450,000 per micro-liter. The highest I had was 723,000 back in August when the Dr doubled my Hydrea prescription. When that also affected my Hgb, they switched me to Anagrelide in Sept. Yes, it more of a factor with my other blood clotting problems.

Shingles (2006-03-29 19:19)

I saw the Dr today and reported that while I was feeling more energetic, I was also getting more aches and pains. My hgb was 10.1, down a little from the 10.6 last week, but no reason for more blood or IgG. Dr not sure if hgb improvement due to IgG or reduced Anagrelide, so will get blood checked every week. My platelets were up more to 655 today and Factor 2 was 35 so my Coumadin was increased a little to compensate.

My joints have been achy since I quit the Prednisone last week. My right knee is especially bad, sometimes too stiff to bend. It also was my life saver 18 months ago when I was supposed to have it replaced. The preop physical was when my anemia and shortness of breath was first noticed.

But the right side of my neck has been achy, numb and warm recently. I thought it was just more arthritis, but Dr thinks it may be [1]shingles, herpes zoster. He also noticed some bumps that might be a start of the shingles blisters. He prescribed Acyclovir, 800 mg 5x per day, for the next week to try and knock it out. I hope it does, because I had shingles on one side of my back in the early 70's while in grad school. That was one of the most miserable experiences of my life.

Stay tuned for the next episode, hopefully not before next Tuesday's blood test.

1. <http://en.wikipedia.org/wiki/Shingles>

Northern Born Southerner (2006-03-30 13:01:00)

Ouch! I hope it's not shingles either or they caught it before it is full blown. Take care!

In Christ,
Chris

Anonymous (2006-03-31 19:43:00)

Gosh, Joel. This reminds me of the suffering of Job.

Ken Brandt

Anonymous (2006-03-31 21:20:00)

Hope the acyclovir can suppress an outbreak. It certainly helps me when I feel a cold sore coming on. I carry around a tube of it in my purse all the time. Hope it will help you, too.

Marge

1.3 April

God will make a way (2006-04-01 09:51)

While resting in bed this morning, I was listening to a playlist from my iTunes library. I have a couple playlists that I go to sleep with, never seeming to make it past the first few songs before I am asleep. This playlist starts with "The Lord's Prayer" by the Statler Brothers. Anyway, the second song had special meaning this morning. It is "God will make a way", sung by [1]Janet Paschal, who incidently has struggled with cancer over the past year. I first heard Janet sing this song on one of the Gaither's televised concerts and then downloaded it from the [2]Apple iTunes music store sometime last year.

The complete lyrics and song by Don Moen can be found [3]here.

God will make a way,
Where there seems to be no way
He works in ways we cannot see
He will make a way for me

May he make a way for you as well.

1. <http://www.janetpaschal.com/newsletter/index.html>
2. <http://www.apple.com/itunes/>
3. <http://my.homewithgod.com/heavenlymidis2/makeaway.html>

Anonymous (2006-04-01 20:28:00)

I think this is a powerful concept. Thanks for sharing it.

Ken Brandt

Northern Born Southerner (2006-04-05 10:57:00)

Still in my prayers!

More IgG (2006-04-05 18:19)

I was in for blood test yesterday and saw the Dr this morning. My Hgb was down to 9.7 and my platelets were up to 907, proving that reducing the Anegrelide did more harm and questionable good. I am now back to my original prescription of .5 mg per day. Also since my Hgb is starting to drop, I will get more IgG on Friday. Dr plans to repeat IgG every two weeks over the next three months while monitoring the results. My Factor 2 was also still up at 37, out of the target range of 15-25, so my Coumadin is being adjusted as well. While Drs do not think there is a connection between these three medications, my bet is that my Factor 2 will be below 15 next week and we will be adjusting that again as well.

Psalm 6:2

Be merciful to me, LORD, for I am faint; O LORD, heal me, for my bones are in agony.

I mentioned before that my arthritis has been acting up again since I quit the Prednisone. My right knee locks up some times, especially when I roll over in bed and bend my knees to avoid the twist from my feet. I have completed the week dose of Acyclovir for my "emerging" shingles with no change to the ache, numbness and warmth in my neck. The Dr thinks that the "bumps" on my neck possibly from shingles have disappeared, but I haven't noticed any difference. So next week I see an orthopedist to have a look at both problems. I am also allowed to again take Aleve which seems to help the arthritis pain somewhat better than Tylenol.

It is a little frustrating to still not have a solution to my problem, but I am encouraged that the IgG seems to work and look forward to getting more energy from a higher Hgb level.

Anonymous (2006-04-06 15:45:00)

Joel,
You continue in my prayers that the Lord will continue to give wisdom to the medical staff and strength and hope to you. It certainly is a complicated situation. May you know the Lord's peace and joy.

Love,
Charlotte

Anonymous (2006-04-06 22:00:00)

Gosh. I hope they come up with something.

Ken Brandt

Big brother (2006-04-07 10:10:00)

We will keep praying that the doctors will get all the treatments and medicines adjusted right.
Thanks for your witness of faith in God and Jesus through all of this.

Spring Ahead (2006-04-11 17:43)

We switched our clocks ahead a little over a week ago, but I feel like I am falling back. I did have an IgG IV last Friday while spending seven hours at the Day Hospital. I think the dose of 55 mg was 1/4 of what I received in the hospital over the weekend of March 11. I had also resumed my previous Anagrelide dose of .5 mg per day. But the results of my blood test today show my Hgb is down further to 9.0 and my platelets have increased further to 931. My Factor 2 results have not come in yet. I can sense the drop in Hgb since I get winded quicker, though still managed to work a couple of hours in the yard last weekend.

Dr has now adjusted my Anagrelide to 1 mg per day, back to my original level in September, last year. At that time we had to reduce it within two weeks because it was causing me headaches and a pounding pulse. My Hgb also dropped to 6.4 at the time, requiring a third blood transfusion within 5 weeks. That might have been a result of the Hydroxyurea that I had been taking since my Hgb then held steady for over 3 months. It will be interesting to see what happens in the next week. Haven't I seen this movie before?

But on the bright side, Spring is here. It was sunny and 79 degrees yesterday and still is 70 today, though rain is threatening. There are pros and cons of having my medical care at the University. During these Spring days, all of the students shed their winter clothes and become more active. There are joggers, roller bladers and bicyclists. Not sure if it makes me feel younger or older to share the streets with all this energy around me. I guess I do tend to suck it in and walk a little more briskly. Have to watch more carefully where I drive as well. It is certainly a diversion from sitting around the office.

Charlotte (2006-04-12 11:42:00)

Joel, Hang in there! I know it must be discouraging to see the Hemoglobin drop again. May the Lord sustain you by His grace and give your hope and joy in Him. My prayers continue for you.

Love,
Charlotte

Anonymous (2006-04-12 18:51:00)

What an ordeal! You and the doctors continue to try different approaches. Hope one of them works.

Ken Brandt

Don't do necks (2006-04-14 20:43)

Well after living with my achy neck for three weeks, I thought I might get some relief. Hematologist referred me to orthopedist since I have had more knee and neck pain. I saw U of MN orthopedist yesterday. Nurse had me put on bright red shorts during x-rays of my knees. She joked that patients don't walk out with them anymore.

When Dr came in and saw my blood results, he said there was nothing to be done. Scared him away and no potential for expensive knee replacement. He said they could give me a cortisone shot in my knee, but I don't let it get that bad. I suppose if I did overwork it and it got inflamed and swollen, that might be an option. But my big

disappointment was that he did not do necks. Would not even look at it. Referred me to another Dr in the same who could not see me until May 31 since I was a new patient. I told them I had neck pain for over 3 weeks already, would not wait that long and walked out.

I came back to my office and called my family doctor. I thought it might be good time to get a general practitioner to review what I was going through and see if my records were being sent back there as well. I had an appointment this afternoon and noted that they were up-to-date with medical reports sent from the Univ Med Center. I now have an MRI of my neck scheduled on Monday. Maybe I need some therapy which I could get locally. Getting tired of going to appointments; third time this week, week is not over and not looking better next week.

More blood needed (2006-04-14 21:37)

While I was at local med center for my neck today, I got a quick finger prick blood check. My Hgb was down more to 8.2. Since it was 9.0 on Tuesday, it will probably be down to 7.5 by Monday. They faxed the results to my hematologist. We arranged for a blood type cross and match at an open Univ clinic on Saturday afternoon so that the blood bank can get me some blood for transfusion early next week.

I am now scheduled for transfusion on Tuesday, but wait listed for Monday. May end up with conflict and need to reschedule MRI. I had planned to drive to Rochester and visit my mother-in-law on Saturday, but will now stay in Minneapolis for the weekend.

King's move (2006-04-17 19:43)

My schedule for the week changed this morning when I was able to get in for my blood transfusion. The MRI for my neck switched to Wed and the IgG IV to Thursday. I also have a dentist appointment on Thurs at 7am to make it four related medical appointments for the week, just like last week. A blood test before the transfusion this morning confirmed a drop in my Hgb to 7.9, but should be pushed back up to close to 10 by now. The increase in my anagrelide is helping to lower my platelets back to about 600, but also gives me a little heart pain, one of its side effects. Once it gets down below 400, I will return to my original level of anagrelide that was fine for six months.

With all this time spent away from work, I have arranged to telecommute from the hospital. Dr gave me a note saying that it was ok, both for my health and the day hospital, for me to work during my transfusions. I connected my laptop wirelessly through the U of MN network into our company network and telecommuted a couple of hours today. I would have done more, but the Benadryl they gave me with the transfusion made me sleepy. I came home afterwards and took a two hour nap.

So how does all this relate to the "King's move"? Yesterday, I made it to our church Easter service (before driving to Rochester to visit my mother-in-law and then stopping by my sister's place for dinner with my mother and other relatives). The pastor's sermon illustration was about a painting titled "Checkmate" that was on display in an art gallery. A master chess player examining the chess pieces noted that it was not a checkmate since "The king had another move". The pastor related this back to Moses at the Red Sea, Daniel in the lion's den, David facing Goliath and Christ dieing on the cross. In each case, the "King" had another move. In my case as well, I believe the King has many more moves to make and even when I face death, like we all will, he will have one more move. "For God so loved the world that he gave his only begotten Son, that whoever believes in him shall not perish but have eternal life." John 3:16

Anonymous (2006-04-18 23:29:00)

What a positive thought. I hope the next "move" will be a better one.

Ken Brandt

Negatives (2006-04-20 19:49)

Dr. Tony Evans has an inspiration spot titled "[1]The Alternative View" which aired on [2]KTIS radio this morning (April 20). He used the analogy of developing photographs to what good can come out of negative tough times in your life. Some people, especially professionals, still use photographic film where a picture is captured as a negative. The developer takes the film negatives into darkroom where through a process that most of us do not understand, converts the negative into a positive multicolored image. In a similar way, God can take our negatives, and in a way which we do not understand, turn them into positives.

Today, I was in the day hospital for the IgG IV which took about 4 hours. They speeded it up from last time and I was able to work again while watching it drip. The effect of the Benadryl and probably the IV made me tired out so I came home and slept for 3 hours. I started out the day with a dentist appointment and also was out part of yesterday for an MRI of my neck. The MRI showed some degeneration which I need to review with a neurosurgeon. Actually, my neck is not hurting that much any more so I am not in a big hurry to see another doctor.

1. http://www.oneplace.com/ministries/The_Alternative_View/

2. <http://ktis.nwc.edu/page.php>

King's move 2 (2006-04-21 22:40)

Just a note that the sermon illustration about the "King having another move" can now be found on the Redeemer Lutheran Church's [1]message audio page. Click on one of the audio links for the April 16th sermon on Hope by Pastor John Niewald. The "King's move" starts about 2/3 through the sermon, but the whole sermon is worth listening to. The sermon started out with the playing of a [2]video about Jason McElwain, an autistic teenage basketball benchwarmer who hit six three-pointers in the final four minutes of his last high school game.

1. <http://www.redeemerfridley.org/messages/2006messages.jsp>

2. <http://www.crooksandliars.com/2006/02/25.html#a7298>

Amazing Grace (2006-04-23 09:01)

Most of us are familiar with the words of the song "[1]Amazing Grace", written by John Newton in the late 1700's. Robert Schuller, Jr. used the story of John Newton as a [2]sermon illustration this morning. After listening to Schuller, I did a Google search and learned more about [3]John Newton and the song. It was interesting to learn that the song has been modified over the years and that the original words had a special meaning to me in these times. The last two "original" verses that I had not seen before are:

Yes, when this flesh and heart shall fail,
And mortal life shall cease;
I shall possess, within the veil,

A life of joy and peace.

The earth shall soon dissolve like snow,
The sun forbear to shine;
But God, who call'd me here below,
Will be forever mine.

1. <http://www.littleleaf.com/amazinggrace.htm>
2. <http://www.hourofpower.org/video/video.cfm>
3. http://www.anoointedlinks.com/amazing_grace.html

Anonymous (2006-04-23 09:35:00)

Those are beautiful verses to "Amazing Grace" that I had not been aware of. Thanks for sharing them. Marge

Big Brother (2006-04-23 18:49:00)

God's Grace is so great there are never enough words or songs to explain it. John Newton had to experience it before he could attempt to describe it.

Another great song "Grace grace; grace that is greater than all my sin.

Anonymous (2006-04-24 11:23:00)

Dear Joel,

I just read your updates from the past week. I was out of the office on Friday taking care of my granddaughters. They were with me from Thursday til Sunday.

It is good to hear how the Lord is fixing your eyes on Him. The words of the last verses of Amazing Grace are so comforting. It is good, too, that you've been able to telecommute from the hospital. May the Lord continue to be your joy and hope in the midst of so much uncertainty. He is faithful.

Love,

Charlotte

Anonymous (2006-04-24 18:37:00)

Those are comforting words. Thank you for sharing.

Ken Brandt

Positive results (2006-04-28 20:21)

The results of my blood tests yesterday show that my Hgb is up to 10.1, my platelets are down to 513 and my Factor 2 is 23 %. All of this is positive. My Hgb was 9.7 last week just before my IgG IV so that may be taking effect. There are no changes in my medications this week, but I expect my Anagrelide will be reduced back to its original level when the platelets drop even lower. I am scheduled for another IgG IV next Thursday and every two weeks so hope to see Hgb going up some more.

It was an interesting visit with my doctor. He had a med student into observe and was explaining my medical history, demonstrating some of the checkup techniques, examining my color, listening to my heart, checking my spleen, etc. When the med student finally felt my spleen, after several tries, she was thrilled because this was her first.

The doctor also described my condition as a [1]Coombs' positive auto-immune hemolytic anemia and then included my other complications. He also explained that my [2]JAK2, analyzed by Mayo Clinic, was negative. He stated that my MPD was like ET (essential thrombocythemia) and downplayed the MDS that Mayo had highlighted a year ago. It is unclear whether a negative JAK2 is good or bad. I don't have that gene mutation, but then may not be able to benefit from treatment that comes from further research related to it. Anyway, it was an interesting discussion between the doctor and the med student who could ask more intelligent questions than I could.

1. <http://www.nlm.nih.gov/medlineplus/ency/article/003343.htm>

2. <http://cmlsupport.blogspot.com/2005/12/american-society-of-hematology.html>

Big brother. (2006-04-29 09:58:00)

PTL for the good report. Thanks for the new medical info. I will look up the website.

1.4 May

IgG but blood still needed (2006-05-04 23:06)

I was in for another IgG IV today and also had a blood test. Turns out my Hgb was down to 8.2 so need to go back tomorrow for blood typing and have another blood transfusion on Monday. My platelets were now down to 441 which is within the normal range. My Factor 2 for clotting was 28, a little high so had to take extra coumadin tonight. The IgG along with low Hgb made me so tired that I went home and took a three hour nap.

I was able to work on my laptop through the wireless network at the day hospital so only took 1/2 day of sick time. Over the past 12 months, I have taken about 130 hours of sick time. This has been minimized only by working 9 or more hours on days that I did not have a medical appointment.

I have kept a log of all medical events over the last several years. The log has 147 entries. I had 70 entries for all of last year and already have had 40 so far this year. While I cannot complain about a lot of pain and generally feel good, I am getting tired of an average of 2.5 appointments per week.

Anonymous (2006-05-05 14:57:00)

I am glad you are still able to work. The way you "hang in there" is really impressive.

Ken Brandt

Big brother (2006-05-05 18:24:00)

Keeping the log may prove useful for future medical research.

Anyway You can name it III Chronicles and call it a Bible story.

Anna (2006-05-10 23:54:00)

that's a lot of doctors appts. we've switched, now i don't go to the doctor as much. i used to go the equivalent of every week to see someone i think i figured out once.

Hgb back up (2006-05-11 19:01)

Well, I had a blood transfusion on Monday and a blood test today. My Hgb is back up to 10.5 and my platelets are 446 (holding steady). Since my Hgb was 8.2 last Thursday and it would have dropped further during the 4 days before my transfusion, it appears that the IgG is working. The two units of blood should have raised the Hgb about two points. It will be interesting to see what it is next week before I get some more IgG.

I also had a birthday, turning 58 on Tuesday. I am thankful for all the cards and gifts that I received, but primarily that I am still with all of you 18 months after my initial blood clot in November, 2004. Thanks for all of your support over that time as well.

Rewind two weeks (2006-05-18 20:09)

Well, I am right back to where I was two weeks ago. Had an IgG IV today, but the blood test showed my Hgb was down to 8.4. Exactly two weeks ago I had an IgG IV and Hgb was 8.2. So today they took more blood to test and I have to go in tomorrow to give more blood for a cross match. I will back in at 7am Monday for more blood. Not sure on the other blood factors, but no one has instructed me to change medications. Doesn't seem like this IgG is helping any.

I have now had 14 transfusions, 29 units of blood on an average for every 32 days in the last year. Average this year is every 22 days. Shortest time between transfusions was 12 days in September, then the longest was 112 days from then until January. I had just started Procrit in August so it probably just started working in September and may now have lost its effectiveness.

What's next? Maybe a BMT.

Big brother (2006-05-19 16:01:00)

Sorry to hear the news.

When do you see the doctor again to check plans?

We will ask Dr. Jesus for wisdom and healing.

More blood (2006-05-22 23:22)

I had another blood transfusion this morning, starting at 7 am. It went pretty quick so that I made it to a luncheon at 11:30, part of a conference where I spent the afternoon. A blood test before the transfusion showed that my Hgb was 8.2, higher than I thought it might be. I also found out that my Hgb was actually 8.9 on Thursday, not the 8.4 that I had been told. With two units of blood, it should be over 10 by now. I am supposed to have another blood test on Thursday and will then decide what I do this weekend. I would like to travel to Michigan with my mother and the rest of my brothers and sisters over Memorial Day.

Anonymous (2006-05-23 19:10:00)

It seems like good news. Hope you can make the trip to visit your family.

Ken Brandt

Don't Do That! (2006-05-24 21:52)

There is an old joke by [1]Henny Youngman that goes:
The patient says "Doctor, it hurts when I do this." "Then don't do that!"

That's essentially what the neurosurgeon told me today after looking at the MRI of my neck. I have numbness in my neck since back in March. He looked at the MRI, said that he did see arthritis bone spurs, but did not see any that could be causing the numbness. Since it only goes numb in certain positions, he suggested that I avoid those positions.

You may remember that my hematologist thought it was shingles back on March 29. Then I saw an orthopedist on April 13th that said he could not do anything about the arthritis in my knees and that he didn't do necks. The orthopedist could have used another one of Henny's jokes:
"Doctor, my leg hurts. What can I do?" The doctor says "Limp!"

I think both doctor's are not going to do any elective surgery because of my blood clotting problems. Both problems are minor annoyances compared to bigger blood problems.

My hematologist said I don't need another blood test this week and can travel to Michigan this weekend. Just have to get out and stretch every 90 minutes. Next appointment is June 1 for another IgG.

1. <http://funny2.com/henny.htm>

Detours (2006-05-26 12:28)

While I had planned to travel to my childhood home in Michigan this weekend, I have decided to stay here in Minneapolis. Last night, I attended a 3 1/2 hour high school band and choir concert including an awards ceremony and ice cream social. While seated in the cramped auditorium seat, I felt a few pains in my legs. Later at home I felt a little pain in my chest. During the night, I woke up with terrible cramps in my legs. After a trip back from Boston last year, I felt the same way and another blood clot was discovered in my lung. While I don't feel too bad at the moment, I decided it was best to avoid driving 7-8 hours and stay near my medical support.

There is a lot happening around here this weekend as well. I will miss the fellowship with my mother and siblings, but will enjoy being with my wife, son, daughter and friends. Besides, it is our 35th wedding anniversary on Monday.

While sitting here, watching the TV and cruising the internet, I happened upon a page of the [1]Urban Network Gospel News where there was a clip playing of Bishops Joel Trout's sermon titled "Detours" . You can listen to this sermon plus others [2]here.

No matter how you plan your trip through life, you have to take the detours. What seems like a detour for you is God's planned route for your life. It is in the detours that you find God.

1. <http://www.urbannetwork.com/gospelspotlight.html>
2. <http://www.apostolicpower.org/onlinesermons/index.htm>

Anonymous (2006-05-27 17:51:00)

I admire your sense of humor and your positive attitude.

Ken Brandt

Anonymous (2006-05-28 20:51:00)

I am sorry to hear about the leg cramps. You continue to be in our thoughts and prayers. Marge Harter

Pneumonia (2006-05-30 11:44)

The detour is more complicated than I suspected though it was a good idea to stay home and not travel. After helping Anna move on Saturday, I felt a sore throat starting. Sunday morning, I could hardly speak. Went back to bed and by noon, I had the chills and a temperature of 101.5. When it reached 102.8, we called the triage center and headed for the emergency room. Temp peaked at 103 before they started antibiotics. Xray and CT Scan showed that I had pneumonia, but no blood clots. My Hgb was 10 and white cells were 26000. I have gone through a couple of days of antibiotics and cycles of chills and sweats, but feel pretty good at the moment. But then just 4 hours ago, my temp was back up to 101.8 but just now was 100. I may have a few more cycles of temperature swings before this is over. Doctors just breezed through as well, said I would go on an oral antibiotic and that I could probably go home tomorrow. I told Marilyn that she should know I was sick since I had not been on a computer for two whole days.

Big brother (2006-05-30 15:09:00)

Sorry you were sick with pneumonia.

Glad they diagnosed it however.

We had a good trip home and back.

Did some work on roof and cleaning up in back shed.

Hope to talk with you by phone tonite.

Our prayers are going up to the throne of grace for you.

Home again (2006-05-31 17:11)

I just got home from the hospital. Marilyn picked me up about 4:15 and we stopped by McDonald's for a Flurry. First thing I did when I got home was to water my bushes. All of the storms on Memorial Day missed us here though maybe we will now get some rain tonight.

On the health front, my temp is 98.6. It was 101.8 early this morning, but reduced by Tylenol to 99 by 11am. White cell count was down to 11,000 from 26,000 on Sunday. I am on an oral antibiotic to finish off the pneumonia. My Hgb was down to 8.4 and the hospital doc thought they would give me blood this afternoon. He was surprised when I said no, because it would take at least a day to get a blood match. Then they were going to do it Thurs PM after my IgG IV in the morning. I then called the Hematologist office and they postponed it all until Friday.

I connected my computer to the office and worked about 3 hrs remote today. If I feel ok in the morning, I will go into work. If get tired, I will come home for a nap and possibly work more remote later. Of course, I can work from the day hospital on Friday as well, to minimize taking sick leave. Seems like I always get sick on a weekend or holiday, but that does minimize using sick leave. Actually, if I take more than 3 days sick leave spanning before and after a holiday, the holiday is counted as sick leave as well. That happened to me over Thanksgiving back in 2004.

Anonymous (2006-06-01 17:16:00)

Glad you are doing better. It sure is bad luck when you have to take sick leave during holidays.

Ken Brandt

Anonymous (2006-06-01 21:41:00)

We are so glad you are feeling better and are home again. That is great that the antibiotics worked so well. Marge

1.5 June

Last IgG (2006-06-02 22:24)

Since my last entry on Wed, I worked for 5 hrs on Thursday before getting tired. I came home for a nap and then spent a couple of hours cleaning maple spinner seeds out of the gutters and front lawn. I did not feel too bad though did not sleep very well last night. This morning I was up at 5:30am and the day hospital by 7:30am. I had both an IgG IV and two units of blood while getting in a couple of hours of work remote using my laptop. Would have done more, but did not have much to work on. Not much activity at work either on a Friday afternoon.

My blood analysis was all positive today. White cell count was down to 8100 from 26000 on Sunday. Hgb was surprisingly at 8.7 before the transfusion so should be 10.5 or more now. It was 8.4 on Wed, but may have been diluted by all the fluids they were dripping in me. My platelets were down to 259, right in middle of normal range of 150 to 450.

My hematologist stopped by at noon for a quick visit. Anyway, he said that the IgG seemed to be ineffective since I was now having transfusions every two weeks. So no more IgG. Also since my platelets are back under control, he reduced the Anagrelide to one .5mg pill a day. This essentially puts me back to January when we started experimenting with Prednisone, variations on the AG and IgG. Only difference is Levaquin antibiotic I take for the next week. I have a monthly appt with him next Wed when we will regroup and decide what to do next.

It was also great to have my sister and mother stop by for a short visit after lunch to break up the monotony. It was another 9 hour day watching drips after 72 hours of the same earlier this week.

Anna (2006-06-03 11:15:00)

dad, your blog name is kind of hard to remember. I can never get it right. so I'm going to link to it from my blog so that I don't lose it again.

Anonymous (2006-06-04 10:39:00)

I admire your spirit and stamina, and my prayers continue to be with you. EB

Rituxan (2006-06-07 21:41)

I saw my hematologist today and received a couple of surprises. First, my Hgb was 11.5, the highest that I have recorded. Unfortunately, my platelets were also the highest at 1050, up from 359 just last Friday. White cells and Factor 2 for clotting have remained unchanged. So I need to increase my anagrelide which I just reduced on Friday as well. It is very surprising that the platelets would increase so fast, but may be affected some by the Levaquin

antibiotic that I am still taking for the pneumonia.

The doctor also said he has one more thing to try, Rituxan, which is normally used to treat non-Hodgkins Lymphoma. Seems like there has been some success for treatment of autoimmune hemolytic anemia (AIHA) as well. He is still waiting for more blood tests taken today before moving ahead, maybe next week. If Rituxan does not work, a BMT in the September timeframe is the next alternative. I am investigating further.

Anonymous (2006-06-14 19:02:00)

Good luck with the new medication.

Ken Brandt

Good week (2006-06-14 20:54)

It has been a good week after a little vacation at the lake cabin near Bemidji. Went up Saturday and came back on Monday, missing the traffic. Beautiful evenings with the full moon over the lake. We beat back the lawn and weeds with surprisingly no mosquitos or wood ticks to bother us. Though it was cold with a high of about 65 degrees, the water temperature was 70 and I took a quick dip to wash up on Monday morning.

My blood test yesterday was pretty good as well. My hgb was still up at 10.8 and my platelets had reduced to 643. White cells and Factor 2 were in normal ranges. I talked with the doctor today and will be scheduling the Rituxan IV treatments for 4 weeks starting next week. I have read a little about it, noting about a 40 % success rate with a small study for anemia at Mayo Clinic. It has been used with 730,000 patients over 8 years, but a few have had fatal reactions during the first dose. I have a good history of no allergic reactions to medications yet, so it is worth a try. Your prayers are appreciated.

Anonymous (2006-06-16 16:35:00)

Joel,

Glad to hear you've had a good week. I continue to pray for you and the family. I am leaving for our AFLC annual conference in the Seattle area on Monday morning and return on Saturday. Pray for me as I have a lot of responsibility there. Happy Father's Day!

Love,

Charlotte

More Rituxan Info (2006-06-17 16:03)

In researching background materials relative to my upcoming Rituxan treatment, I came across a great web site, named [1]CLL Topics, covering CLL (Chronic Lymphocytic Leukemia) but also has information about [2]Stem Cell Transplants and [3]Rituxan treatments. It also has [4]warnings about the Procrit that I have been taking for the last ten months. Please note that a lot of this relates to patients with leukemia or tumors, neither of which I have. My white cell count was back down to 5.3 billion per liter last week where the normal range is 4 to 11.

My main problem now is AIHA (Auto-Immune Hemolytic Anemia) that is requiring my frequent blood transfusions. The article that brought me this web site included [5]Rituxan treatment for AIHA, plus also describes previous treatments of prednisone and IgG that I have had. Easier reading than most of this stuff if you are interested.

My Rituxan treatment starts Wednesday at 7:30 am. It was originally scheduled at noon, but they wanted more time to observe me before letting me go home. I may be there all day.

1. <http://www.clltopics.org/>
2. <http://www.clltopics.org/BMT/OnlyRealCure.htm>
3. <http://www.clltopics.org/Rituxan%20Basics/RituxanRoadBlock.htm>
4. <http://www.clltopics.org/Complications/EpoGettingDarker.htm>
5. <http://www.clltopics.org/Complications/AIHA.htm>

Anonymous (2006-06-17 18:12:00)
Sure hope this works!

Ken Brandt

Anonymous (2006-06-20 19:05:00)
Joel, We will be thinking of you and praying that all will go well. Marge

Rituxan & Purgatory (2006-06-22 21:50)

I had my first Rituxan IV treatment on Wednesday, starting early at about 8 am and finishing about 1 pm. They took it slower this first time and indicate it will speeded up next time. They started earlier than originally scheduled since they wanted more time to observe me, but observed me less than I normally get during a blood transfusion. The nurse took my blood pressure before starting, but that was all for the duration of the treatment. No temperature or any other follow-up. During a blood transfusion, my vitals are checked at least three times for each unit of blood. Actually, I was in a chemotherapy room with at least 12 patients and about 4 nurses. Observation was probably visual while asking me frequently if everything was OK. After the initial introduction of Rituxan, there is probably less risk of reaction than with blood from different people each time.

Before the IV, I also had my weekly blood test. My platelets were 503 and white cells were 4.4, both improvements since last week. My Hgb has dropped some more to 9.6, probably indicating another transfusion will be needed next week.

On a sad note, I attended the funeral of a co-worker that died of lung cancer last Sunday. He was 62 last Thursday, had worked for our company for 39 years and was taking early retirement at the end of this month. Over the past year, my office was close to his and we talked at least once a week, though his work time was very sparse since the first of the year. We often reminisced about the all the changes in computer technology over the years.

He had not been to work for three months and I had last called him at home almost two months ago. Thinking back, I wish I had been a better witness to him though I did direct him to this blog. He had a Catholic funeral mass this morning with very good attendance. Very little eulogy by the priest and an emphasis on baptism and communion as guarantee of eternal life. Made me remember childhood arguments with our Catholic neighbors about [1]Purgatory though there was no mention of that at the funeral today. I am just thankful to be saved by the grace of God through Christ's death and resurrection without needing to depend on others to speed my passage through the torment of purgatory.

1. <http://en.wikipedia.org/wiki/Purgatory>

Sonya (2006-06-23 09:22:00)

Dear Uncle Joel

I have been thinking a lot about you lately and praying a lot for you. I hope that you are not experiencing much pain.

Sonya

Wild Wednesday (2006-06-30 19:09)

I was in for my Rituxan IV on Wednesday. It only took 4 hours, from 12 noon to 4 pm, since I had no reaction last week and they speeded it up. My blood test before the IV showed that my Hgb had dropped to 8.2, from 9.6 last week, so I also had 2 units of blood this morning. My white cells were 3.7 (just a little low) and platelets were 503 (a little high and exactly the same as last week).

What made Wednesday wild was that both my mother and mother-in-law were in the hospital at the same time as I was. My mother-in-law was just coming home on Wed afternoon, but my mother was admitted after being taken to the emergency room on Tuesday night. She had a mini-stroke and lost a little control of her left hand. They discovered a blockage in her right carotid artery to her brain by using a CT scan. They did an angiogram on Wednesday afternoon and would have put a stent in, but discovered a large blood clot that was in danger of moving to the brain. Instead they gave her Plavix and heparin to reduce clotting and try to dissolve the clot. We discussed my blood clotting problems with the Doctor who did not think there was a connection.

My sister and I were visiting with her early Wednesday evening when she started to have difficulty speaking and yawned deeply. Her blood pressure dropped quickly and she passed out. This was shortly after 7 pm in the middle of a nursing shift change so she received plenty of quick attention. My other sister and older brother showed up just as this was happening. We thought that this was the big one and were prepared for her death. She was prepared as well and has mentioned frequently that she has had a good 88 years and is ready for heaven to join my father who died 2 1/2 years ago.

But God had a different plan. The drop in blood pressure was due to bleeding into her abdomen. Possibly the blood was too thin or the femoral artery was damaged during the angiogram when they ran a catheter from her groin up to her neck. Anyway, they gave her five units of blood and reversed the blood thinning drugs. By 11 pm when I left she was talking and moving fingers and toes. A CT scan showed that there was no stroke, but are concerned because of the possibility of more clotting. I saw her again at noon today after my blood transfusion and she is eating and talking fine. They are planning to try the stent again next week, but say she is a time bomb waiting to go off. God's plan did allow my younger brother time to get here and visit with her some over the past two days. It also has allowed us more time to discuss what life care directives should be used in a situation like this.

Anonymous (2006-07-01 13:54:00)

What a rough time for all of you. Hope things get better.

Ken Brandt

1.6 July

Blood Needed - Mom OK (2006-07-05 19:10)

I was in for my third Rituxan IV this morning at 7:30 am. Finished at 11:30 and was back to a meeting at work by noon. Worked two hours through VPN network this morning and six this afternoon. My weekly bloodtest showed an Hgb level of 9.1. It was 8.2 last Wednesday causing me to have a blood transfusion last Friday. It may have dropped to 7.8 or less by Friday and possibly increased to about 10 after the transfusion. Anyway, I will have another blood transfusion tomorrow, making it the shortest time (six days) between transfusions, not considering when I received 4 units over 1 to 2 days in the hospital. Each transfusion is normally 2 units, making this 35 total units over 17 transfusions since June 2004. Trying to keep the average Hgb higher, especially since I would like to go to the lake cabin on Friday.

While I was getting my IV, my mother was getting a stent put into her right carotid artery. Everything worked out OK and they even were able to retrieve the remainder of the old clot during the procedure. Thank God for an answer to prayers. I am heading out to visit her right after posting this blog entry.

Well with my soul (2006-07-08 20:15)

Marilyn and I are at the lake cabin. The moon is just rising in the East even as the sun is setting in the West. It is almost full and looks like it will be a clear evening to enjoy it reflecting off of Grace Lake. It has been a beautiful though hot day, close to 90 degrees, but will be back down to about 60 over night.

We have Anna's old iBook laptop with all kinds of music, video and podcasts stored in iTunes. One podcast from the Speaking of Faith public radio show caught my eye. I fired it up and we both were truly blessed. It was a interview with the late singer and educator Joe Carter, an expert on the African American Spiritual. He explains the origin of the spirituals and sings many of them.

He tells a story about Elijah and a woman who's son had died. When he asked her "How is it with thee?", she answered, "It is well with my soul!" He said that this is typical of especially older people who really have faith. This reminded me of my mother, though with all that she has been through in the last couple of weeks, does not complain. She sets a good example for me, reminding me that all that matters is the condition of my soul.

If you wish to listen to this podcast, you can download it to your PC at the [1]Speaking of Faith web site. You can also listen to his music directly on line.

1. <http://speakingoffaith.publicradio.org/programs/joecarter/index.shtml>

Delayed Status (2006-07-19 21:39)

Sorry that it has been 11 days since the last entry, but life has been slow. The Summer is half over and we are half-baked with about a full week of 90+ degree weather. It was actually 100 on our thermometer a couple of days. We finally got about an inch of rain and temperatures back in the 70s. Forecast looks more moderate for the weekend when Andrew and I will be up at the cabin. I pick him up from Bible camp on Friday and we head up to stay until Monday.

My energy is marginal for the weekend since my hemoglobin was 9.3 today, not quite low enough for a blood transfusion which I certainly will need next week. It only has been 13 days since the last transfusion and my Hgb only dropped from 10.0 last week. Maybe the Rituxan is taking effect and next week will be a good indication. My other counts are in the normal range with white cells at 4.9 and platelets at 436. Last week, my clotting Factor 2 was right on target at 20 so I am not getting it checked every week.

Since I reported on July 5, my mother has been moved to a nursing home and is doing well. She is now getting around some with a walker and had the catheter removed today. We played Scrabble Friday night and went to the chapel service on Sunday morning. When I left this evening she prayed for many people by name, mentioning facts in their lives that we had discussed recently. May God bless her and give us some more time to enjoy her company.

Fish Biting - Clouds (2006-07-23 16:45)

Andrew and I have been at the cabin on Grace Lake near Bemidji since Friday night. Planned to go back home on Monday, but may be tempted to stay a while. Temperature was near 80 yesterday and made it to about 87 today in the shade. I took the thermometer down to the lake where the water temp was at least 79 and the temp in the sun was close to 100.

The fish were biting, but I was not fishing. I think the crappies and sun fish in the lake have been cross-bred with piranha. When I walk into the lake, they swarm around me. If I stand still they try to nibble on my lake shoes, swim trunks and a dark growth on my shin. When I float in the inner tube, they try to bite the moles on my back. If I float on my front, they will "nibble my nipples". They are pestier than any of the flies. Thankfully, I have not seen a mosquito. Must be too dry.

We have a rubber raft that works ok to put something between my body and the fish, but it was too windy today. I quickly became winded trying to paddle against the wind just to stay in front of the cabin. Then I thought of a solution. We have springy steel and wicker style recliner. When on the porch, it springs back so far, it is almost impossible to get out of. But when placed in about a foot of lake water, it works beautifully. The waves cause it to bob up and down, scaring away the fish and continuously splashing water to keep me cool. I placed it under the white birches that overhang the lake and provide shade.

So where do the clouds come in? While cooling off in the lake, I looked up to the heavens and saw several types of clouds. Low in the sky were the cumulus clouds which seem to be constantly changing and could develop into cumulonimbus storm clouds. Just like troubles in our lives, these tend to block out the sun for a while and may develop into bigger storms. But high in the sky were some cirrus clouds at 20,000 feet or higher. These wispy clouds generally occur in fair weather and appear to me as angel's wings, showing God's grace and protection above all of my troubles. Also when next to the lake and when driving here through some wide open farm country, I could see the clouds for miles. There may be a cloud above my head blocking the sun, but not too far away, I can see the sunshine. Quite a change in weather from my [1]"Son Shine" post of Feb 19.

1. <http://myelo.us/2006/02/son-shine.html>

Another transfusion (2006-07-28 23:19)

As expected, I needed another blood transfusion this week. After getting back from the lake on Monday and feeling drug out, I went for a blood test on Tuesday, a day early. My Hgb was at 8.5 so I was back in on Wed for 2 units of "red

blood cells, leuko reduced and irradiated", the typical fare. My white cells and platelets were essentially unchanged in the normal ranges. I did not have my blood clotting checked, but will next week.

I went back to work 4 hours after the transfusion, but then on Thurs after lunch, I felt tired and went home to bed for the afternoon. Today, I felt fine and worked 9 hours. Tomorrow, I need to work on the 97 Malibu's front suspension which appears to have broken a spring.

Overall, it does not appear that the Rituxan is working, but will give it another 4 weeks before discussing a possible BMT.

I visited my mother at the nursing home on Wed and Thurs nights. She now has a bladder infection, but seemed to be more alert last night. When I got there, she was getting a shower and then stayed up until 9 pm with me while we watched "America's got talent" on TV. I did not make it there this evening, but instead got Marilyn's computer data recovered from her burned out eMac. That's another story that I plan to put on my neglected [1]Njerd blog.

1. <http://njerd.blogspot.com/>

Anna (2006-07-29 18:02:00)

Well I'm glad you got her data back, I'm sure mom is relieved about that!

1.7 August

Cycle Continues (2006-08-03 08:39)

Not much to write today, except for status on blood counts. Hgb is back down to 9.3 again, same as it was two weeks ago. After the blood transfusion, it probably went up to about 10.3 and then dropped a point during the week. A very typical cycle. I could have scheduled a blood transfusion for Friday, but planned to go to the lake cabin again, so that's what I am doing. When I get back on Monday, I will have my blood cross matched for a transfusion, probably on Wednesday.

My other blood factors remain about the same in normal ranges and prescriptions are same as well. Seems like just another week closer to a decision on a bone marrow transplant. Not sure how long I can keep up this cycle of transfusions, but while I do, the risks of a BMT increase.

Anonymous (2006-08-03 18:35:00)

Glad you can get to the lake!

Ken Brandt

Anonymous (2006-08-04 09:53:00)

I am standing by for the BMT if necessary.

We pray things will change for the better in the meantime.

Big Brother

Another transfusion (2006-08-11 22:48)

As expected, I needed another blood transfusion this week. After getting back from the lake on Monday and feeling drug out, I went for a blood test on Tuesday, a day early. My Hgb was at 8.5 so I was back in on Wed for 2 units of "red blood cells, leuko reduced and irradiated", the typical fare. My white cells and platelets were essentially unchanged in the normal ranges.

If the previous paragraph sounds familiar, it is. Identical to two weeks ago though I was not tired on Thursday and logged a full 40 hrs (including 8 hrs vacation) for the week. As before, it does not appear that the Rituxan is working, but have another 2 weeks before discussing a possible BMT with my doctor.

Like two weeks ago, I am also working more on the cars. Replaced the battery in the van last night and plan to replace rear struts on the Malibu tomorrow. I did replace the front struts two weekends ago and will get a full 4-wheel alignment after this.

I visited my mother at the nursing home on Wed and again tonight. She still has a bladder infection, but is progressing with physical therapy. My sister and I played Scrabble with her, but she beat us after 5 rounds.

Weekly update (2006-08-18 20:39)

Well, I had my blood tested on Wed with expected results. Hemoglobin is 9.5 with other components essentially unchanged. After the blood transfusion last week, it has probably dropped a point and will drop more by next week. I expect to see about 8.5 next Wed and get another blood transfusion. I also worked a full 40 hours this week, though had to come home for a quick nap this morning and take another when I got home this evening. I was also very itchy when I went to bed last night and woke up several times this last week with terrible leg pains. I have had a recurrence of canker sores and also frequent pimple-like sores that linger for weeks. These symptoms are typical of MPDs.

I also have an appointment with my hematologist on Wed and hopefully will get some direction on where we go from here. Not sure how much longer I can keep up these transfusions before I get iron overload or some other complication. (Interestingly, Marilyn is low on iron and will get extra through IV on Sept 1.) Maybe it is time to get on with the BMT. Certainly there will be a barrage of tests to check my health and the condition of my bone marrow.

BMT Possibilities (2006-08-24 22:25)

Well, I had another blood transfusion this week (Wed) as expected. My hemoglobin was 8.8 on Tuesday when I went in a day early since I wanted to get the transfusion as soon as possible. I was dragging over the weekend though I made it to my mother's 89th birthday party at the nursing home on Sunday night. My platelets were up to 573 and my Factor 2 was up to 31. I missed a day of medication on Saturday and had a big spinach salad at the birthday party. This most likely is related to the rise. Spinach is high in Vitamin K which counteracts the Coumadin.

I also met with my doctor on Wed along with Marilyn and Anna. We discussed what is next and were discouraged from putting much hope in a BMT. Dr still wants to try other treatments first, initially trying a combination of anagrelide and hydrea. I have reduced my anagrelide to one pill per day, rather than taking alternating between 1 and 2 pills each day. This what we tried in early June when I went for 5 days before platelets hit an all time high. My expectation is that this will not help, but Dr will add some hydrea to compensate. I don't expect frequency of transfusions to change though I did go for 28 days at that time. It seems like medicine reduces both platelets and

hgb.

The Dr did talk more about the possibility of a mini-BMT. In essence, they would use less chemotherapy and radiation so all of the old bone marrow would not be destroyed. The new donor stem cells would then battle the old bone marrow for dominance and hopefully take over. In this case, some studies indicate that it would be better to have a MUD (matched, but unrelated donor) than my brother donate the stem cells. The following [1]Only Real Cure article (which I referenced before) describes this very well. It also indicates that my chances of survival could be between 30 and 60 % after two years depending on how many penalty points I rate. I have not found any similar statistics for people receiving blood transfusions or the medicines that I am on. I will also need to add something like [2]Exjade to counter the buildup of iron from the transfusions.

This may not seem very encouraging, but I am thankful for each day that I have. I have survived at least 5 blood clots in my lungs where the chance of death were about 20 percent for each one. By all rights, I am living on borrowed time, by the grace of God. Think about it for a new perspective on life each day.

1. <http://www.clltopics.org/BMT/OnlyRealCure.htm>

2. http://salesandmarketingnetwork.com/news_release.php?ID=2008228&key=deferasirox

Charlotte (2006-08-25 11:18:00)

Dear Joel,

I just read the report on your meeting with the doctor. I continue in prayer for you and the family. The Lord is in control and I pray for healing for you if that would give God glory. The doctor must have good reasons for being reluctant to go ahead with the BMT. The MUD sounds interesting. May the Lord lead. I love you all.

Charlotte

Big brother (2006-08-26 09:45:00)

Sounds like you may be playing in the "MUD". Jesus used mud when he healed someone's eyes didn't HE?

Anonymous (2006-08-26 16:08:00)

Hope something works.

Ken Brandt

Weekly Update Again (2006-08-31 22:06)

It has been another week in what is a repeating two week cycle. Since the blood transfusion last week, my hemoglobin is back to 9.3. It probably was up to about 10.5 after the transfusion and by next Wednesday will be back down to around 8.5 again. Platelets and white cell counts were exactly the same even though I reduced my Anagrelide over the past week. Factor 2 was 16, almost half of the 31 last week, but within range of target 15-25 range. I didn't eat any spinach and fewer greens this week. It is a boring report but good that it is repeatable. Not much, but the frequency of my transfusions has changed in the last year. Then, I was on my third one with about 5 weeks between them.

On the iron storage measure, my ferritin level is 2272 where normal range is 12 to 300 for men and 12 to 150 for women. My doctor is still not concerned and my ferritin has actually gone down some since May. Marilyn's ferritin level is 7 and is getting an iron infusion tomorrow.

I just got back from visiting my mother at the nursing home. She will probably get to return to my sister Lola's house next Tuesday. Once she heard that she could get out if she could get around with a walker, she started

moving. Just needed some incentive. Bad news is that she will need a catheter and bag for her urine for the rest of her life. I was also there on Tuesday when we attended an organ concert and sing along. She seemed to enjoy that as much as I did.

I was up at 3am this morning and drove Anna and Andrew to the airport. They traveled with two cats and are safely at Anna's new apartment in Cambridge, MA this evening. Tomorrow, they tour MIT and Saturday recover Anna's shipped boxes from Amtrac. Sometime in there they are looking to buy some used furniture since all of Anna's is still back here in our garage. They will rent a ZIP car minivan in order to move this stuff. Andrew will be back home to start his senior year in high school on Tuesday. Anna will be starting her second year of graduate study at Harvard Divinity School.

Big brother (2006-09-02 09:54:00)

Thanks for the update.

That ferritin level sounds high.

Does that mean you have rust in your body?

We pray that a MUD can be found for you mini BMT.

1.8 September

Again (2006-09-05 22:35)

Again, my hemoglobin is down to 8.4 and I am scheduled for a transfusion on Thursday. This makes 43 units of red blood cells since my first and an average of every 18 days during this year. Other blood counts were essentially the same though platelets were down some to 534. Strange since they should go up with my reduction of Anagrelide.

Again, my mother is back in the hospital with another stroke. This one was caused by bleeding into her skull on the right side. A 2 inch spot was visible on the CT scan and is putting pressure on her brain. It happened early Monday morning and I met my sister, Charlotte, in the emergency room at 7:30am. Mom is still aware and recognizes people, but has extreme difficulty speaking. She was doing better today, but doctors don't hold much hope for her going home again. Sunday, she was moving on her own with the walker, had control of her bladder and would have gone back to Lola's today. A day later and everything has changed.

Anonymous (2006-09-06 18:09:00)

What a difficult sad time for you and your family.

Ken Brandt

Mom's status (2006-09-09 19:24)

Since I posted on Tuesday, I have had another blood transfusion (43 units over 21 sessions since first June 2005) and my mother has been going down hill. I visited her after my transfusion on Thursday and her response was minimal. Andrew and I visited again Thursday night and she seem to acknowledge when I said "I love you". I went to visit her today as my sister (Lola) relates in the following from an email message:

"Some of you know and some of you don't but my Mom had another stroke on Monday, the 4th of Sept. We were supposed to take her home this week but now she will soon be going home to heaven. She was able to talk

with us some the beginning of the week but as the week has progressed she has gone into a coma. Joel, (my brother), Don, another friend and I went to see my Mom this afternoon and had a little prayer service for her and sang a few songs. She seemed to try to open her eyes a little when we sang and prayed. It is difficult to see her like this but we know her greatest joy would be to wake up in heaven in the arms of Jesus. Please pray for us and for her these days. It may be a few days or it may be a week. It is hard to say how long it will be. Only God knows that."

My problems are forgotten in light of the current family situation. So many memories of my 58 years with my mother come to mind. She has had a good life of 89 years and is ready to go to be with Jesus and my father who died almost three years ago. As I sit with her it reminds me of sitting with my father five years ago and wondering what he was thinking. I related an analogy of a Butterfly on my [1]Story2Tell website at that time. Likewise, perhaps my mother is like a Butterfly as well or soon to be in a beautiful new body in heaven.

1. <http://story2tell2.us/Butterfly.htm>

Mother Butterfly (2006-09-17 22:42)

Sorry for the delay in posting, but my mother died last Monday. My sister called from the hospital just before lunch and my mother died in our arms about 3 hours later. It was difficult to tell whether she could comprehend anything we said to her in those final hours, but I imagine that she was more concerned about us and was in perfect peace, knowing she was going to a better place in heaven. We recited the 23rd Psalm as she took her final breaths. I personally gained strength from this experience, like a direct channel to heaven was open for her and we shared in the power of God accepting her soul. May I be as peaceful and trusting in the end.

Thankfully, my blood counts were good on Wed. My hemoglobin was 10.2, where by past experience the week after a transfusion, it should have been closer to 9.3. My platelets were fairly level with previous weeks. Anyway, it gave me added strength for the week and the funeral on Saturday.

I didn't work the rest of the week, but spent a few days putting together a photo slideshow tribute of my mother's life, from her baby picture to her [1]obituary. I had a lot of recent pictures from her 89th birthday party on August 20. I even scanned pictures from my mother's home on Friday night. The funeral home had a large screen tv which I used to cycle through the pictures throughout the visitation. One of these days I will get these posted on my web site as well.

The many tributes to my mother were tear-jerking. I was composed until my niece, Lori, spoke about my mother as a "Super Woman" who just kept going, working and serving everyone in any way she could. Lori related a story of when she was 8 and asked my mother if she could eat Thanksgiving dinner in the new living room with her big cousins. Then she accidentally dumped her full dinner from the tv tray unto the new carpet. My mother did not get mad, but cleaned up the mess while comforting my niece and making her feel at ease. That was my mother, always gracious and never getting mad. After Lori's story, I was an emotional wreck and could not speak myself. Thankfully, there was no shortage of tributes to my mother's life.

Remember the butterfly story about my father in my last post and the butterfly that showed up in the floral arrangement when I was in the hospital in Nov 2004. Why, there was also a butterfly at my mother's birthday party, there was one on the newspaper section of her obituary and also one on the program for her funeral. Coincidence? No, God-incidence as I once heard in a sermon. The butterfly has now emerged in a new heavenly body.

1. <http://www.dailypress.net/stories/articles.asp?articleID=4372>

Busy week (2006-09-23 21:27)

After getting back from Michigan (Mom's funeral) on Sunday, I took vacation on Monday to be with Andrew during and after his sinus surgery. Tuesday, I had an eye doctor's appointment and went home to sleep for a couple of hours to recover from the eye drops. Wednesday was a wild day. I had my blood test at 7:30am, took Andrew the doctor at 10:30, got a call to go back for a blood type & cross match at 2:30pm, stopped at DHL to pick up my repaired Mac laptop and still managed to work 7.5 hours before getting home about 7pm. I actually worked 9.8 hours on Thursday, trying to make up the time I had missed.

Since my hemoglobin was 10.2 a week ago, I really did not expect it to be 8.6 on Wednesday. I didn't expect it to be 10.2 before either. So I had a blood transfusion on Friday, but was not able to connect my laptop to the university network and to our work computers. Seems like my daughter's university network account has expired and I was out of range of the hospital's guest network. I ended up taking some sick leave to account for the missed hours.

So the count is 22 transfusions, 45 units of packed red blood cells and an average of 18 days between transfusions this year. The last 4 transfusions have been 14 or 15 days between since I slipped from transfusions on Wed to Friday.

Anna (2006-09-24 12:21:00)

I don't know why the account didn't work, I should have it until december.

Blood stats (2006-09-30 22:12)

Not a whole lot to report this week. I actually worked 41.5 hrs while getting in my blood test and taking Andrew to the doctor for his nose checkup. My blood stats are 9.8 for hemoglobin, 5.0 for white cells, 502 for platelets and 16 for Factor 2. Of primary interest is that my platelet count has actually dropped from 573 last month even though I reduced my anagrelide by 1/3. The last time my Anagrelide was dropped to this level, my platelets shot up from 259 to 1050 in 5 days though I also had just finished by the IgG transfusions.

I am sure that my hemoglobin will drop next week and I will have another blood transfusion . I also have another doctor appointment so may learn about what to expect next.

1.9 October

Memorial Service (2006-10-01 21:59)

We had a memorial service this afternoon for my mother at my sister's church in Bloomington. It was a beautiful service with many Minneapolis area people attending. I showed my slide show tribute to my mother during the service. I reduced it to 145 slides and synced it with music from Fernando Ortega: I will sing of my Redeemer and Hear me calling, great Redeemer. I also had the strength to get up and talk about my mother and thought I would summarize it here:

I was a Mommie's boy (at which point my sisters seem to say, Amen!) I was born on Mother's Day in 1948 and every birthday I had since, my mother would say I was the best Mother's Day gift she had received.

I was with my mother many times during the last week of her life and I was there with my sister when she died. Though she could not communicate with us, I believed that she was praying for me and others while we were praying for her. During the last moments of her life, my sister and I were reciting the 23rd Psalm. As the gates of Heaven opened for her and she went on through, I could sense the power of God and the joy within her soul.

I thanked the many people at the service who have been praying for me. The 22 blood transfusions that I have had over the past year have kept this earthly body of mine alive. But it was the big blood transfusion that Jesus Christ gave me on the cross that will keep me alive for all eternity.

Big Brother (2006-10-02 09:27:00)

Thanks for the summary of the memorial service. Thanks for playing F. Ortega's song "Hear Me Calling, Great Redeemer". Wish I could have been there.

Anonymous (2006-10-10 08:18:00)

Thanks for sharing about the service. I talked to big brother yesterday and he did appreciate it. I have had several positive comments on the slide show. The pastor said "who put that together?" he thought you had someone do it. It is an awesome tribute to our Mom. My prayers are with you

Anna (2006-10-18 13:58:00)

that was very beautiful dad.

Blood in Stool (2006-10-07 22:17)

Well, this was a busy week with a few surprises. Last Sunday night after my last blog entry, I had stomach cramps and then a strange bout of diarrhea. It had some dark stool plus something that looked like a worm. I took a sample in for test on Tuesday and blood was found. The "worm" must have just been something undigested. On Wednesday, the doctor said it looked like it might have been from a hemorrhoid, but gave me some cards to collect more samples. I have not been constipated and my hemorrhoids have not been hurting or itchy lately. This morning, I had another loose stool with another bloody piece. It has been about 18 months since I had a colonoscopy, but maybe I will need another.

I also had a transfusion on Thursday starting at 7 am and was back to work by noon. Friday, I had an all day conference at the Mystic Lake Casino, almost an hours drive south of here. I left home at 6:30 am (again) and did not get home until 6 pm. Even with a blood test, dr appt and transfusion, I still worked 42 hours for the week. When I got home Friday night, I went straight to bed for a couple of hours.

On Wed, my Hgb was 8.8, white cells were 5.0, platelets were 638 and Factor 2 was 15. Because of increased platelets and itchiness that I have had recently, I have to increase my Anagrelide again. I am also taking Benedryl for the itching from the histamine produced by excess platelets. I also have more headaches and take Tylenol several times a day. Today, I had vision distortion coupled with the headache and took a two hour nap after lunch. Also since it doesn't appear that the Procrit is helping any, I will stop taking it for a month to see what happens with my Hgb. That will at least save the insurance company \$2000 per month.

I did get outside today, shopped at Sam's Club, raked and blew some leaves around and fired up the old '76 Malibu. It started right up after I borrowed the battery from the van. It had not been started for close to a year and took a little cranking to get gas to the carburetor. One of the spark plugs is broken, so it misses a bit, but runs

surprisingly well. I need to get rid of it since it is just rusting away next to the garage. It has not been on the road for three years.

Big Brother (2006-10-09 10:43:00)

We hope the most recent symptoms are not serious. We continue to pray for you.

Anonymous (2006-10-10 08:20:00)

Little sister says:

Sorry to hear about the most recent symptoms. We will pray for you. My small group continues to pray for you too.

Anna (2006-10-18 13:57:00)

Oh, I should take my car back to Boston. I miss it.

More blood in stool (2006-10-14 21:18)

Since my last doctor appt, I took 3 stool samples in for testing on Wed. One the three showed blood confirming what it looked like to me. I assume the doctor still feels it is a bleeding hemorrhoid.

My other blood counts were typical: Hgb of 9.5, white cell count of 4.5, platelets a little lower to 439 and Factor 2 of 14. I reduced my Coumadin for one day to raise the Factor 2. I took my last Procrit shot on Monday. It supposedly took the Procrit some time to take effect so I expect I wouldn't see any big change this week. We suspect that it not helping anyway and my Hgb will not change from its current two week cycle.

I will probably need another transfusion on Thursday, but also need to break the two week cycle. I plan to attend a conference in Texas during Nov 13-16 which is 4 weeks away. I will try to get extra blood on Nov 2 or 9.

Cycle Continues (2006-10-20 23:45)

I am still on my regular cycle of blood transfusions every two weeks, like clockwork. I had my 24th transfusion yesterday, total of 49 units of blood so far. My blood counts were hgb=8.5, wc=4.5, platelets=433 and Factor 2=23. I was surprised that my Factor 2 was up after being low last week. I don't remember eating anything much different. My stools seem to have been normal over the past week as well. It has been over a week since I had my last Procrit shot. Procrit is supposed to stimulate red blood cell production. It will be interesting to see if it has any effect on my frequency of transfusions.

I had a hard time going to work this morning, but went since I had a meeting. Both my wife and son were home from school so I took a 1/2 day vacation in the afternoon. I am getting a little depressed about working though I am fortunate to be able to do so. I feel trapped because I have to work to get the insurance and pay the bills. There has to be more to this life, even the unknown portion that I have left.

Yesterday, I received a beautiful get-well card from my niece and her family. Made my day! It had some drawings of a fox, an octopus, a tank, a volcano and a person drawn by the kids. The card said "I am the Lord who heals you" and "Praying His healing power will restore you to health soon".

My daughter, my Harvard theologian, has some deep spiritual thoughts on her [1]Grace Freewill blog. Check

it out if you haven't recently. It helps me grapple with what I am going through, especially her recent studies on the books of Job and Kierkegaard. Maybe, I just need to be a "knight of faith" and should proceed with the BMT. Like Abraham, prepare for the worst outcome of a BMT with the faith that God will heal me through the process.

1. <http://gfreewill.blogspot.com/>

Anonymous (2006-10-21 18:06:00)

Glad you could take the half day of vacation to be with your family. I know it must be difficult to keep on going to work with everything else that is going on. As I have said before, you are a real "profile in courage" to be dealing with this the way that you are. M. Harter

Anonymous (2006-10-22 02:49:00)

I am impressed with your courage.

Ken Brandt

Blood History (2006-10-26 21:32)

[1] 

I thought I would do something different this week, otherwise it has been typical. I keep a medical history log in a spreadsheet. So far I have 192 entries starting six years ago. My records are sparse for the first four years with 17 entries up to October 19, 2004 when my orthopedist scheduled me for knee surgery (see my first blog entry). I actually started the log in early 2005 by reconstructing the history to that point. About six months ago when the doctor started experimenting with different medicines, I started a chart showing how my hemoglobin and platelet count varied with the changes in medication.

If you click on the graph shown here you can see a larger version. The date scale is not linear though pretty consistent with one entry per week over the last three months. Note that the top red line is my hemoglobin and the dark blue line is the platelet count (scale on left). The vertical bars are infusions with the red bars being my blood transfusions. The other lines are pills or shots. If anyone is actually interested in the details of the medications, just post a comment asking for more info.

So what does this show? In June 2005, I was hospitalized with a bad infection and high fever after getting a pneumonia vaccination. Before that my Hgb was steady around 10 and my platelets were normal count around 400. Then my platelets started up and doctor prescribed Hydrea. But the side effects caused me to switch to the Anagrelide (yellow) that I have been on ever since. The brown line is my Coumadin level which is varied to keep my Factor 2 between 15 and 25. That controls my blood clotting which is also affected some by the platelets. All the other medicines are attempts to control my hemoglobin and red cell count.

It will be interesting to see if stopping the Procrit will have any effect on my Hgb and frequency of blood transfusions. Over the last month, my Hgb has been inching down based on my regularity of getting my blood tests on either Tuesday or Wednesday. With my Hgb of 9.4 on Tuesday this week, I will probably go in for my blood test on Monday next week. One of these weeks, I have to get an extra unit of blood to get me through the week of November 13 when I plan to be in Dallas. Maybe I can get blood earlier next week (Nov 1) and then again the following week (Nov 10) when I also have my next doctor appointment. That should put my Hgb over 10 for the trip.

1. http://myelo.us/uploaded_images/MedicalGraph-788240.jpg

Big brother. (2006-10-28 10:23:00)

It is typical of engineers like us to want to graph and chart data to to see trnds and better interpret things. You are to be thanked for your work on this. I am sure this will help your doctors and other patients with similar symptoms.

The Whole World (2006-10-29 09:19)

I got home from work a little early on Friday and watched the end of "Millionaire". The last contestant went out on a \$2000 simple question about which continents the Sinai Peninsula was between (or part of). The obvious two choices were "Africa and Europe" or "Africa and Asia". The contestant chose it wrong as I would have. It actually is in Asia though part of Egypt which is part of Africa. It just didn't seem right that it (and Israel) are considered part of Asia. They are part of the Middle East or South West Asia.

Anyway, I Googled and found a web site named "[1]Ilike2learn.com". I spent about an hour taking their quizzes on where the countries are and didn't do very well. Just think, I am nearly 60 years old with a PhD and still have so much to learn. You can never stop learning.

Last night, I fired up "[2]Google Earth", a fantastic application. This is one program that sucks up bandwidth and taxes the dual processors of my new [3]MacBook Pro. I can fly around the whole earth and zoom into any area composed of satellite images all stitched together. I spent a couple of hours visiting North Korea, Japan, Tonga and the UP of Michigan. I relived my honeymoon trip to [4]Brockway Mountain Drive and [5]Tahquamenon Falls.

As I was doing this, I thought of the song, "He's got the whole world in his hands". With Google Earth, you can start with the earth at about 3 inches in diameter and it first zooms in so that the diameter of the earth and North America fills your screen. You can give the world a spin with your mouse or zoom in at any point to see houses and cars. You have the whole world in your hand and in your control. Imagine how great a God we have that can do this with the universe and still zoom in to touch our lives.

1. <http://www.ilike2learn.com/>
2. <http://earth.google.com/>
3. <http://njerd.blogspot.com/>
4. http://hunts-upguide.com/copper_harbor_brockway_mountain_drive.html
5. <http://www.exploringthenorth.com/tahqua/tahqua.html>

Big Brother (2006-10-30 12:00:00)

I don't know if I should try to Google Earth with my computer?

Anyway it is a good illustration of how God has the whole earth in His "hands".

Thanks brother. (My brother has always been my resource for the latest in computer and internet technology.)

Anonymous (2006-11-02 02:15:00)

i don't know why my computer won't let me go to certain websites. I tried the quiz one and I couldn't go there. but when i go into windows, I can usually get to sites that otherwise i can't. Apple is being weird.

1.10 November

50+ (2006-11-03 21:41)

Well, I reached a milestone of 51 units of blood received since June 2005. Over the last 9 times, the average time between has been essentially 2 weeks. I also have one scheduled for next week (Nov 9) to get ahead of the curve and prepare me to make it through the conference in Texas, Nov 13 - 16.

This has been a strange week health-wise. On Monday after my blood test at noon, I went back to work for a hour, then felt very tired and went home to bed. I worked a little at home to account for 6 hours. Tuesdays, I was all energized and worked 10.5 hours. Wednesday, I had the blood transfusion and worked 6 hours, 3 during the transfusion. Thursday, I worked 5 hours before going home with a bad headache at 1 pm and slept for 3 hours. Today, I felt better and worked 10 hours. In all that, I ended up taking 3 hours of sick time.

I may have some small virus since my white cell count was up to 7.3 on Monday. My Hgb was 8.6 (typical), but my platelets were up to 555. Strange though that I have energy one day and not the next. Other MPD patients have much more bouts of fatigue though.

I downloaded a new iTunes song this past week. Sung by Janet Paschal with great lyrics which I wish I had for you. The title says it all: "It won't rain always". Check it out for \$.99 at the [1]iTunes music store, the only way I buy music any more. iTunes is free for either Mac or Windows.

1. <http://www.apple.com/itunes/store/>

Anonymous (2006-11-05 21:57:00)

I admire your ability to be flexible—to come home and rest when you feel lousy and then to go back and work when you feel better. Sounds as though you are on a sort of roller coaster but that you are just "going with the flow." Sounds like a good way to do it. I am trying to do the same with my frequent colds. It's amazing how little work tasks that seem unbearable when one feels lousy are quite do-able when one feels better. Hope your trip to Texas goes well but that you stop and rest whenever you need to. Marge

The Heart (2006-11-05 23:07)

Tonight, I was reviewing old bookmarks that I have saved and came across the following on the [1]Christians Unite joke website. Look under the Doctors category for joke titled, "The Heart". Are you a lamb in His flock? Will the doctor find Jesus in your heart?

"Tomorrow morning," the surgeon began, "I'll open up your heart..."

"You'll find Jesus there," the boy interrupted.

The surgeon looked up, annoyed "I'll cut your heart open," he continued, to see how much damage has been done..."

"But when you open up my heart, you'll find Jesus in there," said the boy.

The surgeon looked to the parents, who Sat quietly. "When I see how much damage has been done, I'll sew your heart and chest back up, and I'll plan what to do next."

"But you'll find Jesus in my heart. The Bible says He lives there. The hymns all say He lives there. You'll find Him in my heart."

The surgeon had had enough. "I'll tell you what I'll find in your heart. I'll find damaged muscle, low blood supply, and weakened vessels. And I'll find out if I can make you well."

"You'll find Jesus there too. He lives there."

The surgeon left.

The surgeon sat in his office, recording his notes from the surgery, "...damaged aorta, damaged pulmonary vein, widespread muscle degeneration. No hope for transplant, no hope for cure. Therapy: painkillers and bed rest. Prognosis:," here he paused, "death within one year."

He stopped the recorder, but there was more to be said. "Why?" he asked aloud. "Why did You do this? You've put him here; You've put him in this pain; and You've cursed him to an early death. Why?"

The Lord answered and said, "The boy, My lamb, was not meant for your flock for long, for he is a part of My flock, and will forever be. Here, in My flock, he will feel no pain, and will be comforted as you cannot imagine. His parents will one day join him here, and they will know peace, and My flock will continue to grow."

The surgeon's tears were hot, but his anger was hotter. "You created that boy, and You created that heart. He'll be dead in months. Why?"

The Lord answered, "The boy, My lamb, shall return to My flock, for He has Done his duty: I did not put My lamb with your flock to lose him, but to retrieve another lost lamb."

The surgeon wept.. The surgeon sat beside the boy's bed; the boy's parents sat across from him. The boy awoke and whispered, "Did you cut open my heart?"

"Yes," said the surgeon.

"What did you find?" asked the boy.

"I found Jesus there," said the surgeon.

1. <http://jokes.christiansunite.com/>

Anonymous (2006-11-06 11:53:00)

What a great story. I think you are doing a great job managing your energy by resting when necessary. Hope you enjoy the convention.

Ken BBrandt

BMT Option Back (2006-11-07 23:41)

I had a couple of surprises today. My hemoglobin was only 9.1 and my doctor says to start planning for a BMT (blood marrow transplant).

It was only 8 days since my transfusion last week and I expected my Hgb to be about 9.6, the average of my Hgb measured a week after the last 6 transfusions. I was already scheduled for a transfusion on Thursday, in preparation for the trip to Texas next week. If I wasn't, the doctor would have scheduled one anyway. I hope I make it through next week, but will be in for a blood test on the 17th, right after I get back.

Back in August, the doctor said that a BMT would be too risky and a last resort. Today, he said that he recommends we proceed with one. It turns out that my last two [1]Coombs (direct antiglobulin) tests have been negative, meaning that my immune system is not destroying my red blood cells as we thought it was before. I also stopped taking Procrit a month ago and did not see any immediate change. The doctor does not think that the Coombs test result is related to the Procrit. This is all complicated by the fact that my Anagrelide medicine, needed to reduce platelets, also reduces red blood cell production. We need to take another BMB (bone marrow biopsy) to see what is happening where the blood cells are produced.

The current thought is to wait until January for the BMB which would followed by a BMT within one month. The doctor recommends a mini-BMT where the chemotherapy and radiation does not completely wipe out all of my current bone marrow and also does not kill me off before the new stem cells can engraft in the bone marrow. The new bone marrow would hopefully finish off the old bone marrow. He also says that my brother's marrow (stem cells) could still be used, but that umbilical cord stem cells may be used instead. Cord cells are taken from the umbilical cord blood (UCB) of a newborn baby. That is beneficial since UCB has not accumulated a lot of antibodies. The U of MN has one of the most experienced [2]UCB transplant units in the country. (Note that the linked Fairview web site is one of the top returns when searching for "cord bmt" in Google.)

My current thought is to get another opinion from Mayo Clinic in Rochester, but would go with the U of MN and Fairview for the BMT.

1. <http://www.itxm.org/TMU2000/tmu10-2000.htm>

2. http://www.fairviewbmt.org/Program_Information/Umbilical_Cord_Blood_Program/index.asp

Anonymous (2006-11-09 10:07:00)

I am glad you are planning to get the BMT. The status quo must be getting unbearable.

Ken Brandt

Big brother (2006-11-09 20:06:00)

The mini BMT sounds like a good idea.

We will keep praying.

Anonymous (2006-11-10 19:38:00)

This is an interesting and potentially hopeful turn of events, isn't it? Glad you are getting a second opinion, though. Marge

Two years (2006-11-12 18:13)

I knew it was close but just realized today that it has been exactly two years since I entered the hospital with a lump and labored breathing. See "The Mystery Begins", my second blog entry. The lump turned out to be an ingrown hair and the labored breathing was a pulmonary embolism, possibly 3 blood clots in my right lung. I have had at least two clots since then. With a 20 % mortality rate for a blood clot, by all rights, it is a miracle that I am still here today.

So what does the future hold? A BMT has a mortality rate of 40 to 60 percent, depending on many factors. Or is that a survival rate? Is the glass half-full or half-empty? When asked this question, an engineer might say that the glass was twice as large as it needed to be. How many years of life do you or I need?

Here are some wise words from this morning's sermon by [1]Dr. Robert H. Schuller, titled "The 10 Commandments of Thankful Living", :

"I'm seventy-eight years old and it still shocks me to say that I have never had anything happen in my life, including tragedies, near disasters, that did not turn out to be blessings in disguise. "

...

"Are you disappointed or discouraged today? Don't turn the TV set off. Don't close the book. Don't walk out of the movie ... the story isn't over yet. Give your story a happy ending. Thank God for the hope that springs eternal. Because of Jesus Christ, we know that life has no end."

...

"God will always have the last word, and it will be beautiful! Hallelujah."

With God, the glass will not become empty, but is being continually refilled. Just like when Jesus turned water into wine ([2]John 2:1-11). "Everyone brings out the choice wine first and then the cheaper wine after the guests have had too much to drink; but you have saved the best till now."

1. <http://www.hourofpower.org/booklets/bookletdetail.cfm?ArticleID=4628>

2. http://www.biblegateway.com/passage/?book_id=50&chapter=2&version=31

Anonymous (2006-11-15 20:38:00)

That is a beautiful meditation on life. Thank you for sharing it. MH

Rough week (2006-11-18 10:17)

I traveled to Texas on Monday and woke up with a dry, sore throat on Tuesday. Though I could not speak very well I attended about 8 hours of the conference. The place, [1]Gaylord Texan Resort, was so large and spread out that I had to walk too much. Tuesday night I slept for 12 hours. I attended most of the meetings but skipped the social times which would have required standing and talking. The flight back on Thursday was great. I caught an earlier flight and took a couple of Benedryl. It wasn't until evening that I got some pain in my right ear. I took some Drixoral, slept ok and went to work on Friday (yesterday). Since I had a blood test set up, I called ahead and was able to see the physician assistant as well and got an antibiotic prescription.

Last night I took the initial dose (2 x 250mg) of Azithromycin along with another Drixoral about 5 pm, but within an hour started experiencing rapid and irregular heart beat. This was similar, but not as bad as I had in March when I went to the emergency room. We called the triage doctor on call who advised me to just rest and see it through. By 9 pm, I was feeling better, but skipped my evening Anagrelide pill which also sometimes affects my heart rate. This morning, I am just into trying to throw this infection off. Now just congestion, sinus pressure, drainage and coughing up nasty stuff.

My blood tests results were mixed again. White cell count was up to 10.9 as a result of the infection. Platelets were 422 which is good. Hgb was 9.0, meaning I am scheduled for another blood transfusion on Monday. Its a good thing I had the last transfusion before going to Texas or last nights episode would have been more difficult with any lower Hgb. The average time between transfusions has dropped to 11 days over the past month.

1. <http://www.gaylordhotels.com/gaylordtexas/>

Big Brother (2006-11-20 10:28:00)

We will pray for recovery from this latest infection.

Anonymous (2006-11-20 23:21:00)

What bad luck! Hope things get better soon.

Ken Brandt

Mayo Appointment (2006-11-21 23:48)

My procrastination is over. I finally made an appointment with [1]Dr Alalew Tefferi at the Mayo Clinic in Rochester, MN on January 8. I could have gotten in as early as December 20, but delayed until January. This way I should be able to have one bone marrow biopsy that would satisfy Mayo and still be timely for U of MN prep for possible BMT in February. Dr. Tefferi is recognized as one of the leading authorities on MPD in the world. Not a day goes by where he is not mentioned on one of the MPD email lists that I subscribe to.

On current status, I had a blood transfusion yesterday, #27 for a total of 55 units so far. My Hgb was down to 8.6 and platelets were 445. White cells were down to 8.1, indicating improvement on my sinus head cold which has almost cleared up. I took my last Azithromycin today and currently only have a slight headache.

1. <http://www.mayoclinic.org/hematology-rst/10441646.html>

Anonymous (2006-11-23 01:59:00)

Good plan! Hope things go well.

Ken Brandt

Heinz 57 (2006-11-30 23:24)

Maybe I now have [1]Heinz 57 steak sauce running in my veins. That is, I now have had 57 units of red blood cells transfused, most likely from 57 different donors. Each unit potentially leaves a trace of its anti-bodies behind. But since red blood cells live about 120 days, any that I received before the last 20 units are long gone. It took me about a year to get the first 29 units, but only six months to get the rest.

I was surprised that my Hgb was only 8.7 on Tuesday, requiring the transfusion that I had this morning. It was only 10 days since the last one and the average time is now 16 days for this year.

1. <http://www.snopes.com/business/hidden/heinz57.asp>

1.11 December

BMB Scheduled (2006-12-05 22:53)

I was in for my weekly blood test today and learned that I am scheduled for a bone marrow biopsy (BMB) on Monday, Dec 11. Doctor wants it in prep for my appt with him on Dec 13. I think he also wants it prior to my

visit to Mayo in January. The last BMB was on January 11 while I was in Fairview Hospital. My Hgb had dropped to 7.2 after over 3 months being stable at about 9.5. The BMB is the key test as to whether I need the BMT in February.

Surprisingly, my hemoglobin was 10.2 today. I would have guessed that it was closer to 9.2 considering how it has been going recently. White cell and platelet counts were normal. I will probably need a transfusion next week as well, but that is better than needing one this week. Maybe, it will get back to every other week.

Anonymous (2006-12-06 19:29:00)

I hope things go well with the BMB.

Ken Brandt

BMB Experience (2006-12-11 21:57)

Even though I have had a [1]Bone Marrow Biopsy (BMB) three times before, the one this morning was a different experience. I had my first in March, 2005, at the Masonic Day Hospital, the same place as today. My wife came with and drove me home afterwards since I had some sedative prior to the procedure. Today, I did not have a sedative since I was driving myself. My second BMB was in May, 2005, at Mayo Clinic where I had no sedative but don't remember a lot of pain. I drove back home afterwards. My third was while in Fairview Hospital in January for other tests as well. I must have had a sedative at that time as well, even though I didn't go anywhere afterwards. Next time I think I will have a sedative.

Some things may be changing with my bones as well since it took four attempts to get the bone marrow sample this morning. Though I did not have sedative, I did have some local Lidocaine to numb the tissue in the test area. The local anesthetic does not numb the interior of the bone. The first attempt hit upon scar tissue or hard bone that the tool could not penetrate easily. (A [2]bone marrow biopsy uses a special tool that twists into the bone. You may feel pressure at the site and hear a crunching sound as the tool twists into the bone.) The second and third attempts hit soft marrow that crushed easily and did not provide a good sample. These two attempts were the most painful, once making pain shoot down my left leg. The fourth attempt was good retrieving a sample about 2 cm long and about 3 mm in diameter. Four samples of aspirate were also sucked from the bone marrow, about 10 ml total volume.

Even though I had three or four holes drilled in my hip bone, there was little pain afterwards and I drove back to work. But after a couple of hours at work, I decided to go home to my recliner since sitting in my desk chair was somewhat uncomfortable. A couple of Tylenol helped as well.

I also had a blood test this morning. While my hemoglobin was 10.2 last Tuesday, it was only 8.2 this morning, the biggest drop in six days that I have had. Maybe the bigger difference is error in the tests or variations by different lab technicians. I will get the results of the BMB and will have another transfusion on Wednesday.

1. <http://www.mayoclinic.com/health/bone-marrow-biopsy/CA00068>

2. http://www.webmd.com/hw/lab_tests/hw200221.asp

Anonymous (2006-12-12 11:12:00)

I'm sorry it hurt so bad!

Anonymous (2007-01-02 22:06:00)

Wow, you are pretty tough Uncle Joel. I never do bone biopsies on anyone without using a lot of sedation since they can be so painful. You are in our prayers.

Love,
Mark

BMB Results Delayed (2006-12-14 23:49)

I saw the doctor yesterday, but he did not have the final results of the BMB yet. Still very similar to previous ones so far with more blasts (young cells) and fewer red blood cells. The term myelodysplastic and myeloproliferative are still being used. Will know more later and then get opinion from Mayo in about a month. Since it does appear that the RBC production has dropped since I stopped the Procrit, he prescribed Anasesp which is similar. I will get a shot every two weeks when I am in for my blood test. My BMB puncture wound is healed, at least on the outside. I have had little pain since the BMB and main discomfort was from the bandage.

Anonymous (2006-12-17 20:14:00)

I am so sorry that you are having to go through this. I agree with you that it might be a good idea to hold out for a sedative next time, even if it means that someone needs to drive you home or that you end up taking a cab, etc. M.H.

Transfusion #30 (2006-12-22 00:29)

Well, I had another transfusion today. While pretty routine now, the biggest story was in the scheduling. Prior to my previous transfusion on Wed, Dec 13, my Hgb was 8.2, so it was no surprise that my HGB was 9.3 yesterday. Because of the Christmas holiday coming up, I pushed for a transfusion on Friday. But there was no room at the "Inn". All of the alternative clinics at the Fairview U of MN medical center were booked up. The earliest that I could get in was on Tues, Dec 26. By then, my Hgb would certainly be close to 8 and wouldn't have the energy to really enjoy Christmas.

My doctor said he would "throw his weight around" to get me in, but called me back this morning saying that "he was not heavy enough". I had two alternatives: check into the hospital or go to the emergency room, either of which insurance might not pay for. Of course, if I did have real shortness of breath or heart problems like I did back in March (Hgb dropped to 5.9), I would have no problem going to the emergency room.

So after deciding I would wait until Tuesday, I received a phone call at work this morning. The Day Hospital where I have my transfusions had a cancellation and my blood was ready. The big snow storm (2" for us) caused someone to cancel, providing time for me. It also turned out that I no longer need to wait 2 days for a blood match, since my Coombs test is now negative.

So I had my 30th transfusion and 61st unit of packed red blood cells during mid-day and made it back to work for a few hours this afternoon. Instead of dragging this weekend, I should be at my highest energy (Hgb) level since June. I also have made an appt for Jan 3 for another transfusion so that I don't get caught in the after New Years scheduling rush.

Since I probably will not post again until next week, remember that "Jesus is the reason for the season." Have a Merry Christmas.

Anonymous (2006-12-25 15:40:00)

Glad you could get in for the transfusion, and hope you are having a nice Christmas!
MBH, BJB, and EGB

Transfusion #31 (2006-12-30 00:47)

I didn't expect it to be so soon, but I had another transfusion yesterday (Thursday). When I went in for my blood test and Aranesp shot on Tuesday, my Hgb was down to 9.4. The week before on Wednesday, it was 9.3 and I had a blood transfusion the following day. I really expected it to be higher this week, but ended up in the same situation as last week where my Hgb would drop below 9 by the weekend. I had no problem in getting in for a transfusion this week. Actually, the lab now draws enough blood for a type & cross match when they do the standard blood test. I am already scheduled for a transfusion next week, anticipating they will be busy after the New Year holiday.

My other blood counts are normal. I have ordered a copy of my records to take to Mayo Clinic on January 8th and look forward to making a decision of what to do next. BMT?

2. 2007

2.1 January

iWoz vs I AM (2007-01-01 22:10)

I recently read the autobiography of Steve Wozniak titled "iWoz". Steve was the creator of the original Apple computer. You can read my review of the book on my technical blog [1]njerd.blogspot.com

After reading the book, I realized that an autobiography is an "I was" story. Considering my health situation, I have started my own autobiography, not to publish, but as a legacy for my family and future generations. Believe me, it is difficult to do under the circumstances, but something I wish all of my ancestors had done. It is difficult to remember those early years, even the later years. But every time I work some more at it, I cannot help but think of the future. What is in store for me over the next year? Will I survive a BMT? If I do, what torture do I have to endure from GVHD (Graft vs Host Disease)? Why me?

Then I remembered what God told Moses in [2]Exodus 3:14, "I am who I am" and that Moses was to tell the Israelites, "I AM has sent me to you". God says his name is "I AM", not "I WAS". God is the same yesterday, today and forever. I just need to remember that through my belief in His grace that "I am" forever as well. This body is just my earthly home though I would like to live here as long as possible.

1. <http://njerd.blogspot.com/2006/12/iwoz.html>

2. <http://www.biblegateway.com/passage/?search=Exodus%203:13-15;&version=31;>

Anonymous (2007-01-02 19:59:00)

Your blog was thoughtful, profound, and inspiring. Good for you!

Ken Brandt

Anonymous (2007-01-02 22:31:00)

That is great that you are writing your autobiography, which I know will be cherished by your family and by future generations. You are dealing with this health adversity that you are going through with a lot of class and are an excellent role model for the rest of us. Thank you for that. MBH

Hgb - Chocolate Theory (2007-01-03 00:13)

Surprise, my hemoglobin was 11.1 today, the highest since last June when it hit 11.5. But at that time, it was after cutting my Anagrelide from 2 pills per day to 1. At that time my platelets also hit a high of 1050 which was not good. Within one week, I was back to 1.5 pills per day to get the platelets back down. I was still on Procrit at that time as well.

So what did I do different in the last week? Was it the eggnog, the turkey or the Aranesp? I had my second Aranesp shot last Tuesday, but then I had a little Hgb rise to 10.2 after Thanksgiving turkey as well. I also drank a gallon of chocolate milk last week and ate many helpings of chocolate candy. Chocolate seems like the best theory to me, so I will go have some more fudge.

Anyway, I do not need a transfusion this week and will be at Mayo Clinic on Monday. BMT decision time is getting closer.

Anonymous (2007-01-03 21:33:00)

Yes, it sounds as though your theory is a good one. Definitely a good excuse to enjoy some more chocolate fudge! MBH

Anonymous (2007-01-03 21:35:00)

That is a very cute little boy pictured on your home page. It's great that you have kept track of your childhood photos. MBH

Anonymous (2007-01-04 19:15:00)

We are all thinking of you and praying for you, and are so admiring of the way in which you are coping with this. It's great to see the nice photo and such a wonderful thing to begin writing your autobiography. I'm sure it will be very much treasured. We hope things at the Mayo Clinic go well. BJB

Mayo Results (2007-01-08 21:03)

Well, it seems like I have been to Mecca. Got back from the Mayo Clinic in Rochester about an hour ago. After driving down this morning for a blood test at 10 am, I met with Dr. Alayew Tefferi about 3:30pm. I actually met with a med student from India for about 45 minutes while she reviewed my case and summarized it for the Dr. I spent only about 10 minutes with the Dr.

In summary, he cut right to the chase, saying that I was seeing him because he was THE expert. He said that I had chronic myeloid disease, a general term to cover all the variations of MPD and MDS. It does not matter what you call it since it eventually all leads to AML, acute myelocytic leukemia, when the bone marrow shuts down and all blood counts drop. Medicines and transfusions can reduce the symptoms but it is just a matter of time, maybe 5 years. He did say that my current marrow was not that critical, with less than 5 % blasts (undeveloped cells). He looked me straight in the eye, with his hand on my knee and said "If you were my brother, I would recommend a BMT, sooner rather than later". He said my brother's marrow stem cells were the best option and if I delayed further that they should be harvested and frozen. As I was driving home, listening a classical music station on the radio, I stopped at the Trinity Lone Oak Church in Eagan for a stretch and a short prayer asking God to tell me what to do. Then I got to thinking. What better sign than one of the top (self-acclaimed) experts in the world telling me what he would tell his brother. Time to start planning in earnest.

Interestingly, my Hgb was still up at 10.1 today though still a typical drop of 1 point over the past week. Looks like I can delay a transfusion another week. I still need to go in for a Aranesp shot this week. Maybe that stuff is working though I am still working the chocolate milk theory.

Anonymous (2007-01-09 19:12:00)

Glad you got another expert opinion.

Hope things go well.

Ken Brandt

Big brother (2007-01-10 11:05:00)

Brother: Let me know the next step in the schedule. The chocolate theory sounds best to me too. Shall I be eating more chocolate?

And isn't there a verse in the Bible that says "Jesus stays closer than a brother"?

Anonymous (2007-01-11 10:11:00)

we will be praying for the plans for the BMT.

your little sister

Transfusion #32 (2007-01-10 20:38)

I didn't expect it to be so soon, but I will have another transfusion tomorrow (Thursday). This will make the count 65 units of blood. When I went in for my blood test and Aranesp shot today, my Hgb was down to 9.4. On Monday at Mayo Clinic, it was 10.1 and I did not expect it to drop .6 in two days. I ended up in the same situation as last week where my Hgb could drop below 9 by the weekend. I could not chance making it to next week since Monday is a holiday again (Martin Luther Day). I already had an appointment for a transfusion scheduled for tomorrow; just did not think I would need to use it. I was scheduled for a transfusion last week as well and then did not need it. I cannot predict the next week and cannot guess what my Hgb is going to be when I get it checked. Probably another symptom of my failing bone marrow and time to address the problem with a BMT.

My other blood counts are normal.

Anonymous (2007-01-15 14:29:00)

Sorry that you had to have another transfusion, but glad that you got an opinion from a world expert. Best wishes as you continue to think and plan.

Anonymous (2007-01-17 21:36:00)

Hi Joel, just read your latest blog. I know chocolate has loads of antioxidants (how spelled) in it. The darker the chocolate the better. JP and I have a piece everyday instead of other deserts. It has been proven, Look it up. We get Hersey darkest chocolate bars at Walgreens two for \$3. Go for the BMT. You will have a lot of prayers behind you. God Bless, SAP & JP. Neighbors

BMT Planned (2007-01-17 22:59)

Well, I met with my U of MN doctor today and decided to plan the BMT for around May 1st. This will be the best for my family since I will spend the first 3 to 6 weeks in the hospital and then will need to be isolated at home for another 8 to 11 weeks. The first 100 days are the most critical while the new bone marrow takes hold and my immune system is restored. The doctor will contact the BMT Center and we will meet next on March 7.

My Hgb was 10.2 today so I can wait until next week for another blood transfusion. Next week will be wild with a dentist appt as well. I should work a little extra this week to compensate. I am thankful that I feel as good as I do right now and it seems strange that I am going ahead with the BMT. "Walking through the valley of the shadow of death" (Psalm 23:4) is taking on a whole new meaning.

Anonymous (2007-01-20 22:18:00)

I hope and pray that the BMT will help and certainly wish you and your family the best as you plan for it. It might be nice to have some time as you recuperate to read, do computer stuff, etc. MBH

Anonymous (2007-01-23 00:40:00)

I hope things go well. It seems like a wise choice.

Ken Brandt

Transfusion #33 (2007-01-25 00:01)

I didn't expect it to be so soon, but I had another transfusion yesterday (Tuesday). This makes the count 67 units of blood. I felt so tired Monday morning that I went home from work at 11am and took a 2 hour nap. I then called the clinic and got in that afternoon, a day early for my blood test and Aranesp shot. My Hgb was down to 9.0 so they got me in for a transfusion on Tuesday instead of Thursday. I felt like my hgb was even lower then and needed a nap this evening as well. It was 12 days since the last transfusion and the running average over last 4 times is now 10 days. As typical over the last couple of months, I made an appt for a transfusion for next week (Thursday) as well.

My other blood counts are normal.

Anonymous (2007-01-25 21:23:00)

Thank goodness for transfusions! It sounds as though they make a big difference. Glad you are taking naps when you feel you need to. MBH

Anonymous (2007-01-29 23:06:00)

I have been following your progress and I hope things go well with you. Like I said before take care of yourself first and the rest will follow. I know the way you worked in the past and I think you have always put too much time into it. Once you get your BMT (not the subway kind) and you start to feel better you can go back to your normal routine.

I do not have a google account so I signed write this under Anonymous. I will keep following your progress and be praying for you.

Your friend and X-Coworker.

Domingo

2.2 February

Transfusion #34 (2007-02-01 23:03)

Sounds like a broken record, but I had another transfusion today, only 9 days since the last. This makes the count 69 units of blood. I was in for my weekly blood test on Tuesday and discovered my hgb was 9.2. Yesterday, I felt so tired that I went home from work after lunch and slept the whole afternoon. After the transfusion today, I still took another nap as well. I have also had a lot of headaches and have been very itchy lately. I take Tylenol and Benedryl several times a day in addition to my regular medicines. As typical over the last couple of months, I made an appt for a transfusion for next week (Thursday) as well.

My other blood counts are normal.

Big brother (2007-02-02 10:50:00)

Itchy symptoms maybe due to allergic reactions to Benedryl or just dry air from heating system in the winter.

Still praying and hoping for the best.

OK this week (2007-02-07 20:52)

Turns out my Hgb was 10.0 on Tuesday so that I don't need a blood transfusion this week. But figuring the typical drop in Hgb, I scheduled one for next Tuesday after a blood test on Monday. Other blood counts were 346 for platelets, 6.6 for white cells and 19 for Factor 2, all of which are normal.

Though just a formality, I received official approval from my insurance company to proceed with the BMT. Doctor has also approved my travel to a conference on April 12-15. I still need to get company approval for the travel expenses.

Anonymous (2007-02-08 19:42:00)

Glad you got the approvals. Hope you enjoy the conference.

Ken Brandt

Victorious Engineer (2007-02-13 00:14)

Before I explain the title of this blog, my Hgb was 9.1 today and I will have transfusion #35 and my 71st unit of blood tomorrow afternoon. When I went in for my blood test today, I really thought my hgb would be lower since I felt more winded than usual and have been having frequent headaches, another symptom of low oxygen levels.

Last week, I saw a TV commercial that stated that elevated CO levels cause the same symptoms and that CO detectors become less effective with age. Ours was over 6 years old and should be replaced every 5 years. Since temperatures here were below zero for a whole week, our furnace had also been working overtime. I bought 2 new CO detectors, one with a digital display. The display has been reading zero every day downstairs near the furnace. The other unit is upstairs near our bedrooms.

Back to the title, I received a personal invitation to the "[1]The Congress on the Future of Engineering Software" last week and approval from my employer to attend. The conference is on April 12-15, within about 2 weeks of my planned BMT. Doctor says it is OK for me to travel out to Scottsdale, AZ which is also near a branch of Mayo Clinic. Anyway, I appreciate the vote of confidence from my employer as well as my family and the doctor. I have something to contribute to this conference and to gain for use after my recovery from the BMT.

I AM getting there on the title. One of the principals in the conference is a very talented journalist named [2]Joel Orr. A good first name, don't you think. Well, back in 1999, I received a book written by him as a gift after hints to my wife. Remembering the book, I went to my bookcase. There it was, "[3]The Victorious Engineer". Not a coincidence, but a "Godincidence" which I consider further support for my decision to move ahead. I will be victorious over this disease as Christ was over death.

In reviewing the book again, I could quote positive encouraging statements from almost every page. For example, on the title page:

"A man who wins may have been counted out several times, but he did not hear the referee." H.E. Jansen

In the preface, "Of all human types, the engineer is one of the most God-like. Engineers design and make things of all kinds."

On the back page, Joel Orr states, "But all that comes to me is a quiet bubbling thankfulness ... and to God for giving me this wonderful life." He ends with "The Lord bless thee and keep thee; the Lord make His face shine upon thee; the Lord lift up His countenance upon thee and give thee peace."

After reading one of his articles years ago, I sent him an email asking him if he was a Christian. To paraphrase his answer since I don't have the exact words of his reply:

"If I am ever indicted for being a Christian, may there be enough evidence to convict me."

1. <http://cofes.com/>
2. <http://joelorr.com/>
3. <http://joelorr.squarespace.com/joel-writes/>

Anonymous (2007-02-13 12:04:00)

I like the analogy of the Victorious Engineer and your planned BMT. We pray that it will be truly victorious for you!! You are in our thoughts and prayers.

Your little sister

Anonymous (2007-02-13 19:52:00)

Congratulations on being selected to attend the conference. Maintaining your high performance in your profession improves chances for a successful recovery from the BMT.

Ken Brandt

Big brother (2007-02-14 10:14:00)

I never heard of that book.
Sounds interesting. Thanks for your comments. I will have to get a copy.

Transfusion #36 (2007-02-22 20:00)

Still sounds like a broken record since I had another transfusion today, only 9 days since the last. This makes the count 73 units of blood. I was in for my weekly blood test on Tuesday and discovered my hgb was 9.1. Yesterday, I felt so tired that I went home from work after lunch and slept the whole afternoon. After the transfusion today, I still took another nap as well. As typical over the last couple of months, I made an appt for a transfusion for next week (Thursday) as well.

My other blood counts are normal.

Unit #75 (2007-02-28 23:37)

Well, I will have my 75th unit of blood (packed red blood cells) on Thursday. My Hgb was 9.6 on Tuesday, but normally not low enough for a transfusion. But with my history of dropping about .2 per day, it would be down to about 8.2 by next Tuesday. It will probably be 9.2 anyway on Thursday. This is also my 37th transfusion. Average time over last 4 transfusions is 9.8 days between. Other blood counts are normal.

I have a Dr appt next week on March 7th, but most likely no transfusion. Will start planning the details of the BMT which is only about 2 months away.

2.3 March

Getting closer (2007-03-07 20:20)

I met with my Dr today and we talked again about scheduling the BMT. He called the BMT clinic to get things rolling. I need to call them tomorrow and start deciding on the details. In general, it may start the week of April 16th with about a full week of various physical tests to assure that my health is good enough to proceed. The BMT may be close to my 59th birthday on May 9th.

On the current front, my Hgb was 10.6 today so I don't need a transfusion this week. I have one scheduled now for next Tuesday, a span of 12 days since the last. But since the last was a little early at 7 days, the average interval of about 10 days should continue. My other blood counts are normal.

I thought for sure that I needed a transfusion this week since I was so tired. I went to bed at 7:30 last night, slept until midnight, watched TV for a couple of hours and then slept until 6:30 am. I was still tired most of today. But then, fatigue is part of this disease.

Big Brother (2007-03-08 10:52:00)

Are you still counting on BB to be the donor? Do I need an exam soon?

You are in our prayers.

BMT Schedule (2007-03-08 20:26)

I talked with the coordinator at the [1]U of MN Fairview BMT program today and scheduled my BMT, actually a Peripheral Blood Stem Cell transfusion. I will start on Monday, April 23, for 5 days of outpatient tests to confirm that I am healthy enough to proceed and establish a baseline for comparison during recovery. One of the first procedures with insertion of a [2]central line that will be used for months for IVs, antibiotics, chemotherapy and the actual BMT. They will then test me from top to bottom.

My brother will also have a physical that week, though a lot less thorough, only taking about 1/2 day. Hopefully, this can be completed in Missouri where he lives since he will not need to be at the BMT clinic until a week later.

On Monday, April 30, I will check into the BMT Unit 4B at Fairview - University hospital. On Tuesday, May 1, they will start chemotherapy to kill off my bone marrow. From May 3 to May 6, my brother will receive growth

factors to mobilize stem cells from his marrow to his blood. This procedure is done on an outpatient basis, once a day. On May 7 and 8, stem cells will be filtered from his blood and shortly afterward transfused into my blood stream.

Then the miracle happens, a rebirth, close to my actual 59th birthday on May 9th. Somehow, the stem cells find their way into my bone marrow and start producing new healthy blood cells. If all goes well, I should be out of the hospital early in June and back to work by the end of the summer.

1. <http://www.fairviewbmt.org/>

2. <http://www.cancerbackup.org.uk/Treatments/Chemotherapy/Linesports/Centralline>

Transfusion #38 (2007-03-12 23:06)

As expected, I will have my 38th transfusion and 77th unit of blood today (Tuesday). I was surprised that my hemoglobin had dropped to 9.0 today. That is down from 10.6 on Wednesday, only 5 days ago. That's the biggest since a drop from 10.2 to 8.2 in 7 days back in December. But the worst was back in March last year. My hgb dropped from 7.4 on a Wed morning to 5.9 by midnight on Thursday. I went to the emergency room with irregular heartbeat, was admitted to the hospital and had 4 units of blood on Friday. Now, we try to keep my hgb above 9.0 so I feel a lot better and am able to work.

Actually, it has been 12 days since my last transfusion and the average is 10 days between. I felt very tired and short of breath this weekend and my heart has been beating harder. I took a day vacation today since my wife is home from school teaching this week. Probably would have had to come home from work today anyway to take a nap. In spite of all this, I made three quick trips to Home Depot this weekend. I disconnected the water to our old refrigerator, replaced two venetian blinds and fixed the vanity and shower faucets in the master bedroom. I just worked a little at a time and rested in between.

I also completed 3 health care reimbursement forms to recover \$2200 in medical expenses. Not too bad considering I have only paid in \$500 so far in the first two months this year. Actually, this was recovering part of over \$2500 that we have paid on medical expenses so far. The advantage, of course, is that the HCRA is taken from my paycheck before taxes. I also found out that the Aranesp shot that I get every two weeks costs about \$4400 of which I paid 10 %. At that rate, it does not take too long to pay the \$2500 yearly maximum on my insurance.

Thank God for insurance. Over the last three years, my total cost for health care has been \$487,292 though I have only paid \$8113. The BMT is supposed to cost about \$250,000 and my lifetime maximum is only a million. I still need to find out how much insurance has actually paid since they don't pay all that is billed. For example, the Aranesp shot is actually billed at \$6800, \$2400 of which the provider is not paid.

Big Brother (2007-03-13 17:04:00)

Yes, thank God for insurance.

I do not complain about premiums, since us healthy ones can help our sick ones.

BMT clinic at UMN says I ned to Have physical there.

Anonymous (2007-03-14 09:37:00)

Thank God for insurance. Mom's bill was \$137,000 and medicare and insurance only paid \$67,000. the rest is written off.

We have started praying for you in our small group and Bible studies re: the BMT.

Your little sister

Blurry vision (2007-03-20 22:49)

My Hgb was 10.1 today so I will try and make it until next week for my next transfusion. My other counts were normal, but then my eyesight was a little blurred this morning. I didn't notice anything at breakfast reading the newspaper, but when I got to work I had a hard time focusing on my computer screen. I noticed some problems last week as well.

I called and got right into the eye doctor who said she did not find any problems though I was still having problems focusing there. The thought was that maybe my eyes were dry so she gave me some sample eye drops to try. Of course, she dilated my right pupil which really caused blurry vision. Thankfully, it was an overcast day as I drove to get my blood test. I then went back to work and sat in a meeting for an hour. It cleared up OK and did not bother me for the rest of the day. Though my prescription did not change, I will get new glasses through our work optician, safety lenses free and \$40 frames. I could spend more, but am not fashion conscious.

Big Brother (2007-03-23 09:25:00)

Could it be something simple as auroras - diamonds floating across the eye. I get those and then I can't see clearly for awhile. These are a precursor to a headache which can be prevented by immediately taking an aspirin.

Or it could be cataracts. I started to have trouble reading fine print that became fuzzy. I had cataracts removed by removing lens in my eyes and replaced with artificial ones. Eye are back to normal now.

Things to do (2007-03-24 22:43)

It is just 4 weeks to go before I start my physical tests for the BMT and then another couple more weeks before the actual BMT. But what should I do with this time? I have a lot of things that I have been putting off for years, but now need to be done just in case I don't survive the BMT recovery process. During this time I would like to get up to the Bemidji cabin, possibly over Easter, and then have the COFES conference on April 12-15. I won't be doing any traveling for probably a year after the BMT.

We also have a birthday party scheduled for my son (turned 18 yesterday) and my sister (turned 65 today). Also planning a birthday party for my mother-in-law (93) and me (59 on May 9th). I will miss my son's high school graduation at the end of May, but I am very proud of him. He has been accepted and is registered at the U of MN College of Biological Sciences in preparation for medical school. He already has been awarded full scholarships based on his 4.0 grade average and community participation. It will be good to have him around as I recover over the next couple of years.

Anyway, what is on my list? Top priority are a will, a medical directive and power of attorney. Then there are all the secrets about where I have all the money hidden. Actually, since I have managed all the finances, I need to document my use of Quicken, banks accounts, 401k plan, insurances, etc. Also need to complete our income tax forms for last year.

On Friday, I met with my supervisor and the benefits administrator at work. We discussed all the Short Term (STD) and Long Term Disability (LTD) benefits. It appears that I have optimized my STD such that I will have just 3 hours short of 26 weeks. I have worked extra hours to make up for time that I needed for Dr appointments, blood tests and transfusions and was last sick only 3 hrs back in November. Since our STD is a rolling year total, any time I

took before November will drop out of the total of 26 weeks which will be over on October 26th. I also accumulate vacation while out on STD so will have that pay to bridge the gap to LTD if I need to. Unfortunately, 14 weeks of STD is at 65 % pay and LTD is at 60 % pay. I also found out that after the 26 weeks of STD, I will no longer be an employee, but can continue with the same benefits plan if I pay for it directly. I still need to check into taxes on this income as well as Social Security disability. Anyway, plan for the worst case and hope for the best.

Another item that I worked some more on this evening is my life story. The outline and about 10 % of rough notes totals 14 pages so far. It is not an easy thing to do, but something I recommend that everyone does. We have some stuff from my mother and diaries that she kept for years, but it would be great to have something similar from my father and other ancestors.

I am also trying to clean out old stuff that may have seemed valuable to me, but certainly not to anyone else. Again, there are a lot of memories and stuff to document. How any one know what is really valuable unless I make some notes?

Just thinking about all this makes me wonder if I am doing the right thing in getting a BMT. But I have to trust the advice of the doctors to move ahead and the power of God to carry me through it.

Anonymous (2007-03-29 19:40:00)

I suggest you clarify how long you can pay directly for your health insurance after you stop being an employee. I suspect it is only 18 months.

Ken Brandt

Transfusion #39 (2007-03-28 23:07)

Just a short post to let you know that I had my 39th transfusion and 79th unit of blood yesterday. My Hgb was 8.9 though I felt like it was lower. I feel more tired these days for the same levels of hgb. It had been 14 days since the last, but the average is still 10.5 days between. White cell count was 4.7 and platelets were 325, both about the same for the last several months. There seems to be a slight long term drop in platelets, but that is what the anagrelide is supposed to do. It could indicate my bone marrow is making less platelets with the same dosage of anagrelide, but nothing alarming. If anything, like the increased frequency of transfusions, it could indicate that my bone marrow is starting to fail. Eventually, all my counts will drop to zero without a BMT.

33 days until hospital checkin. 40 days until BMT.

2.4 April

Countdown -32 days (2007-04-04 21:14)

If all goes as planned, I will have my BMT in 32 days on May 7. But it still all depends on a week of tests starting in 25 days on April 23. I saw the Dr today and all is still go from his perspective. My Hgb was 9.8 today so I should not need another transfusion until next week just before I head for the COFES conference in Scottsdale on Thursday.

We had a great party here for my sister (65) and my son (18) on Sunday. I overworked my legs and arthritic

knees and had terrible leg cramps early Monday morning. My right knee still hurts when I walk but I don't think that there were any blood clots.

I had fun showing off our new 46" wide screen HD TV which I decided to get before going in for the BMT. I figured that it would be great to have while sitting around the house for months after getting out of the hospital. I am also enjoying it right now.

Anonymous (2007-04-06 08:05:00)

Glad you got the TV, which sounds great! Maybe you would want to get some interesting books to read, too. I have found that time goes by much faster if I have something interesting to watch on TV or read. MBH

Transfusion #40 (2007-04-10 22:26)

After a little torture, I had my 40th transfusion and 81st unit of RBCs today. Seems like my veins are starting to hide or becoming scarred so it is getting harder to get needles in. It took 4 tries yesterday to get the blood sample and 3 today to start the transfusion. The day hospital was also busy and short staffed so it took me 2 1/2 hours yesterday and 7 1/2 hours today away from work. I had my MacBook Pro with me today so got some work done of my report that I would like to turn in tomorrow.

My Hgb dropped rapidly since last Wednesday when it was 9.8. It was down to 8.0 yesterday, so dropped 1.8 points in 5 days. It was probably 7.8 or less today and I was really dragging. This is the lowest it has been since last April 17 when it was 7.9. Interestingly, that was also over an Easter weekend, remembering the blood that Christ shed for me. Over the past year, we have attempted to keep my hgb above 9.0, allowing me to work a full 40 hours per week.

I am heading to Scottsdale, AZ on Thursday for the COFES conference and will be back on Sunday. Next week I need to wrap up everything I am working on just as if I will not return to work. I will make it back into the office for a few hours the following week if only to pick up my expense check for the AZ trip.

Countdown is 13 days to start of tests, 20 days to check into the hospital and 27 days to the actual BMT.

Big Brother Donor (2007-04-13 09:20:00)

Our prayers are with you.

I saw my new doctor yesterday, and I have a clear bill of health.

So everything is "Go" from this end.

Anonymous (2007-04-16 10:55:00)

You are in our thoughts and prayers as this time draws closer! Glad you enjoyed the conference - We are all thinking of you and supporting you!

BJB and Family

Joe (2007-04-18 07:56:00)

I admire your courage and steadfast faith as you prepare for your BMT. You are choosing life and I find that inspiring. I was reading James this AM and verse 1:12 made me think of you. Please read it. My family is praying for your successful procedure and I look forward to working PDM stuff with you in the future!

Transfusion #41 (2007-04-18 19:23)

My next transfusion is scheduled for tomorrow afternoon. This will be #41 and 83rd unit of rbcs. My hgb was 8.8 yesterday so I am a little tired but not as bad as last week when it was a point lower. I also made it to the dentist, the lawyer, the bank and the pharmacy yesterday. I only worked 2 hours after lunch and came home for a nap. Today, I worked a full day.

I had a good trip to Scottsdale last week. Flew out on Thursday and back on Sunday. During that time I spent at least 26 hours in meetings and discussions in between. I had leg pains at night from too much standing and skipped the BBQ and star gazing out in the desert on Friday night. I am still working on the trip report, but got my expense report in and payment back in two days. Certainly a record time for me if not the company.

Countdown is 5 days to start of tests, 12 days to check into the hospital and 19 days to the actual BMT. My next post will probably be on Monday after my initial appointments.

My brother has started a series of daily scripture promises which we are posting on the [1]Caring Bridge web site that my daughter started last November. That site also has a guestbook that you may wish to use. If you don't already know my identity, you can find out there.

1. <http://caringbridge.org/visit/joelgerdeen>

Anonymous (2007-04-20 21:51:00)

Good luck with your BMT and the recovery in the next few weeks, I am sure all will go well for you and your family. You are going to have to invite me over to watch a game on your new wide screen.

DG

Keep moving forward (2007-04-22 20:00)

My son and I went up to the lake cabin near Bemidji, MN, on Friday and came back today. Yesterday, we went to a movie theater in Cass Lake. It is just a single screen theater to which we like to give business. Where else can you get a movie for \$3.50 and large popcorn and two medium drinks for \$8.75 these days. But then you have no choice of movies so we went to see "Meet the Robinsons", an animated Disney film about a genius orphan looking for a family. Without giving up the plot, the theme was Walt Disney's own, "... We keep moving forward...". It also is very appropriate to my decision going forward with the BMT.

While we were at the lake, the ice went out. This was the first time that we experienced this since we have never been there before in April. My mother-in-law says it always happens around her birthday which was on the Thursday. It was dark when we arrived on Friday night though we had enough light to see that there was just a little open water near shore. Since we had no running water and the septic tank was still frozen solid, we went into town for breakfast and a toilet. When we came back, we could see noticeable cracks forming in the lake ice. When we got back from the movie about 3:30 pm, we saw movement in the ice. We sat down near the lake and could hear the ice cracking, see it shifting and piling up in some places along the shore. It rained over night and when I looked outside in the morning, there was an expanse of open water out about 100 feet, parallel to shore. A rock that my son threw out on the ice had moved down the shore and about 50 feet closer as well. Later as we were packing to head home, we noticed a path of open water going straight across the lake. One the cracks opened up about 100 feet wide over the space of at most 30 minutes. I have evidence of the changes in digital photos.

Since I see positive signs in many things, I see it in the open water as well. Just like Moses was parting the Red Sea. I believe the ice is going out in my medical situation. Both my wife and brother mentioned that Evel Knievel was on the "[1]Hour of Power" this morning. The show is available on line if you wish to watch it. After many years of high and low living, he recently told the devil to get out of his life and Jesus Christ to come in. He was baptized by Dr. Schuller and followed by many other people doing the same. Has the ice gone out of your life as it has in Evel's?

Tomorrow, I start my pre-BMT tests and attend a BMT class. In one week, I check into the hospital. Check out [2]CaringBridge as well for more posting by other members of my family.

1. <http://www.hourofpower.org/>
2. <http://caringbridge.org/visit/joelgerdeen>

Anonymous (2007-04-24 22:10:00)

I also believe the ice will go out.

Ken Brandt

Fitted for Suit (2007-04-26 17:48)

Well, it has been quite a week of medical tests starting on Monday and wrapping up with a final review with the Dr and approval to move ahead this afternoon. Actually, the consent forms that I signed are still subject to results of tests that my brother had today but won't be known until Monday. The start of the process has been delayed until Tuesday, May 1, when I should check into the hospital.

The first thing that will be done is placement of a central line, a dual-lumen catheter that is inserted into my chest and goes under the skin to my jugular vein near my neck. This will be used for all IV and blood draws for the next several months. A review of that procedure was the subject of one of my consultations this week. I had other consultations about all of the chemotherapy and side effects. I signed about 6 different agreements for research studies relative to the main BMT or related tests.

One was related to the study of osteoporosis in BMT patients. I had a bone density scan that showed that I did not qualify since my bones are denser than average. [One benefit of being overweight.] I had a pulmonary function test that showed my lungs were operating at about 75 % of normal. A chest x-ray, a CT scan, an EKG and a [1]MUGA heart scan did not show any problems. In fact, my lungs seem clear from the blood clots that I had before though there has been some permanent damage.

The big test was a Bone Marrow Biopsy which still showed all of the same results that it has for the last two years. This biopsy was about average level of torture of the five that I have had. I did it with just local lidocaine and novocaine. There was pressure as they extracted the bone marrow sample with a hollow needle and then pain as they sucked out aspirate three more times. The December test took three attempts before they got a good bone sample.

So why am I being fitted for a suit. That was actually a joke with the doctor who I consulted with about the radiation therapy. I will get a TBI, total body irradiation. The radiation is given from both sides of my body. In order to assure that the radiation is uniform between narrow parts of the body, such as the head, versus wider parts such as through the arms and chest, the technician makes up filters to reduce the x-ray beam to the narrow parts. In order to make the filters, the patient's body is measured with wide calipers, similar to being measured "for a suit". The actual radiation will probably be given on Monday, May 7, and is at a level about 1/5th what they use normally. That will be after about 5 days of chemotherapy and just before the actual BMT.

1. <http://heartdisease.about.com/cs/otherriskfactors/l/blmuga.htm>

Big Brother (2007-04-28 20:32:00)

I am the best man, and they only told me to wear sweat pants during the BMT.

Transfusion #42 (2007-04-27 22:10)

The last thing I did at the BMT Clinic yesterday was to get a blood test with type and cross for a blood transfusion today. Since I was now at a different clinic, I had to convince the lab technicians that they should take more vials of blood for the blood bank to match the extra antibodies that I have in my blood. I worked about 3 hours this morning and called the clinic to confirm that they had the blood for me. Again, I had to insist that they check with the blood bank to assure that they actually had the blood. So when I got to the clinic at 12:30 pm, I knew the blood was waiting.

But the nurse told me that they could not give me blood because my hemoglobin was at 9.1 yesterday and not below the 9.0 level the doctor had ordered. Again, I insisted that they check with the doctor since my hemoglobin was probably already below 9.0. I even pulled up my history of hemoglobin change on my laptop, showing that my hgb dropped at least one point per week and would be too low by the time I entered the hospital and they got me blood next week. I didn't need to talk to anyone else before they took me to a new area for the transfusion.

The first nurse tried two times to get the IV inserted and then passed responsibility over to another who did it on the first try. The BMT Clinic seems to transfuse blood at a faster rate so I was finished by 4pm just in time to stop by the pharmacy to pick up some Lovenox. This was my 42nd transfusion and 85th unit of rbcs.

In preparation for insertion of the central line on Tuesday, I need to be off of my Coumadin blood thinner. I am now back to giving myself injections of Lovenox twice a day. Coumadin takes about 5 days to clear my system while Lovenox takes less than a day. I can stop the Lovenox injections one day and have the surgery to insert the central line the next.

It has been a long week with at least 15 appointments. I have also been into work three times though worked less than 8 hours total. I still need to make it in one last time to clean up some of my files. I am looking forward to my last weekend before going in for the BMT

Big Brother (2007-04-28 20:34:00)

I as donor have it easy. They took me off aspirin, and put me on Tylenol instead.

It's a Go for BMT (2007-04-30 13:06)

I just got word from the BMT Clinic that the BMT is moving forward. Both my brother (the donor) and I have been given a clean bills of health. I check into Fairview University Hospital at noon on Tuesday and have a central line placed at 1:30 pm. Chemotherapy to wipe out my old bone marrow starts on Wednesday. I have radiation on Monday and then receive the BMT on Tuesday, next week.

I went to work this morning for a few hours. Cleaned off my desk and filed a few more things. Then came home home and mailed my last Health Care Reimbursement Request for the year. There is plenty of things I need to do around home, but I think I will take a nap for a few hours.

Anonymous (2007-04-30 16:03:00)

Hi Joel,

Just read your blog again. You surely have been through the mill but so thankful the BMT is a go, that you and Jim checked out good. You continue in our prayers. The Lord is faithful. "The eternal God is our refuge and underneath are the everlasting arms." Deut. 33:27. The Lord is bearing you up. You're not going through this alone. We love you and entrust you into the Heavenly Father's strong arms.

Love,

Charlotte & Dave


P.S. Our prayers are with Marilyn, Anna, Andrew too.

Anonymous (2007-04-30 16:17:00)

Joel, We are thinking of you and praying for you. Love, Marge and Donald

2.5 May

Central Line (2007-05-01 20:20)

[1]  I have checked into the hospital after getting my central line put in. It took a couple hours of paper work and vital signs before they started the procedure and then about a hour to complete. I was settled in my room by about 4 pm.

Prior to starting the procedure, they shaved my chest, but did not do a wax. It may be hard to see in the photo (that is reversed left for right by the camera on my laptop), but there is an incision up my neck above the jugular vein on the right side. This area was numbed up with lidocaine, a needle was inserted and then a wire that went down towards my heart to measure the distance. A "straw" was inserted over the wire to hold the jugular vein open. Then about 4 inches lower, an incision was made and a tunnel made through the fatty tissue up to the other incision. A rod was pushed through attached to the catheter which was then pulled through. The catheter was inserted through the straw into the vein and the straw was split and peeled back like a banana. The catheter was pushed further in towards the heart and the upper incision was glued shut.

That is the place that is hurting this evening since whenever I move my head it tends to stretch the skin in the area. A stitch was placed around a little cuff on the catheter just where it exits my chest. There are two lumens that can be used for blood draws and IVs. The catheter has a divider inside for its full length. The red one is used for blood draws like the 14 vials of blood they took out when I got to my room.

My wife was with me all afternoon except for the placement of the catheter. My son rode his bicycle down to the hospital and back later, a round trip distance of 20 miles. We took a tour of the BMT ward and then walked about three blocks outside to Sally's for a cheeseburger. I have been back in my room for a couple of hours. I am feeling pretty good so far, but the chemotherapy starts in the morning.

Thanks for all of your comments and prayers. I really appreciate everything you are doing. By the way, do not send any flowers which are not permitted in the BMT ward. If you wish to call, my phone # is 612-273-0205. Cellphones cannot be used on the ward. If you wish to visit, I am in the BMT ward 4B, room 221. It is probably best to wait a few weeks though since I will probably be pretty miserable over the next week and susceptible to infections after that. Surprisingly, they do permit up to 3 visitors at a time, but make you wash your hands and wear a mask if you have any sniffle.

1. http://myelo.us/uploaded_images/Joel-Central-Line-743762.jpg

Anonymous (2007-05-02 08:55:00)

We will continue to pray for you, Joel. You get a lot of credit for how you are handling all of this and are a great role model for the rest of us, who are likely to face a serious illness ourselves at some point. Marge

Anonymous (2007-05-02 15:10:00)

Joel: I've been reading your progress accounts and am amazed at all you've had to endure. Today's the day you start chemo so I expect you won't feel like dancing for a while. Reg and I hope everything goes well and you can kick this disease. Take care and we're praying for you. Karen

Chemo Started (2007-05-02 10:26)

I had a pretty good night of sleep interrupted occasionally by bathroom needs, vitals and then labs at 4 am. Then I was awoken by the sunrise since my room windows face the east. I showered, ate breakfast, had my central line dressing changed and donated my weekly cultures of stool, urine and mouth swab. They have been giving me fluids and measuring all my outputs. My hemoglobin is 8.4 which is low considering that it was 9 on Friday when I got a transfusion. By my history, it should be close to 10. Nothing to worry about since they monitor everything closely and I will get more blood whenever it is needed.

The nurse just started the first chemotherapy called Fludarabine which I will have for a hour a day for five days. The side effects are not too bad, though the nurse put on a special gown and wore rubber gloves to protect herself in case she spilled any while hanging the IV. In an hour, I start on the Cytosan which is supposed to be the worst as far as nausea but that is a one time 2 hour dose. Then, I get Allopurinol for 6 days. I also get ATG (Anti-thymocyte globulin) and MP (Methylprednisolone) for 3 days.. The first three supposedly kill off most of my bone marrow while the last two suppress my immune system. All this is subject to review and change as the doctors monitor my reactions and condition. The regimen is called a mini-BMT, not a full BMT. They do not eliminate all of my bone marrow, but weaken it so that my brother's donor cells can take over.

BTW, I have better wireless access (5 - 7 mbps so far) to the internet here than I have through my wired access through ComCast at home. Time will tell how the speed holds up.

Anonymous (2007-05-02 14:57:00)

Glad the worst drug from the standpoint of nausea is only a one-time dose and that they will give you more blood as needed. Hope you don't have to suffer too much with the drugs. I heard a preacher say recently about God that "if he takes you to it, He'll take you through it."

Chemo going OK (2007-05-02 20:43)

[1] ✖

My chemotherapy is going a lot better than I thought it would. After all of the chemo I mentioned earlier, I have not had any nausea. My biggest problme has been the constant need to urinate due to all the fluids, IVs and Lasix. Then with the ATG (horse serum), they had to monitor me almost continuously the first couple of hours. When I had to rush to the bathroom, I was tangled up in all the blood pressure, finger cuff and temperature lines. I finally just got a couple of extra urinials to keep by the bed so I did not need to get disconnected and reconnected each time. I am still getting a slow dose of ATG, but the next one at 11 pm will be speeded up since I have tolerated that as well. Now just

waiting for my hair to fall out.

My wife said the picture that I posted last time was pretty grim, so I have attached a better one. I really am in good spirits. This picture was from from last using the Mac PhotoBooth distortion capability.

1. http://myelo.us/uploaded_images/Grim-Joel-741576.jpg

Kris (2007-05-03 08:41:00)

Is it the horse serum that makes you look like that!?!?!? LOL

Praying you stay nausea free and "tangle" free for "potty breaks".... :)

Blessings!

Anonymous (2007-05-03 08:57:00)

Like the photo! It's great that you can keep your sense of humor as you go through this. Hope that things continue to go well.
Marge

Charlotte Fruehauf (2007-05-03 11:50:00)

Hi Joel,

Good to hear that as of last night, you weren't nauseated. When I saw your picture, I thought "The chemo did it!!!" Glad to see you still have a sense of humor. That will help in your recovery. I will be calling you soon. My love to you and Marilyn and the family.

Love and prayers,

Charlotte

Joyce (2007-05-03 17:20:00)

chortle*

Like the photo a lot!

Stay well!

Status Day -5 (2007-05-03 17:17)

[1] ✖ Today is going fine after a night of light sleep. I received an ATG IV starting at midnight accompanied by more Lasix. I was urinating every 30 minutes. Then they took my daily blood tests at 4 am so that the doctors have results in the early morning.

My Hgb was 8.0 today so I am getting a blood transfusion. Still just red blood cells, but they will have to transfuse platelets later. Platelets have dropped to 133 from 272 when I checked in. Platelets have an average lifetime of 10 days and the chemo is wiping out their source as well.

Not enough blood had been drawn for a correct type & cross, so they had to take 4 more vials of blood. The blood bank would have caught the need to check for the other antibodies that I have, but I asked my nurse to check before it would be delayed even more.

This is day -5, only 5 days to go before the BMT. My brother is in town and starts his treatments to build bone stem cells

tomorrow. He came to visit this morning as did the assistant pastor from our church. I appreciate everyone's support.

See the new picture of my central line with clear bandage while referring to a previous description of the procedure.

1. http://myelo.us/uploaded_images/Central-Line-2-721657.jpg

Anonymous (2007-05-04 09:57:00)

Appreciate the update. Glad that you are making progress and that they are monitoring everything carefully. Hope you will be able to get some real sleep soon! Marge

Anonymous (2007-05-04 15:27:00)

You're in my thoughts and prayers.

Jenne

Status Day -4 (2007-05-04 21:29)

The process is still being pretty good to me. I have survived the worst of the chemo without nausea, but expect that as it reaches its goal of wiping out my immune system, the worst is yet to come. I have great support from many people; family, church, work and old friends. I cannot remember all the prayer chains that people have told me about. I have had six visitors today. I sincerely appreciate all of your support and my prayers go out for you as well.

My brother, Jim, stops by every morning after his growth factor injection at the BMT clinic. It will be interesting to hear from him in the morning about any pains from his bone marrow responding to the stimulus. It is great to visit with him, one on one, after years of just seeing him at special occasions, mostly with other relatives. He used to ride me around in his bicycle basket when I was young, but left home for college when I was 8. I lived with his family for a year while I was going to college. His strong faith and devotionals help to uphold me through these trying times. See the CaringBridge website in the sidebar.

Seems like everyday, I get a sign from God that he is still watching over me. For example, just I was typing this and listening to KTIS radio, a Newsboys' song, named "Something beautiful", started playing. The first words of the song are "I want to start it over, I want to start again. I want a new beginning, one without an end. ... It's the voice that whispers my name. ... Something beautiful." We saw them in person at the Target Center last Fall. As I checked my iTunes music list for my Newsboys album another song was at the top of the list, "Everything is going to be alright".

Yesterday, I was visited by a total stranger who appeared something like angel in my room. She was distributing a care bag from the Care Partners and Club Butterfly of the Children's Cancer Research Fund. Inside the bag where many little snacks, reading materials and even a pre-paid calling card that I used last night to call my younger brother, Bob.

But the one thing that caught my eye was a butterfly pin on a card with the saying "From the cocoon of treatment and isolation, a child emerges - beautiful and ready to take flight. The butterfly is significant to me since back in 2001 as I reported on my [1]Story2tell web site. Again when in the hospital in 2004 during the first days of my current ordeal, my friends at work sent me flowers with a butterfly as part of the arrangement. I will come out of this situation as the butterfly does out of a cocoon, either renewed for further life and purpose here on earth or in a totally new heavenly body.

Now, "Just the facts, Ma'am" as Joe Friday said. My Hgb was 9.3, expected up since I got rbcs yesterday. Platelets up some to 155 up some probably due to the Anagrelide wearing off. I did not see a reading on white cells, but expect that to drop as the treatment continues. They will give me more rbcs and platelets to keep me alive while giving antibiotics to prep for any infections that the wbc's would have taken care of.

Sometime in the next two weeks you may see what I look like bald.

1. <http://www.story2tell.us/Butterfly.htm>

Joyce (2007-05-05 18:06:00)

I'll be waiting to see how your next set of photos comes out! It's interesting watching your changes. I'm thinking of you.

Anonymous (2007-05-05 22:06:00)

Glad you are continuing to do okay and that the nausea has not hit yet. That is great that you are having such good visits with your brother, too! Marge

Anonymous (2007-05-06 17:01:00)

You are really being brave and positive. Hang in there!

Ken Brandt

Anonymous (2007-05-07 17:53:00)

Lavelle sent around an email of the phone call today with you. I'm glad to hear your doing well. Two important things happened today at work - one announcement of a new AS President and the other announcement that IS will report to AS Engineering immediately. Bet you can't wait.

Reg

Anonymous (2007-05-08 12:22:00)

Joel: Well, it looks like it's a GO for your BMT today. Reg and I wish for the successful outcome of this procedure and that you'll soon be on the road to recovery. Keep the faith!

Karen

Anonymous (2007-05-08 14:44:00)

Hi Joel, We've been monitoring your blog for your progress. Sounds like things are going per plan so far. That's great because I've already got lots of questions for you when you get back. You might want to have your wife or daughter screen your pictures before you publish them. You're not the most photogenic guy we've ever seen. Haha. Keep up the battle. John

Day 0 BMT (2007-05-08 21:03)

I have a few rough days where I did not even think about posting my status. My wife posted on The CaringBridge site and I have talked to many of you and appreciate all of your thoughts and prayers.

The first part of the BMT took place this evening after my brother donated his stem cells earlier. He said that they only harvested about 80 % of what they needed so will be back tomorrow. The first transfusion has caused no side effects yet and I am feeling pretty good. I survived a bout of premature atrial contractions yesterday and more

nauusa today.

My family had a prayer service for me from 5 to 6pm today while I listened to a great CD from an angel at our church. People from all around the world were praying, even people of Brazil. I could feel the power of God taking holding the BMT. It is the start of a new life, a new birth. That it continues tomorrow is even more symbolic. I am 59 years old on 5/9.

Anonymous (2007-05-09 04:27:00)

Thank you for the update. We have all been thinking of you and praying for you and will continue to do so as you continue the procedure today. Marge

Anonymous (2007-05-09 08:57:00)

Joel!

Glad you are doing so well! Your struggles are inspirational. You have chosen life and you WILL succeed. Keep it up. I am praying for you everyday.

Joe Moorman

Kris (2007-05-09 09:22:00)

(Just in case you don't read your CB guestbook today... I repeat...)

What this birthday is all about....

Jeremiah 31:4, "I will build you up again and you will be rebuilt.. Again you will take up your tambourines and go out to dance with the joyful."

(Do you know how to dance?) :-)

Praying and waiting with you!!!

Anonymous (2007-05-09 10:54:00)

Sorry I missed the prayer service as I had to work late. I am praying for you every day and know that the Lord Jesus is watching over you.

Love,

Mark Oswood

Anonymous (2007-05-09 12:00:00)

Happy Birthday Joel! We were going to get you a present but then when we consider what your brother and family have given you we can't come close to those gifts. We are all monitoring your progress and pulling for you all in our own ways.

John L.

Joyce (2007-05-09 12:27:00)

Happy birthday Joel! We're thinking of you. Wishing and praying for the best.

Day +5 (2007-05-13 13:53)

Sorry that I have not posted recently. My wife and brother have been keeping up better on the CaringBridge site. Everyday something changes, but in general I have a bloated feeling of indigestion. One day I also had Premature Atrial Contraction, which the heart Dr told me not to worry about. This morning I had shortness of breath and was given a chest xray. I have also gained at least 12 lbs, which must be in fluid so they have started more diuretic. So I am now tied to a minimum of three tubes and then have to jump up to get to the urinal. So far I had no diarrhea but that have been some quick calls through all the tubes and power cords to get to the toilet.

The drugs are now to prevent or fight infections and to head off Guest vs Host Disease (GvHD), but they all cause nausea. So far I just had one bout of vomiting, which was lite after one bite of sugar cookie and some water. I lay in bed listen to the tv, radio or CD and then fall asleep, waking in the middle of something else. Hours run together and I sometimes am not sure which reality that I in.

The doctors are all reassuring and say I am experiencing what most other patients do and that I am doing very well. As my brother said recently (Psalms 23) "He makes me lie down... he leads me. Even though I walk through the valley of the shadow of death, I will fear no evil, for you are with me; your rod and your staff, they comfort me." When I think out to all my support group, including all of you reading this, praying for me, nursing or doctoring or communicating , "Surely, goodness and mercy will follow me all the days of my life"

Anonymous (2007-05-13 16:44:00)

Joel, Thanks for the update. Sorry you are having to go through this, but am glad the doctors are reassuring. Am also glad you are finding comfort in that beautiful 23rd Psalm. Love and prayers, Marge and Donald

kris (2007-05-13 17:06:00)

Our prayers are continuous... as one leaves off another picks up... amazing the way our Father has this all figured out! I love it when He puts you on my heart... and love the peace that comes as we pray. Sounds like you need to skip the sugar cookies and head straight for the chocolate!!

Anonymous (2007-05-13 18:31:00)

We are glad the doctors are giving reassuring statements. Hope things get better soon.
Ken Brandt

Anonymous (2007-05-14 20:12:00)

Greetings -

Please know how much you are in our hearts during this challenging journey. We think of you and your dear family often and send our prayers across the miles, riding on the fresh new hopes of spring. Love, Judy and Paul Eustace

Day +9 (2007-05-17 22:04)

Sorry for not posting for 4 days earlier, but I have just not the energy, plus they keep me busy. I have not had an appetite and then have had nausea most of the time. I seem to be breaking out and forcing myself to eat despite the taste. I gained at least 15 lbs of fluid and then have to take diuretics to get the fluid.

Guys, specifically, the fluid goes "everywhere" and can be very uncomfortable. It also seems that I have a urinary strapped to each hip. I have tried many setups, but decided the best strategy is to dress lightly for quick release

and always have a urinal close by. Sorry to say, I was slow on the draw a few times.

I got out of my room for some physical therapy today. Will have to walk around and do some exercises 4 times a day. Seems like they are trying to get rid of me, but just preparing for going home some time around May 30. My white cell count is up to 2200, about 1/2 of what it was when I came. Platelet count is 46 and I received another platelet infusion this evening.

Keep looking up.

Joyce (2007-05-18 12:58:00)

It's good to hear you are doing so well! We are looking forward to hearing about your excellent progress.

Take care.

BMT + 10 (2007-05-18 08:18)

This is the 17th day since I checked in the hospital for related donor mini BMT. Doctors tell me that I am doing very well. My white cell count is up more to 3200 and my hemoglobin is at 10.3. My platelets are 53, still too low. I will get more platelets today. Certainly, the nausea, lack of energy will continue, especially after 4 therapy sessions planned for today.

Update 8pm - Around midday, just after the Dr parade passed through (and talked with Lavelle), I noticed numbness in my toes. I could hardly stand due to pain in my ankles which were swollen due to more fluid buildup. I have had more diuretics and am now wearing support hose, just like my mother needed in her later years. The therapy sessions are a help by improving my circulation. [A nurse told me about another potential solution that another male patient used. Picture the combination of Depends held up by suspenders.]

I feel great at the moment, just wondering what is next. Probably, hair loss? I have not figured out what this means for the long term, but will sure have much more sympathy for people in pain or the latter days of their life. Quoting Richard Bach, "Here's a test to find whether your mission on earth is finished: If you're alive, it isn't." Credit given to [1]Kirk Weisler, Chief Morale Officer.

1. <http://kirkweisler.com/>

Anonymous (2007-05-18 10:44:00)

What an ordeal!

But I am glad they say things are going well.

Ken Brandt

Kris (2007-05-19 08:29:00)

So... sounds like when people ask you "How are you today?" You'll have a smirk on your face when you say, "Depends...." LOL

Still praying... rest and grow strong... you're being cared for by the best.... Hugs to all!

Joyce (2007-05-19 20:05:00)

thanks for letting us know that you are improving - and growing (though it sounds rather if you'll be swimming in water soon internally.)

Lavelle has been passing along updates after he talks with you as well.

Take care.

Joyce

BMT + 12 (2007-05-20 12:15)

Last night was my best yet for sleeping, though the heat went out. Rumor is that a major boiler failed. It was down to 66 degrees, but now warmed up to 72 now. I try to keep it set at 68, but thermostat does not control very accurately, plus the air filtering system keeps a constant airflow in the room. I sleep better when it is cooler, but I also had less noise because of less IVs. Docs are changing from IV meds to pills. Seemed like only one was running last night. Less IVs also mean less fluid retention up and less urination.

My platelets are also higher so I go back on the Lovenox anticoagulant. If I can get rid of the fluid and get an appetite back, I may be sent home this week. Then my problem will be care giver support at home and daily BMT clinic visits since my wife works until June 7 and my daughter and son will not be out of school until May 30.

Anonymous (2007-05-21 06:51:00)

Glad to hear you are doing better! Hope they have fixed the heat.

BMT + 13 (2007-05-21 21:48)

I had a pretty good night for sleeping last night, though up every hour to the bathroom and up at about 5 AM to write instructions for cleaning the house before I come home. Then about 8:30, I had my breakfast of 16 different pills. My planned breakfast came about the same time as the pills, but I needed to get the pills down first. I was still water logged and weighed in at my highest of 121 kg, almost 20 lbs more that when I checked in 3 weeks ago. The major concern now is my fluid retention versus the health of my kidneys. My creatine level is up to 1.52 so any diuretics were stopped over the weekend.

I was not able to eat much breakfast, needed to walk and exercise, but did not have the energy. The fluid retention was still restricting my lung capacity and breathing. I was just laying around, feeling sorry for myself, getting up for the bathroom when necessary. Then, my sister, my younger brother and my older brother (the donor) called in succession. Being just uplifted by their calls, an angel from physical therapy showed up to help me walk and exercise.

Since she was following the book, she offered me either a cane or walker, like waving a red flag in front of a bull. Previous times I have pushed the IV pole around, but didn't need to take that with us. Unencumbered, I took off while she followed with a back up wheelchair which I needed to use 3 times to catch my breath. I walked up and down 13 steps on the stairs with no problem, proving that my problem is oxygen input. The paper mask, which I need to wear, also restricts my breathing. We also whipped through some of the physical exercises with no problems.

In the previous writing, I skipped the fact that all my meds have been switched from IV to pill form and the

nurse disconnected all IVs just before my physical therapy. I also received a diuretic about the same time, so have passed a lot of fluids today. I feel that I have passed the hurdle of fluid retention and may be able to go home in a few days. Food tastes better, especially the Ghirardelli chocolate and and Code Red Mt Dew that I had this evening. I am having 3 BMs a day so that end is working as well. My wife, son and I attended a central line maintenance class this afternoon after which I took a 2 hour nap which was te best sleep that I had since coming in 3 weeks ago. I expect more of the same this evening.

My labs show that my hemoglobin has been over 10 for the past week. My white cell count is back down to the 3000 range. My platelets are back over 100 so I am back on Lovenox, a blood thinner. The Lovenox is a precaution until the Drs determine whether the BMT solves my blood clotting problems. Tomorrow's labs, including creatine, will be interesting to see and will be a big factor in when I go home.

BMT + 14 (2007-05-22 13:00)

Situation today is similar as it has been though I have lost some fluids and weight. My platelets were down to 77 today, but white cells and hemoglolin are holding their own. Creatine was up slightly and again may be the deciding factor of whether I go home on Wed. All of these are be adjusted with other drugs at home as well as here. I do feel better today and want go home where I can get more exercise which will help to lose more fluid. I will be back to the BMT Clinic everyday for blood tests and further IVs if necessary.

I took a discharge class this afternoon and should know by about 11am if I will be discharged. It will be a day to day basis of review and decide. My wife is prepared to take days off from teaching, but would work a full day and I would leave here about 5pm.

My hair is falling out and thinning. Today, while taking a shower, it was coming in gobs, but doesn't appear too bad. I am not bald yet.

The physial therapy department signed off on my discharge after session with them this afternoon.

Groundhog Day (2007-05-23 08:17)

It feels like Groundhog Day, the [1]movie. where Bill Murray keeps experiencing Groundhog Day over and over.

As I speculated, my Creatinine level, which indicates kidney function, is too high this morning. Creatinine went up from 1.68 to 1.94 and needs to be going down before I am discharged. They are stopping one medicine to counter GvHD for the day to see if that affects it. Otherwise, we repeat yesterday and see what the Creatinine is tomorrow. So I will be here until at least 5pm on Thursday.

Other blood counts are up slightly, which is good and shows bone marrow is functioning. Another bone marrow biopsy next week will show whether it is my brothers bone marrow. But the fact that Hemoglobin has been over 10 since May 11 is a good indicator.

1. http://en.wikipedia.org/wiki/Groundhog_Day_%28film%29

Anonymous (2007-05-23 14:11:00)

Am sorry to hear about the creatinine level, but am glad it was caught before you went home so the doctors can address the issue while you are there. Maybe it is just as well that you get a little extra time to continue to rest and recover before going home. Best wishes for your continued recovery! Marge

Anonymous (2007-05-24 06:51:00)

Greetings -

Wonderful news that your hemoglobin is up to 10! Darn sorry that your creatinine level may hold you up from getting home for a bit but they'll get that fixed - such patience it takes. You and your family please know that you're in our prayers for continued healing and energy for this journey to health. Love, Judy and Paul

Kris (2007-05-24 08:38:00)

Heard you were singing some old time gospel last night.... did you hear that the Chancellors are coming to church in September??? Yet another reason to build up your strength..!!!! (If you need to hear some of their music, I think I have all their CD's).... It'll be SWEET!!! Have a great day resting while the Lord corrects those levels... Blessings and hugs to all!

Groundhog Day 2 (2007-05-24 07:44)

I will be here at least another day. My creatinine dropped only from 1.9 to 1.8, not enough change to let me go. They are putting me back on a reduced dose of cyclosporine (GenGraf) and will reevaluate again tomorrow. I have also had about an hour of magnesium IV each day.

More hair fell out yesterday when I showered, but still have enough to say I am not bald. I shaved again this morning so that is still growing. To bad that I cannot switch those two.

Going home (2007-05-25 07:53)

[1] 

Groundhog Day is over. It is the first day of Summer. My creatinine level is down and I am going home. My wife is working today and there is a lot of follow up work to do here, so I will not leave until 5pm.

I still need to get a list of everthing to do at home and all the supplies and meds from the hospital discharge pharmacy. It will be great to sleep in my own bed, use my MacBook Pro laptop with the 20" LCD monitor and watch my HD wide screen TV while lying back in my recliner.

Each of the last three days, I have lost hair while taking a shower. The picture above was just taken with my laptop camera and shows the current state. Seems like the dark hair has fallen out and I am left with the grey. I am also still shaving so maybe I will retain some hair on my head.

I will still be coming into the clinic every day and updating my blog, so check back. I appreciate all of your prayers and support over the last 25 days while I have been here at the hospital.

1. http://myelo.us/uploaded_images/JoelLastDay-785889.jpg

Big brother (2007-05-25 09:05:00)

It looks like my bone marrow is making you look older.

Joyce (2007-05-25 09:33:00)

Congrats from here! Have a great Memorial Day - as for the color of your hair - you've just become more distinguished! *grin*
Joyce

Kris (2007-05-25 10:11:00)

God is GOOD - all the time!!!! So happy and excited! I'll hold my breath on the hair situation.. who knows... maybe it'll come back in "red"... :) (We have more fun than blondes!!!)

Anonymous (2007-05-25 11:34:00)

I am glad you get to go home and that you got good news regarding the Creatine.

Ken Brandt

Johnny (2007-05-25 12:04:00)

Hi Joel

We are so happy with your restoration. we all are priviledged to know our God and pray and be heard and be answered. So many don't know Him.

I hope you can share with your friends the mercy of The One who has the power to kep (or not) our hair over our heads.

May God bless you more and more.

Johnny

Rio do Sul - Brasil

Anonymous (2007-05-25 22:04:00)

I wanted to let you know that I'm thinking of you.

Jenne

At home (2007-05-27 15:20)

It is great to be at home and my condition has improved. My creatinine level has decreased some more to 1.49 while my hemoglobin has increased to 11.1 probably the highest in 3 years. White cell count is up a little in normal range while platelets are still struggling at the low end. Most importantly, my fluid retention is decreased and I weigh about 6 lbs less than when I left the hospital, but I still weigh about 6 lbs more than when I checked in.

I keep feeling better and eating better every day, but still feel nauseated after eating just a small portion of food. Taking all the pills don't help either. My taste buds, saliva generation and smelling still have not fully come back.

My wife and son are great support with all kinds of little supplies to buy or find for me. The brake light on the van and the ceiling light in the bedroom burned out. The furnace filter needed to be replaced. The lawn needed to be mowed and plants watered. A lot of things that I cannot yet do myself.

Anonymous (2007-05-27 18:34:00)

That is great that your creatinine is down and your hemoglobin is up! It must be great to be back home. Sorry to hear that you are still dealing with nausea. Hope that things continue to improve each day. Marge

Kris (2007-05-28 08:20:00)

I hope you got the hug I sent your way yesterday (via Marilyn)... It was great to see her smiling face!!! Isn't God amazing?!? So now you just have to learn how to rest while everyone else does the chores... not easy, but somebody's gotta do it.. :-)
Enjoy the quiet times now... you know the lawn will keep growing, the filters will need another change and the flowers - well, you know how they are... Praying for a good appetite and adjustment to all the pills - how can you have any room to eat after those?!? Don't forget the daily dose of chocolate...

Anonymous (2007-05-28 10:12:00)

Glad you are feeling better every day.

Ken Brandt

Anonymous (2007-05-29 12:30:00)

Getting home is the best medicine of all. I'm sure you'll continue improving and will feel better every day. Take care and let us know if we can help with anything from work.

Jeff Lemaire

Joyce (2007-05-29 13:58:00)

Yea! This is great. Will send silly book soon to make you smile techie.

Joyce

Anonymous (2007-05-29 15:57:00)

Really glad to read you are at home now. I asked Karen Friday night if she had read an updated report - she had - and you were doing well. Now at home in the comfort of a recliner, a HD TV (they are great) and your laptop with 20" monitor (I'm jealous) its on the finish line for you. Great news. Reg

Anonymous (2007-05-29 17:31:00)

Hey, Joel! Thanks for reminding me to check our furnace filter! I'm glad to hear you are home and have Andrew and Marilyn to supervise... that is, you are their supervisor!

May God continue to bring improvements your way. Father's Day is coming so soak up all the support and love!

Dorrie & Brad

BMT + 21 (2007-05-29 18:20)

It has been three weeks since the the BMT and 4th day home from the hospital. It was Bone Marrow Biopsy day, the sixth one that I have had. This one was the longest and most uncomfortable because of my position on my nauseated stomach for over an hour, plus numbness forming in my neck, hand and feet. There is a a lot of scar tissue in my hip bones and it is getting more difficult to get a good sample. They had to drill into my hip bone three times. The pathologist who is going to examine the marrow did the procedure so we know he got a good sample.

I also had another platelet infusion as a precaution against bleeding. It is still uncertain whether the BMT will

also cure my anti-phospholipid syndrome problem. blood counts were about the same and I lost another 2 lbs of fluid. From the max of about 20 lbs fluid gain, I have about 4 left to lose.

I take about 49 pills a day plus one injection. The cyclosporine (GenGraf) was reduced from 250 mg to 200 mg twice a day. I take pills about 6 times a day, trying to eat some before each session.

Anonymous (2007-05-29 20:10:00)

Sounds as though you had a tough and challenging day. Glad the doctor got a good sample and that you are continuing to lose the fluid. Hope you can relax and get some rest. Marge

BMT + 22 (2007-05-30 21:59)

Today was another long day at the BMT Clinic. I forgot to mention yesterday that I had a chest x-ray which the Dr said today showed fluid on my lungs. He ordered an EKG and an echo cardiogram which I had this morning. He wants to rule out any heart problem that might cause the lung fluid retention. We won't know results until tomorrow.

I also had an infusion of 4g of magnesium today. That's the equivalent of 10 pills. I am now taking 4 pills a day at home. These two seem to be the major issues for the moment while we wait for results from the bone marrow biopsy.

With travel, we were away from home 6 hours and then behind on medicines. My wife drove me home and then had to pickup my daughter (backup support) at the airport. Tomorrow, my son graduates from high school while I watch on cable TV. Sunday afternoon, he has a party at church while different family members take turns visiting with me about 1/2 mile away. It is great to now have both daughter and son to help in the home care. My wife returns to teaching school for another week. I feel like a king in my throne (recliner) while people do things that I cannot do. Most are things I could do, but need to minimize exposure to germs.

Anonymous (2007-05-31 08:45:00)

Hi Joel,

Sounds like the biopsy you had yesterday was not fun. Hang in there, I'm sure there are better days ahead. I'm not sure I like the sounds of you "feeling like a king"! Just remember, you will be coming back to work and I don't think you "feeling like a king" will work around here.:) So enjoy that while you can we're all pleased that your being taken good care of. john

Anonymous (2007-05-31 11:32:00)

I am glad you have a nice recliner and a good TV screen. Maybe you could get some good movies to watch. Some of my favorites are King Ralph, with Peter O'Toole; Mrs. Miniver (WWII movie); Casablanca; and My Favorite Year (again with Peter O'Toole). I'm sure you have "old favorites" of your own, too. Marge

Anonymous (2007-05-31 13:26:00)

Hey Joel,

Keep up the good work! I continue to check up on you via this site and pray for your continued success.

Joe M.

2.6 June

BMT + 25 (2007-06-02 20:34)

Well, its Saturday and I did not have to go to the Dr today. Yesterday, the Dr said that everything was normal, at least as good as expected for me at this time. My hemoglobin and platelets are still below that for an average person, but still where they should be for a BMT patient. Of course, as long as I am taking all these pills, it is a propped up normal. They gave me more magnesium on Thursday but did not need to on Friday. I get the day off tomorrow as well.

The negative of not going into the clinic is that we have to flush my central line at home. Andrew did it this afternoon, but I was a little nervous.

On Friday after my appointment, one of the clinic Drs asked me to talk to a patient who had completed a week of tests to qualify him for a BMT, but was still not committed to moving ahead next week. This young man discovered he had myelofibrosis last Sept. He has an unrelated donor, but is getting a mini-BMT similar to mine. I related my experiences and directed him and his wife to this blog for further details. I also suggested that they setup a CaringBridge site. I gave credit to God and the power of prayer. Please pray for Keith as well since he decided to move ahead with the BMT.

Anonymous (2007-06-03 07:22:00)

Glad to hear that things are going well and that you are helping others who may be able to benefit from your life experience. We will pray for Keith and his family and wish him and his family well as he undertakes a similar journey.

Anonymous (2007-06-03 19:52:00)

I hope this comment records OK – Just want you to know that we are all praying for you – So glad you are home, and that A and A are home now, too, to help. Glad you are getting to take a couple of days off from doctor visits – It must be so good to be home–We will pray for Keith, too. I'm sure you are a great source of help and encouragement to him!
BJB and family

100% Donor cells (2007-06-04 18:40)

The results of my bone marrow biopsy shows 100 % total donor engraftment. The doctor even seemed surprised when he pulled up the results on the computer this morning. This means that my brother's stem cells have taken over and eliminated my old defective bone cells. My hemoglobin reached a high of 11.9 and platelets have increased from 51 to 79 in the last 6 days, more evidence of the new cells. On the negative side my magnesium was down so I needed an infusion today and my creatinine is up to 1.68.

The challenge now is to manage all of the medicines to prevent GvHD (Graft versus Host Disease) as well as getting my normal digestive functions back in order. My weight was 235 lbs fully clothed this morning versus about 248 on check in to the hospital and 266 with the fluid retention and hospital gown. With all the pills and diminished taste and saliva, I still cannot eat normally and feel nauseated most of the time.

But isn't God great! He guided me through the valley of the shadow of death and will continue to heal the rest of my body.

Anonymous (2007-06-05 08:13:00)

We rejoice with all of you Joel! What an answer to prayer. The journey goes forward with definite evidence that everything is working to the glory of God. You remain in our prayers. Certainly hope your appetite returns soon.

Love, Becky, Emily, and Jenny

Kris (2007-06-05 08:34:00)

Thank you Jesus!!!! He is SOOOOO amazing!!! He is not done with His work in you..... can't wait for more good news!!!! Blessings on you!!

Anonymous (2007-06-05 10:29:00)

That's wonderful news Joel. I bet you're all celebrating and the weight on your shoulders awaiting the outcome of the BMT has been lifted. Hope progress continues as positively as it has.

Karen H.

Anonymous (2007-06-05 11:37:00)

That is great news! We are very happy to hear this, and it must be a great burden lifted. Marge

Anonymous (2007-06-05 11:52:00)

That is great news, and a great burden lifted! Much credit goes to you and your brother for "walking the walk" to get to this point. marge

Anonymous (2007-06-05 15:42:00)

We rejoice with all of you Joel. What a tremendous answer to prayer. God has definitely bestowed his blessings on you. We will continue to pray for continued healing and No Graft versus Host disease and for your medications to be balanced; and for your appetite to return.

Love, Lola & Don

Anonymous (2007-06-05 19:31:00)

Wonderful news!

Ken Brandt

GvHD + 35 (2007-06-12 21:26)

Sorry for the delay in posting but things have been pretty boring. Each day seems like the next, but today may be the start of a new phase. I have been tired recently, napping several times a day or falling asleep watching television. I now see the doctor about twice a week and am gradually reducing medication (now down to about 30 pills a day).

After a shower this morning, we discovered a rash on the inner side of my right thigh. Doctor also ordered a stool sample which I must deliver on Thursday. There has also been some talk about an endoscopy to check my digestive tract. I am still having problems with nausea and lack of appetite and have lost over 25 lbs from what I weighed before checking into the hospital on May 1.

It has been 35 days since the BMT and I am thankful that the new bone cells have engrafted and not all my hair has fallen out. Now it looks like the negative symptoms of GvHD have started.

Pastor Sean Kelly (2007-06-13 07:47:00)

Joel,

Were praying hard for your recovery. My brother's healing process from his marrow transplant was very slow as well. Everyday seemed like the last day, but now 9 months removed, he's so much better! So, don't give up hope.

Blessings, Pastor Sean @ Redeemer

Anonymous (2007-06-13 08:01:00)

Thank you for the update. It must be tough dealing with all that you are dealing with, but you are doing nobly! Marge

Anonymous (2007-06-13 12:54:00)

What a struggle!

Ken

Joyce (2007-06-13 13:53:00)

Looking forward to hearing (and seeing) your first day in the big world again. You rock.

Joyce

Anonymous (2007-07-05 11:44:00)

Dear Uncle Joel,

We continue to pray for you. I think I missed something. Is GvHD, something about the host rejecting the bone marrow or is it something different? Please explain GvHD.

We love you always. I just found a letter you wrote to your mother from Houghton when you went to college. I found it in the little end table that Daddy brought back to me from Grama's house. I couldn't help myself. I read most of it. It was long :)

Well, you are a great writer. It will probably be your second career! It was a treasure that you mother Barbara (Gramma G) hid it there for safe keeping! Now almost 40 years later we get to read it.

I'll be putting it in the mail to you soon. Watch for it.

Love, Lori Younker

Day +41 (2007-06-18 09:16)

Hopefully, I can get a status post out more frequently, but it seems like weekly now. It has been 41 days since the BMT and I may be in a GvHD phase now. Last week, I had three appointments and spent over 14 hours at the clinic. Thursday stretched out with a decision to give me fluids and a blood transfusion. My regular Dr is on vacation so the PA thought they could get the blood in before we left for the day. The blood bank reported back that they still needed more time to match my blood because I still have the extra antigens that existed before the BMT. It is unknown whether those will be eventually cleared up. So we were back in on Friday for another 4 hours. Both the fluid and blood have perked me up some over the weekend

There have been no results of the stool sample from last Thursday and I have an endoscopy scheduled for tomorrow. Both of these should answer part of the GvHD question.

Anonymous (2007-06-18 19:27:00)

Am sorry to hear about all of the hours you are having to spend in a medical environment. Hope the tests will be helpful in figuring out what is going on. You have come a long way and have shown great courage to have gotten this far. Marge

Anonymous (2007-06-20 19:15:00)

I am sorry that the news isn't better, but I am glad it isn't worse.

Ken Brandt

Day +45 (2007-06-22 09:59)

This is my second report this week in only four days. It has been 45 days since the BMT and possible GvHD is still under investigation. The stool sample from last week was negative, but the results of endoscopy on Tuesday were less certain. I will get a final report on the endoscopy next Tuesday.

I still don't have much appetite and feel nauseated after eating and taking all the pills. I am still fighting diarrhea and urination every hour. I was supposed to have a Dr appt today, but felt weak and tired yesterday so went in then instead. My hemoglobin was 10.7 so no transfusion was required. I did get a liter of fluid while I was there and feel a little better today. My next appt is on Tuesday

Kris (2007-06-22 14:52:00)

... still praying.... forced relaxation is never as fun as chosen relaxation... vacation...time off...peace and quiet...etc...
hmmm.... now I'm feeling sleepy... my eyes are heavy...ZZZZZZZ....

hugs to all...

K.

Anonymous (2007-06-23 22:51:00)

We are still praying Joel. We saw some of our church friends today and reminded them to keep praying. It was good to see Marilyn and Eleanor today. Hopefully we'll see you tomorrow.

your little sister

Anonymous (2007-06-26 11:04:00)

Hi, Joel -

Please know you and your dear family continue to be in our thoughts and prayers. The journey to wellness is so hard, with some difficult detours, but please know that our hearts are reaching out to you across the miles. We hope you receive good news this week and that you're able to eat without discomfort.

Love,

Judy and Paul in North Attleboro

Joyce (2007-06-27 18:15:00)

Hey Joel:

I'm hoping you have pleasant plans for the coming official middle of summer July 4th.

And I'm hoping you are feeling much improved.

Take care,
Joyce

Day + 51 (2007-06-28 18:02)

I was to the Clinic twice this week, once on Tuesday and then today. On Tuesday, we learned that the endoscopy showed no GvHD in the upper GI tract but I was still having some diarrhea so I was told to obtain another stool sample. My hemoglobin was down to 9.1 the lowest it has been since before the BMT. My creatinine level was very high reflecting lower kidney function so I also received some IV fluids while at the clinic. The Dr also dropped the GenGraf for a few days and lowered the Acyclovir.

So today I received 2 units of blood (rbcs) and some more magnesium. My creatinine was down and I have had little diarrhea so was not able to get a sample. The Dr has now restored the GenGraf at a lower level and the Bactrium which I also did not take this week.

I was tired due to the low hemoglobin the last few days but my digestive system seems a little better. We are in a period of balancing the side effects of the medicines versus the benefits. Drs say the fluctuating hemoglobin is still ok this early in the recovery, but I worry that my old autoimmune system is still in effect.

Hope to learn more next week after another bone marrow biopsy on Friday July 6 plus a regular appt on Tuesday July 3. There will be no time off on the 4th for me; I will be here popping about 30 pills a day.

Big brother (2007-06-29 09:52:00)

We keep praying that you will recover. We hope that auto-immune problem will be overcome. We pray for you for patience and strength for the days ahead. Let's continue to praise God for the progress so far.

Joyce (2007-06-29 15:46:00)

Hey ho, Joel.

Not everyone could escape the police if they said they were mainlining 30 pills a day. Definitely a historic incident in anyone's life. I'm expecting a review of the best televised fireworks presentation on your huge TV and maybe an update on when you picked up your iPhone.

Will look for your body to pick more human and positive directions as well.

grin*

I'm hanging in there for you.

Joyce

Anonymous (2007-06-30 16:23:00)

Glad you are "hanging in there."

Ken Brandt

2.7 July

Day + 56 (2007-07-03 21:08)

Well, the GvHD question is open again. I was in for an appt this morning after generally not feeling too good the last few days. I have been fighting bouts of diarrhea on Sunday and Monday, but am thankful clear at the moment. Didn't sleep very well last night because of dry mouth.

My creatinine has been high due to the diarrhea and lack of kidney function so I still try to drink at least 8 cups of water a day. I essentially have no appetite but try to eat a variety of food, never able to finish even 1/2 a normal portion. The clinic gave me more magnesium and fluids IVs today. I was told to come in Thursday as well if I have more diarrhea and dry mouth.

Any way, I had a stool sample, a urine sample, and a chest x-ray plus special blood cultures taken. X-ray was ok; no fluid in lungs. I go in Friday at 7:30am for a sigmoidoscopy followed by another bone marrow biopsy. I also had a Schirmer test for dryness in my eyes. This is done by placing a piece of paper under the lower eye lid and measuring how many tears are produced.

I look forward to my July 10th appt to get the results of all these tests and determine what we do next.

Keep looking up!

Big brother (2007-07-04 09:29:00)

We keep praying for the correct diagnosis, so the doctors can treat these problems. On this July 4th let's declsre our dependence on God and give Him the glory.

Anonymous (2007-07-04 13:42:00)

We continue to lift you up in prayer. we will share this with our Brazil team. we are sharing in our classes about our independence on this 4th of July but we are also sharing of our dependence on God and the freedom he gives us from the power of sin in our lives, to live our lives for Him and for His glory. May God be praised now and forever.

your little sister in Brazil

Joyce (2007-07-04 16:34:00)

Ah Joel - I've been wishing, hoping and praying that you were doing well. However diets of 90 pills a day and not interested in the pleasures of chocolate while required to drink 8 cups of water leaves me hoping that tomorrow will be better!

I'll watch the fireworks over Powderhorn Park and think of you.

Best,

Joyce

Anonymous (2007-07-04 17:27:00)

Hope the test results are good.

Ken Brandt

Anonymous (2007-07-04 22:04:00)

Wanted to let you know that I'm thinking of you.

Jenne

Joyce (2007-07-07 08:06:00)

Thank you for your considered opinions on the televised fireworks displays. Since my tv is small and I don't have the range of technologic marvel I am in envy of you the results.

However, I too wish you could have been in Bemiji.

I'm praying for that result!

Joyce

Day + 59 (2007-07-06 17:34)

What a difference a few days make since I have been feeling much better since Tuesday. This was somewhat tempered by getting up early this morning and having both a sigmoidoscopy and another bone marrow biopsy. I still have little appetite but diarrhea and dry mouth have let up.

The initial sigmoid test was negative for GvHD though samples were taken to be analyzed. Other tests of stool, urine and blood culture have also been negative. Blood counts are ok except for the hemoglobin which keeps dropping. I am also now taking eye drops for dry eyes.

The bone marrow biopsy went very well this morning, taking 1/2 the time of the last. The difference was experience of who did it and use of a bigger (8 gauge) needle. I have my next Dr appt next Tuesday when I will learn more from the biopsies that I had today.

[1]GvHD, in answer to Lori's question on the June 12 post, is basically when the new donor white blood cells attack rapidly growing host cells. This is beneficial when the the attacked cells are remnants of previous cancers (tumors). It it not pleasant and can be life threatening if the cells are GI tract, lungs or liver. Skin or eye GvHD can also occur.

For Joyce, my top rating on fireworks, viewed on a 46" HD TV, is for Boston. Of course, the only other one I watched was New York. NY was 30 minutes long and seemed to be launched from a broader location. Boston was only 20 minutes and seemed more concentrated. Both were choreographed to music, but you can't beat the Boston Pops Orchestra for smooth medley transitions. I especially liked the Sesame Street song synched with fireworks in the shape of a toy block or the numbers 2 and 3. NY synched those with "Take me out to the ball game". Over all, I would have much rather been with my son and daughter in Bemidji, watching their fireworks from the beach.

1. <http://www.dcmsonline.org/jax-medicine/2000journals/nov2000/graft.htm>

Anonymous (2007-07-08 13:00:00)

I am glad the tests continue to be negative.

Ken Brandt

Day + 63 (2007-07-10 19:02)

Well, I went down hill after Friday and had to go into clinic on Monday for some more magnesium and fluids. This helped me some but now I get more blood on Wed. I saw the Dr again today and will again on Thurs.

Other than hemoglobin, my blood counts are ok. Dr. also reported that my last bone marrow biopsy looked good with all cell lines growing well and still showing engraftment. Since none of the tests confirm any acute GvHD, the Dr ordered a lip biopsy which was done this afternoon in the Dermatology Clinic. They took a piece of salvia gland from inner lower lip and a sample of some flaky skin. They also examined my whole body for anything suspicious.

Dr. thinks that I may have chronic GvHD which normally occurs after 100 days. If it is cGvHD, treatment would probably be Prednizone and could continue for several years.

Big brother (2007-07-11 09:12:00)

We talked about this yesterday. But several years on prednizone could have side effects, right?

We keep praying. "In God we trust".

Joyce (2007-07-11 18:40:00)

May I be a little left handed humourous? In God we Trust (and in Rome we pay our bills.) Thus to God those items that God desires, and money makes the World go around.

I'm hoping that several years of prednizone is the worst that happens in your progress! (I'll toast you with 8 glasses of water,)

Take Care

Joyce

Hospital again + 75 (2007-07-22 19:15)

Sorry that it has been almost 2 weeks since I posted. The week of 10th, I was into the clinic everyday and couple unplanned to get fluids. Most of the tests were negative for GvHD except for the [1]D-Xylose test that I had last Tuesday. Just got results back today from Mayo Clinic and it definitely indicated GvHD. I am now on 90mg Prednisone per day and added CellCept back for treatment as well. Got to drop Ursodiol but added 4 "horse" tablets of Bactrim each day.

Also the clinic had taken blood cultures for several days starting the 13th. They got the first results back on Tuesday (after I got home from a day of D-Xylose) and had me go straight to the hospital. I didn't feel too bad but Drs were worried since it was a very septic infection in my blood. On Wed, they pulled out my central line and ran cultures on that as well. On Thurs, they ran a [2]PICC line which accomplishes the same purpose as the old central line. It hangs out of my right bicep area down to my elbow, dangling from under any short sleeve shirt. I got out of the hospital about 1pm on Saturday and was back at the clinic at 8:30 this morning. Already have appts for Monday and Tuesday and probably more this week.

It is good to have some confirmation of why I have not had an appetite and I have lost weight. Official weight from this morning was 197 lbs, 70 lbs less than my bloated high back in May and 55 lbs less than when many of you saw me last.

Thanks for all your prayers. Last Monday, after my sister came back from a 2 week mission trip to Brazil, we had a family prayer meeting at my house. Little did we know that the blood culture test that may have saved my life was already underway. Just a few days later and results could have been much different. God works in mysterious ways.

1. <http://www.webmd.com/ibs/D-Xylose-Absorption-Test>
2. <http://www.webmd.com/a-to-z-guides/Central-Venous-Catheters-Topic-Overview>

Big brother (2007-07-23 09:12:00)

We thank our sisters Charlotte and Lola for scheduling the prayer meeting. Thanks to all who have been praying.

Anonymous (2007-07-23 11:37:00)

Greetings -

We are grateful that the infection was found, and that you'll be able to start feeling stronger and able to eat. Please know that we send prayers daily to you and Marilyn and your family.

Love, Judy and Paul Eustace

Bev (2007-07-23 15:12:00)

We're so glad that you are back home, and that the source of the infection was identified. You are in our thoughts and prayers.

Hope you feel better soon!

Bev and Family

Joyce (2007-07-23 19:43:00)

Home again, Home again!

(And a diagnosis to work with.)

Many good wishes.

Joyce

Anonymous (2007-07-30 16:44:00)

Hi Joel, were keeping tabs on your progress here at work. Keep up the great battle and you'll prevail. We're keeping your desk ready for your return. john

GvHD + 84 (2007-07-31 18:48)

Only 9 days since last posting so doing better with only 4 appointments to report. Still battling potassium and creatinine levels in my blood, indicating possible kidney problems. So I get IV fluids on each visit and need to keep drinking more water. There have also been more adjustments of medicines to help out. The prednisone is helping my appetite, but I still don't have my taste buds back. I have lost a few more lbs so my gut is probably not absorbing enough yet as well.

As part of the GvHD treatment, I am participating with a [1]Fred Hutchinson Research Study where I either get MMF or a placebo along with the normal treatment. This is another 8 pills a day, though they could be what I took during the engraftment phase. This study could last up to two years and is meant to determine whether MMF helps in the GvHD phase. Note that the study is not listed at the web site so may be closed to participating research groups.

Not sure when I will be back to work. Earliest may be 2 months due to immunity problems and need to stay relatively isolated from people. Otherwise, I am feeling much better and getting things done around the house.

1. <http://www.fhcrc.org/>

Anonymous (2007-08-01 15:43:00)

Glad to hear that you are feeling better and getting things done around the house. That is great news! Marge

Anonymous (2007-08-01 17:19:00)

How nice it is to get positive news. Hope you continue to feel better.

I heard very good things about the "Hutch" when I lived in Seattle. Glad you are participating in their study.

Ken Brandt

bjbach (2007-08-01 19:48:00)

I'm so glad you are feeling better - that is great news!

Bev

Joyce (2007-08-04 20:52:00)

It's great to know you're looking up! Even looking towards returning here (now that you've missed the humidity and the turning down of the air conditioning.)

Joyce

2.8 August

35W Bridge (2007-08-02 13:25)

Just a note that we are all safe after the collapse of the 35W bridge yesterday. We had many calls from relatives since we drive close to it for every doctor appointment. We drive down either Washington Ave or University Ave near each end of the bridge though rarely cross the 35W bridge itself. Just last week, Anna and I drove across as we detoured to stop at the Dinkytown post office. Now have to contend with detours on the Washington Ave side from I-94. Our prayers go out to all the affected families.

I just got back from an appointment where things are going better still. Got some more fluids and they took some more blood cultures to check on the previous infection. I am back on GenGraf since my kidney function has improved and will start a taper on the prednisone next week.

Anonymous (2007-08-03 08:26:00)

We rejoice that all of you are safe with the recent tragedy! It is a small world medically. Here in Seattle we are so familiar with Fred Hutch and have participated in annual fund raising events for them. I'm so glad they may be able to provide help in dealing with this disease process. You remain in our prayers!

Love, Becky,Emily, and Jenny

BMT + 3 months (2007-08-07 21:43)

It will be three months tomorrow since the first day of my BMT on May 8th. Besides the GvHD which seems to be coming under control, I am feeling pretty good. I have stopped losing weight and starting to gain again. Due to the prednisone, I have an appetite, somewhat uncontrollable. I am starting a taper of the prednisone from 90 mg every day to 40 mg on alternating days. I have little nausea and normal bowel and urinary functions.

My blood counts were all within reason today though platelets and hemoglobin are still a little low. I did not need any fluids today, but there is still a question about a possible blood infection. So for the first time since May 2, all tubes have been removed. The PICC line that was put in several weeks ago was removed so next time they will start picking me with IV needles again.

But for the first time, I don't have an appointment for a whole week. The Dr says that I can even leave town and travel to the lake cabin in another week. Possibly in a couple of weeks, I can get out in public as well. It all depends on how things improve further. I did make it to the neighborhood party this evening though wore my mask and did not shake any hands.

Anonymous (2007-08-08 08:22:00)

Joel, it's so nice to hear that you are feeling better! We are so thankful for that, and hope you continue to improve, day by day.
Bev and Family

Big Brother (2007-08-08 09:29:00)

Thanks for the good news.

Glory be to God.

We keep praying that medicine and prayer will sustain you.

Anonymous (2007-08-08 20:17:00)

Joel,

We are so thankful to GOd that you are feeling better. We will continue to pray for continued recovery. It was good to be together last weekend.

Lola & Don

Anonymous (2007-08-16 09:21:00)

Hi Joel,

I keep our office updated on your progress. We have been praying for you throughout the whole process and continue to do so. Praise the Lord that you are doing so well. I pray that the results of the biopsy will be good and that you will have a relaxing time at the cabin this weekend. I'll be in touch.

Love,

Charlotte & Dave

BMT + 100 days (2007-08-18 08:53)

Actually my 100th day since the bone marrow transplant passed a few days ago, so I have made it pretty far since entering the hospital on May 1. I had my 9th bone marrow biopsy on Thursday when they tried some new needles which seemed to work better. My biggest problem with the biopsy is lying in a cramped position which affects my arthritic knees. The quicker it goes, the better. I get some results back on Tuesday but don't expect any surprises.

I am feeling much better the last couple of weeks and am starting to get out. Did some shopping for a car battery and carpet for our washroom. Dr says I can stop using the mask and go to church on Sunday. Hope to see some of you there. We also plan to take a trip to the cabin in Bemidji next week. This will be the first time for me since Andrew and I were there in April and saw the ice go out. All of my care givers go back to teaching or attending school in a couple of weeks, but I am getting pretty independent and now driving as well.

While I am proceeding with applications for long-term disability and social security, I may be back to work before mid-October. Still need to taper medications and see how I react to the changes plus build up my endurance. A short trip out shopping or working around the house still tires me out. Still need approval from the Dr before going back to work

Anonymous (2007-08-19 22:58:00)

Greetings -

Thrilled to hear that you are getting out some and feeling stronger! It must be a joy to do a daily task that so many of us take for granted. Here's to getting to the lake and enjoying the beautiful view!

Love, Judy and Paul Eustace

Anonymous (2007-08-20 09:52:00)

We are so happy to hear that you are feeling better! It was so nice that you could go to church with the family, do some driving and things around the house, and get up to the lake! We are so happy and thankful, and hope that you have a wonderful time at the lake!

Anonymous (2007-08-20 09:53:00)

I meant to mention that the last "Anonymous" comment was from us - Bev and Family!

Joyce (2007-08-20 20:01:00)

Joel:

This sounds great! I'm so glad to know you are escaping the traps of the huge TV and the outside mask.

(I've got to make you sound as if you're a superhero somehow, no?)

Good work, and I look forward to your return.

Joyce

Anonymous (2007-08-21 13:52:00)

Joel,

Thanks be to God for your progress! Please let us know when you will be back at work. I will be sure to fly up for a business call and be one of the first to welcome you back.

Keep going!

Joe M.

Anonymous (2007-08-27 18:48:00)

Glad things are going better.

Ken Brandt

2.9 September

Day 115 (2007-09-03 17:06)

These postings are getting further between since I have little to report on my health. Everything is pretty stable and it is two weeks between appointments now. My last was on Aug 28th so next is on Sept 11. My blood counts are good with hemoglobin staying above 11 (11.4 at last test). Dr is still concerned about seeing some hemolysis so it should be higher. They are also watching my urine since some blood and protein were noticed a few weeks ago. I have now reduced my prednisone to 90mg every other day from the every day when I started on it.

We made it to the lake cabin near Bemidji the week before last. It was a nice trip though I could not do a lot that I would have liked to. We did have to cut up a large tree that had fallen across the lane. Just fun to be there with the whole family.

I made it to church again yesterday. It was the first day of the month and communion. It reminded me of the blood and body of Christ being similar to the blood and bone marrow received from my brother. Together, they make a miracle of extended life on this earth plus external life after that.

Anonymous (2007-09-04 18:24:00)

Glad you are feeling better and that all of you enjoyed yourselves at the lake.

Ken Brandt

Joyce (2007-09-05 20:11:00)

Return to us!

good to know you're improving though.

Joyce

Day 123 Changes (2007-09-11 19:23)

My health has still not settled down and changes are underway. I am still feeling pretty good though experienced some nausea, stomach cramps and diarrhea in the past week. I will probably be experiencing more as I back off some of the medications.

My Dr says it appears that the engraftment is going backward since we started the prednisone in mid-July. Recent tests showed that 30 % of my immune system is still active, a JAK2 genetic test is now positive again and there is still hemolysis of red blood cells. It is a battle between the new and old immune systems and the current medications are fighting the new while the new fights my body. The old immune system was fighting my red blood cells as well before the BMT. A DLI (Donor Leukocyte Infusion) from my brother may be required as a booster for the new immune system.

Anyway, I will drop out of the Hutchinson study on the chance that I was really getting MMF and not the placebo. I will taper off of the GenGraf (cyclosporine) within a week and reduce the prednisone from 90 to 40mg every other day. I will also restart the Bactrium which was stopped back in July. Rituxan IVs are also a possibility. I am back to Dr appts every week and cannot go back to work until November.

My application for long-term disability is progressing well for possible start on Oct 28 while I also work on the Social Security Disability application. The way things are progressing, I may need both though still hope to be working part time by then. Your prayers are once again appreciated.

Joyce (2007-09-12 12:44:00)

I'm doing my best praying and wishing for you. I miss talking with you in person. Say hello to your patient wife as well!

Joyce

Big brother (2007-09-16 09:29:00)

Sorry to hear of the setbacks.

Hope the adjustments in medications help. I am available if you need that infusion from me.

We keep praying for God's help.

Day 136 (2007-09-22 09:46)

It has been a few days since my last Dr appt on Tuesday. My hemoglobin has dropped from a high of 11.5 on August 21 to 10.2 on Tuesday. Dr is still concerned about hemolysis (breakdown of red blood cells) but sees less jaundice in my eyes. He has added folic acid back to my medicine list. I took folic acid for several years, but stopped when I entered the hospital in May. I have also transitioned off the GenGraf and MMF, reduced Prednisone and started back on Bactrium. I am not sure if it associated but my appetite has reduced and taste has changed.

I have applied for both LTD (long term disability) from Aetna and Social Security Disability. I heard back from both about questions and their initial positive impressions. My short term disability from my employer ends on October 18th and, if approved, Aetna LTD would start October 28th. The SSD will take several months and will only offset part of the Aetna LTD. I will discuss possibly working part-time with my Dr at my next appt on Oct 2. The next month will be a time of some major changes either in my daily activity and/or income level.

Joyce (2007-09-29 18:41:00)

I wonder how you're doing?

Joyce

2.10 October

Flashback to April (2007-10-15 16:00)

Seems like I am back to my situation back in April. Though not scheduled for a Dr appt for another two weeks, I sensed that my hemoglobin was low. I was tired, out of breath with little exertion, dizzy spells and getting slight headaches. So this morning, I called in and arranged for a blood test this afternoon. Turns out that my Hgb was 8.4 and white cell count was 2.3, both the lowest that they have been since I left the hospital in late May. My platelets are up to 133, the highest since before my BMT.

So, I will be in for a blood transfusion on Tuesday and the Dr has increased my prednisone. I have been on 20 mg every other day and now moving to 60 mg every day. I assume that after this, I will feel pretty good again. I was approved for long term disability pay through insurance and await a response from Social Security. I am seriously considering going back to work 1/2 time to see how that works out. It will seem like April again, working with regular trips to Dr for blood transfusions.

Over the past month, I have been taking inventory of my old TI99 computer collection and plan to travel to Chicago for a computer faire on Saturday. My son will help drive and we will stay part of Sunday to sightsee as well. My first home computer was the TI99/4 in 1980. I now have about 10 spares, 150 cartridges and miscellaneous hardware. There were close to 500 different cartridges produced, many after TI discontinued the computer in 1983. My most recent addition was a newly developed hard disk interface with a 2GB HD. There is still an internet based user group with over 500 members, 50 of which will probably show up in Chicago.

Anonymous (2007-10-15 18:27:00)

Hi, Joel - I'm sorry to hear that you are not feeling as well as you were; hopefully, the transfusion and the increased dosage of Prednisone will help. I hope you and Andrew have a great time in Chicago, and that you enjoy the computer faire!

BJB and Family

Anonymous (2007-10-15 20:32:00)

I think I remember you showing me that computer. I was very impressed.

Hope the Prednisone works and you can go back to work half-time.

Ken Brandt

Anonymous (2007-10-16 08:06:00)

Thank you for your update Joel. You are always in our thoughts and prayers. I'm glad you are in the caring hands of specialists. Enjoy your trip to Chicago with Andrew.

Becky, Emily and Jenny

Further setback (2007-10-17 23:31)

I was in yesterday for a blood transfusion and a further talk with my primary Dr. I discovered that my blood cells are now 30 % donor (my brothers) and 70 % my original. A few months ago it was reversed and supposed the change is in the bone marrow as well. In this light, the Dr has recommended that I do not go back to work on Friday.

I also met with my employer HR and health departments, who advised me that starting work on Friday would delay the start of my LTD payments. I would have to work 60 % time just to offset what LTD will pay if I am not working. So, I will be classified as a "suspended" employee and will still be part of the company group plan as far as insurance benefits are concerned. I will be billed for my share of the costs and will have to pay those out of my LTD monthly check. There are also a lot of other benefit and organizational changes going on at work so I plan to let that situation settle down and consider going back to work in early 2008. Of course, there is no guarantee that my job will be there to return to. Hopefully, by then, my medical situation will be figured out as well.

Your prayers and support are still appreciated.

Big Brother (2007-10-18 09:29:00)

I am so sad to hear this. CS Lewis says "God whispers to us during our pleasures, but shouts to us during our pain". Let us make this disappointment be a God appointment. May God draw us together again in prayer. We said no matter what happens we will give God the Glory. God give us the faith to trust You more.

Anonymous (2007-10-18 18:20:00)

I'm so sorry to hear that things are not going as well as hoped. You continue to be in our thoughts and prayers as you deal with what must be difficult and stressful insurance/work-related issues as well. We are thinking of you and praying for you and the family-

BJB and Family

Anonymous (2007-10-19 17:29:00)

We are so sad to hear the results of our bone marrow. We continue to hold you up in our prayers. As big brother said we will give God the glory and look to God to give us faith to trust him more.

Your little sister.

Anonymous (2007-10-24 18:34:00)

I hope you feel better soon. You are in my thoughts and prayers.

Jenne

Joyce (2007-10-27 02:23:00)

We miss you here, and I'm praying that you get better and can return.

Joyce

Stable again? (2007-10-25 00:02)

I was into the Dr on Tuesday and my hemoglobin has stabilized at least for a week. After the blood transfusion a week ago, it should have gone up two points to about 10.4 and that is where it was this time as well. The transfusion was with A neg blood which may have affected the higher level as well. Since I am A pos, I can get blood from A or O,

either pos or neg.

My white cell and platelet counts are somewhat low though which will also need watching. The Dr has adjusted my prednisone down a little and I have an appt again next Tuesday.

Other than that I am feeling ok. My son and I traveled to Chicago last weekend and attended a TI99 home computer faire on Saturday. The Chicago User Group sponsors this every year to share and exchange hardware and software for this 27+ year old computer. About 20 people attended with a few reporting from a similar meeting in Germany last month. There is an internet based user group of over 500 members to which I belong.

We went downtown Saturday night for Gino's famous deep dish pizza. We walked part of the Magnificent Mile shopping area, visited the Apple Computer store and paid \$32 for 3 hours of parking. Sunday, we visited the Science Museum for 5 hours and then drove back to Minneapolis. Traffic in Chicago was terrible, taking us an hour just to get from downtown to the O'Hare airport area. I made it home about 12:45 AM and slept later in the morning.

2.11 November

Looking up (2007-11-01 20:16)

I was surprised on Tuesday when my blood test showed that my hemoglobin was up to 11.4 from 10.4 last week. It had just been 2 weeks since it was 8.4 and I had a blood transfusion. Going in, I was feeling somewhat dizzy and tired, but surmised I may have been low on fluids and am trying to drink more. On the down side, my white cell count dropped from 1.6 to 1.4 and platelets from 88 to 64. Both are about half of normal though my Hgb is also still below normal as well. The Dr took me off of Acyclovir and Bactrim DS and reduced the prednisone to 40 mg every day.

I have my 6 month bone marrow biopsy on the 7th and the next Dr appt on the 13th. Hopefully, we will then know more details of how the engraftment is progressing. I had blood drawn for a Cytomegalovirus (CMV) test as well.

Other than that, I am feeling pretty good and getting things done around the house. I was also approved for Social Security Disability (SSD), though that payment will go to Aetna insurance to offset my long-term disability payments which are now being coming through. It is rare that anyone is approved for SSD on the first application and it normally takes 2-3 months for a response. I must have impressed them with my medical history.

Anonymous (2007-11-06 21:21:00)

I am sorry about setbacks.

But I am glad the LTD and the SSD are in place.

Ken Brandt

Joyce (2007-11-07 14:57:00)

Good to know you're still here. I'll keep watching for your words.

Comment changes (2007-11-05 16:44)

I have been getting a lot of spam comments on this blog (145 just today) so have changed some of the setup. You will have to enter that funny character string and I will have to approve the comment. I have not figured out how to delete comments after the fact so at least this may clean up what you see.

As always, your comments and support are appreciated.

Biopsy #9 (2007-11-07 20:12)

I had my 9th bone marrow biopsy this morning. The first was in Feb 2005 and I have had 5 since the first going into the BMT at the end of April. I won't know the results until next week, but this was one of the easiest. Each time, I have about three holes drilled in my hip bone, typically alternating between the two sides. They need about 5 cm of bone marrow that is about 3mm in diameter. Then they extract 3 vials of blood with a separate needle that does not use one of the marrow sample holes. These holes heal and form scar tissue which make it more difficult during future biopsies. This was done under just a local lidocaine injection and no other pain killer since I drove myself today. It is the aspirate part that hurts the most because of the pressure change within the bone marrow where lidocaine has no effect.

On another note, my blood test today showed my hemoglobin going up to 12.4, the highest it has been since I started recording in June 2005 when I had my first blood transfusion. For the record, I have had 46 blood transfusions and 93 units of blood, though only 3 and 6 since just before my BMT. My white cell and platelet count went up a little today as well, though all blood counts are still below normal. My CMV test from last week was also negative. I look forward to getting the biopsy results next and seeing where I go from here.

Anonymous (2007-11-10 20:54:00)

That is great that your hemoglobin is so high. Hope the biopsy results are favorable, too. MBH

5000 Served (2007-11-13 20:35)

Great news today. I found out that my bone marrow is now 87.6 % from my donor (brother), a big change from the estimate of only 30 % last month. This latest is direct from the biopsy that I had last week, while last month, it was from a blood test. It is possible that the blood test reflected destruction of cells by my old immune system. Anyway, it appears that the problem may be resolved since my hemoglobin was 13.6 today. This is a new high and actually in the normal range of 13.3 to 17.7 g/dL. Unfortunately, my white cell and platelet counts are still very low and I need to be cautious of infections and injuries. Every little bump now causes bruises.

Relative to this blog title, the [1]BMT clinic was having a celebration today of having performed 5000 bone/stem cell transplants since they started with the (world's) first in [2]1968. I got some cake and a tee-shirt that says "What's in your marrow?" on the front.

1. <http://www.fairviewbmt.org/index.asp>

2. http://www.marow.org/PATIENT/Plan_for_Tx/Choosing_a_TC/US_NMDP_Transplant_Centers/Detailed_Center_Information/tc_idx.pl?ctr_id=506&p_src=state

Big Brother (2007-11-16 10:31:00)
Thank the Lord for the good news.

Anonymous (2007-11-18 14:21:00)
That is great news about the bone marrow percentage change! Must have been a festive party, too. Marge

Joyce (2007-11-20 21:27:00)
Sounds great! You've marvels to be thankful for.

Joyce

Diapers (2007-11-20 19:13)

Things change quickly. At my Dr appt last Tuesday, I had good news about my bone marrow and hemoglobin. Then on Wed, I developed diarrhea. On three occasions before Monday, I didn't make to the toilet in time and had a mess to clean up. I called the BMT clinic on Monday and arranged for an appt at 1pm. Since I was running to the bathroom every 1 to 2 hours, I had to pick up some Depends at the local Walgreens and wear my first 'diaper' in over 55 years. Then at the clinic, the diarrhea held off for 4 hours though I was able to get the lab a stool sample before I left. When I got home the original 1 - 2 hour cycle started again. Seems like it might be easing off some today.

The Dr is concerned that the Graft versus Host Disease (GvHD) may be returning. That was diagnosed in July after I had lost over 50 lbs. I had some diarrhea back then but nothing comparable to this. I have a colonoscopy scheduled for Wed afternoon and have changed some of my medications. Now, I am essentially fasting and need to take 3 different laxatives and get an IV before the colonoscopy. I still have an appetite and am looking forward to Thanksgiving dinner.

On the good side, my hemoglobin is still at 13.6 and my platelet and white cell counts are improving. The white cell count was 4.6 (in the normal range), but may have been responding to whatever is causing the diarrhea. Either way that is good since it is responding correctly.

Anonymous (2007-11-22 18:17:00)
I admire how you "hang in there."

Ken Brandt

Big Brother (2007-11-26 10:39:00)
We hope it is a flu bug ather than something more serious.We keep praying

2.12 December

More diarrhea (2007-12-04 23:38)

Everything was ok for 10 days and then I got another bout of diarrhea last Saturday. I had a Dr appt today, but could not produce a stool sample at the clinic. It has now been 12 hours since the last rush to the bathroom so maybe it is over. Dr wants me to cut back on milk and dairy products to see if that makes a difference.

On the blood count side, my hemoglobin was 13.4, about the same over the past three weeks and still in the normal range. My white cell count is also ok, but my platelets have dropped back to 72. This means that I need to keep taking Lovenox (blood thinner) injections. If it had stayed above 100, I could have switched back to coumadin tablets which I last used in April. Dr has also reduced my Prednisone and Levaquin doses so I am down to only 10 - 13 pills a day.

Otherwise, I feel pretty good. We have had snow twice in the last 4 days and I have shoveled a couple of hours each time. Yesterday, I even cleaned out my mother-in-law's driveway. I resurrected her old electric snowblower which had not been run for over 30 years, but then hit a piece of wood under the snow and sheared the auger pin. I fixed it this morning and will get back over there tomorrow to clean up this latest snowfall. My 25 year old gasoline snowblower has a frozen exhaust valve that I am also repairing.

Big Brother (2007-12-05 10:20:00)

Maybe the diarrhea was from too much turkey? We pray your condition gets better.

Anonymous (2007-12-05 20:09:00)

So glad you could help Eleanor.

Ken Brandt

Joyce (2007-12-14 16:35:00)

Stay warm, have a great holiday!

joyce

Merry Christmas (2007-12-21 09:25)

For those who check this over the next week, have a Merry Christmas and a Happy New Year! I have included a in-line copy of our family's Christmas letter at the end of this post as well. Thanks to all of you for your support over the past year. I am not "out of the woods" yet, but certainly feeling the best that I have over the past 3 or more years.

I saw the Dr on Tuesday and don't have another appt scheduled for 4 weeks. In previous cases, I have not made it more than two weeks before having to go in for something, but I am feeling positive this time. One reason is that my hemoglobin is even higher at 14.9, up from the 13.4 that it was two weeks ago. The normal range is 13.3 to 17.7 g/dL. Actually, my red blood cell count is still low at 4.1 billion/L, though that has also increased from 3.61 two weeks ago. RBC normal range is from 4.4 to 5.9.

Unfortunately, my platelets are still down at 70. Normal is 150-450 million/L. This affects my blood clotting and makes me easy to bruise. At my next appt, they plan to run more blood test relative to antiphospholipid syndrome. This was my original problem when I had the pulmonary embolism (blood clots in lungs) three years ago. I still give myself a shot of Lovenox in my abdomen every day and have not been able to switch back to the little coumadin pill. White cell counts are in the normal range at 5.3. Importantly, my liver tests are normal and my spleen is only enlarged a little.

Here is the Christmas letter:

Christmas 2007

Grace to you and peace from God the Father and from our Lord Jesus Christ. Amen!

Hope your family is doing well. Here's a rundown of news about our family:

We are thankful that Joel is doing quite well after his bone marrow transplant last May. He is on long-term disability, so enjoys staying at home, working with his old computer collection and fixing things around the house. We have finally replaced the driveway, patio and garage door. Joel is also keeping up on his career technology and learning new programming skills through the Internet. For a weekly update of his health progress, please go to www.myelo.com.

Marilyn continues to enjoy teaching English Language Learners at Hayes Elementary School in Fridley. Each day brings new challenges, but she is thankful for her job and for her fascinating students with different languages and cultures.

Anna is working on her master's thesis and plans to graduate from Harvard Divinity School in 2008 with a Master of Divinity degree. She and her two cats spent most of the summer living with us in Fridley where she enjoyed a glorious summer of doing nothing but spending time with the family, biking, reading and watching movies. She does not currently have definite plans for next year but is expecting the unexpected.

Andrew has been enjoying his first semester at the University of Minnesota in the College of Biological Science. He has been taking honors classes and has been doing well. He is still considering pre-med and is planning to major in biochemistry and chemistry. We typically see him a couple of times a week as he helps out with the youth group at our church, Redeemer Lutheran, here in Fridley.

Marilyn's mother, Eleanor (93) has struggled with serious health problems this year and has been spending the last few months in the Camilla Rose Nursing Home in Coon Rapids, MN. Marilyn spends as much time as she can with Eleanor.

Unfortunately, our beagle, Velvet, died in November due to kidney disease. Our two cats, Moses and Zacheaus, have taken over her begging role and seem more affectionate as well.

May your Christmas be a Christ-filled one!!!

Love, Marilyn, Joel, Anna, and Andrew

3. 2008

3.1 January

Eight months Plus (2008-01-15 19:11)

Well, I am finally getting back to posting here. It has been 4 weeks, but that was how long I went between Dr appointments. Similarly, my next is scheduled out 4 more weeks. I had the BMT on May 8 & 9 so it has been 8 months now. The report today indicates that my blood is essentially 100 % that of my brother who was the donor. Praise the Lord!

My hemoglobin also came in at 17.0, a new high and actually higher than my son had when he last gave blood. Unfortunately, my platelet count is still low at 73 and I still bruise easily. Additional blood clotting tests were run today to see my original clotting problems remain and whether I need treatment. I am still taking Lovenox shots to thin my blood, but that may be keeping my platelet count low. I would like to get back on coumadin or, better yet, not have to take anything.

My white cell count was a little high at 9.9, but then I have been nursing a sinus infection for almost 3 weeks. I have a few minor dizzy episodes which the Dr thinks was from the sinuses and my left ear which looked inflamed. I am now on 5 days of Azithromycin antibiotic, replacing the Levaquin that I normally take.

Since the BMT seems to have been successful, we are starting a taper of the prednisone over the next 2 months. I have been on 20 mg every day for the last month and will taper off 5 mg on alternating days every week. So this next week, I am taking 20 one day and 15 the next. Eventually, I should get down to 5 mg a day and then off completely. But then, it all depends on how things go. Looks promising though many BMT patients go through many cycles of less and then more prednisone. Some can never get off it completely. This is only my second attempt to get off the stuff, but then I am still taking 8 other medications as well.

Big Brother (2008-01-17 10:33:00)

Thank the Lord for the good news.

We pray the playlet count will go up.

Anonymous (2008-01-17 16:13:00)

Glad you could report positive news!

Ken Brandt

Phlebotomy? (2008-01-30 19:43)

I wasn't due to see the Dr for another 2 weeks, but decided I needed to get my cough examined. It has been around for a month now and the last antibiotic did not knock it out. So yesterday I called and set up an appt for Thursday, the earliest the BMT clinic could see me (not an emergency). Then this morning, they called me and said the Dr did not want to wait and asked me to be in by noon. I was there early for a chest xray at the Imaging Lab, but they did not have the orders. After waiting for 40 minutes I went up to BMT Clinic for my lab work and waited for another 45 minutes before they got to me. I went back for the xray which was then pretty quick. After waiting some more for

the Dr who had been ready for me twice by then, the appt went pretty quick. The Dr prescribed another antibiotic which I then had to wait for at the pharmacy. I finally walked out at 3:30.

I also have a lump on my abdomen which the Dr says is a hematoma and should be watched for the next couple of weeks. Two weeks ago, I could sense something there, but the Dr could not feel it. It is not from all the Lovenox shots I give myself since it is higher up on the right side just even with my rib cage. Maybe I bumped myself there but there is no bruise there like there is in many other places. Since I was called in a day early, I was not able to skip my Lovenox shot last night and get a good clotting test today. So it will be at least another 2 weeks before I can get away from these shots.

There was more good news today, following the 100 % engraftment I found out about last time. Another test showed no evidence of the Antiphospholipid (Hughes) Syndrome that I also had before the BMT. If my JAK2 chromosome test comes back negative, I will be clear of all blood problems. That is except for my low platelets, though those were up to 90 today.

I will also be getting an iron (ferritin) test, but expect it to be high because of all the blood transfusion that I have had. The Dr is considering giving me phlebotomies in which blood (and iron in hemoglobin) is taken from me. As new blood is regenerated, it will pull iron out of my body's reserves. I am not sure how many times this would be needed, but there are other drug alternatives. The Dr is consulting with others for advice in this situation.

For those reading that are not in Minnesota, we had a 56 degree drop in temperature in about 18 hours. I cleaned all the ice off the driveway and patio yesterday when it was 42 degrees. This morning, it was 14 degrees below zero. Windchill was actually down about 40 below.

3.2 February

Coumadin Again (2008-02-12 23:50)

I saw the Dr today and am progressing towards getting off some of the medications. I started taking Coumadin again (for blood clotting) and will get my [1]INR checked on Monday. If OK, I will stop the daily Lovenox injections, but will continue them until the Coumadin takes hold. Hopefully, when I get off the Lovenox (heparin), my platelet count will get back up to normal levels.

I have also stopped taking two antibiotics, Acyclovir and Levaquin. My prednisone taper is down to 10mg one day and 5 mg on alternating days. Another three weeks and I will be off prednisone, assuming no problems arise. I still have a little cough, but it is a lot better than it has been over the past six weeks. With the temperature below zero for most of the weekend, I have been staying in the house.

My JAK2 genetic test came back negative. It was positive before as it is for most MPD patients. It is another indication that my brother's bone marrow has taken over. Unfortunately, a [2]Coombs test came back positive, indicating I still have problems with my immune system and red blood cell hemolysis. Possibly, the reductions in medications will help this to improve.

My [3]ferritin level is at 4423, well above the normal range of 12 to 300. This is result of iron buildup from the 93 units of blood that I had transfused over the past 3 years. The Dr is contemplating using phlebotomies, with-drawing blood to reduce the iron level. It is too bad I cannot donate this blood. Not sure how many draws it

would take since the transfusions were of packed red blood cells which certainly had a higher percentage of iron content than normal blood. An alternative is a drug named [4]Exjade, but my immune system may preclude it.

1. http://en.wikipedia.org/wiki/Prothrombin_time
2. http://en.wikipedia.org/wiki/Coombs_test
3. <http://en.wikipedia.org/wiki/Ferritin>
4. <http://www.drugs.com/exjade.html>

Joyce (2008-02-14 20:31:00)
Good to know you are improving!

No more Lovenox (2008-02-19 00:11)

I was in for a quick blood test today to check my blood clotting INR. I have been taking Coumadin since last Tuesday and my INR was up to 2.6. This was enough for me to stop taking the Lovenox injections. It is great to over with that after 9 months of sticking myself in the abdomen each day. Since my target INR is between 1.5 and 2.0, I will reduce the amount of Coumadin that I take. I will alternate between 5 mg and 2.5 mg each day and get my INR checked again next Monday.

The cough is still persisting, though primarily in the morning or after being out in the cold. It will be great when the weather warms up some. It was in the 30s for a few days and now back down to zero and headed lower.

INR & Peer Gynt (2008-02-26 17:56)

Things are slow on the medical front. I was in for another INR (blood clotting) test yesterday and learned today that I have to reduce my Coumadin some more. I will have another INR test next Monday and then my next Dr appt on March 10.

Last Saturday, my son and I went to a play named "[1]Peer Gynt" at the Guthrie Theatre. A good review of the history of the play can be found at [2]Wikipedia. This is a play written by a 19th century Norwegian and most of it takes place in Norway. Portions take place in the Sahara desert and on the ocean. The Guthrie had a unique way to portray the sand dunes and waves with an [3]undulating floor. (Note that YouTube has a couple of other videos of the floor, as well.)

Peer is a story teller that lives in a fantasy world. In the end he meets the "button moulder" who claims that Peer has not been himself and his soul must be melted down because he has no list of sins. I cannot say that I understand it all, but would enjoy reading the script for the play. The only version I have found so far in in [4]Norwegian.

1. http://www.guthrietheater.org/whats_happening/shows/2007/peer_gynt
2. http://en.wikipedia.org/wiki/Peer_Gynt
3. <http://www.youtube.com/watch?v=9sKcbwRmbPI>
4. <http://runeberg.org/peergynt/>

Joyce (2008-03-10 18:42:00)
I recall Peer Gynt from several years ago. I think the burning boat burned more than it should at least at one performance.

3.3 March

Aches & Pains (2008-03-08 10:21)

It has been a miserable week. Started out ok with an INR that was done locally, saving a trip to the BMT Clinic. I am also getting my prescriptions at the local Walgreen's since my BMT Clinic visits are about once a month. My INR was 4.2, high above the target range of 1.5 to 2 so I skipped 2 days of warfarin and reduced the dosage some more. I will get that checked again on Wednesday.

Maybe unrelated to that, I started getting pains in my joints on Wed. The pain moved around from my left shoulder, to my knees, my right elbow and my left jaw. The left jaw pain became an ear ache as well and I could not chew without sharp pains in my jaw. On Thursday I talked to a BMT Dr who advised me to take some Levaquin antibiotic which I have in my "home" pharmacy. I last took it in January after taking it for 8 months. It seemed to do some good, eliminating most of the joint pain and reducing the ear pain. Maybe just a coincidence since yesterday the pains moved to my right ear and left elbow. The elbow pains may be related to my lying more on the side opposite my primary ear pain. Seems to be clearing up some this morning though I am tired since I didn't sleep very well the last few days.

I see my primary BMT Dr on Monday when I will ask him whether these pains are related to my going completely off of prednisone last Sunday. My recent strange, loose stools may also be related though I have not eaten much solid food with my aching jaw. It seems like some tomato soup that I had on Thursday went right on through so my digestion is not working correctly. I hope I am not reverting back to the GvHD of the gut that I had last June and July. I lost 65 lbs at that time, but have gained back about 20 lbs. I would just as soon keep off the weight, but not this way.

Anyway, your prayers are appreciated. Keep looking up.

Regression (2008-03-10 15:18)

It has been a rough week and a long day. I have reported my aches/pains and digestive problems in the previous post. I saw my BMT Dr this morning after waiting around for 2 1/2 hours. It took a total of 4 1/2 hrs of my day. All the while I was in pain with my right leg, knee and back: could hardly walk. Anyway, the Dr feels that since I had stopped taking prednisone that the GvHD has come back, attacking at least my joints and musculature. I was also able to leave a stool sample so they will test whether the GvHD of the gut is back as well. Either way, I am back on a high dose of prednisone and start a taper again, probably never getting off completely. Most GvHD patients end up on a low maintenance dose. The important point is that the Dr checked the "regressed" box and put "unknown" in the return to work date field on the form that we sent into the disability insurance company.

On a positive note my blood counts are all OK or improving. Platelets are now up to 107 though the normal range starts at 150. My INR was 5.4 but Dr feels it was affected by the Levaquin antibiotic that I have been taking. Target INR is still 1.5 to 2.0. So far I have not seen any blood leaking out anywhere since it is too thin. I will have my INR checked locally on Wed and then see the Dr again on Friday.

Remember that GvHD is essentially the new transplanted stem cells (immune system) fighting the old body. Seems like there may be a sermon illustration in that statement. My late brother-in-law once gave a sermon titled "The Old and New Nature". The sermon was based on Ephesians 4:22-23, "Put off your old nature which belongs to your former manner of life and is corrupt through deceitful lusts and put on the new nature, created after

the likeness of God in true righteousness and holiness." Send me a personal email or leave a comment if you are interested in the complete sermon.

Anonymous (2008-03-12 20:07:00)

I am sorry that some of the old issues seem to be coming back. You are coping with it with very commendable courage and faith. Hope things get better soon. Marge

Anonymous (2008-03-12 21:54:00)

I'm so sorry that you are in pain and not feeling well, Joel. We are thinking of you and praying for you, and hoping you will feel better soon!

Bev

Back on track (2008-03-19 10:58)

The return to using prednisone has really helped me over the past week. Actually within one day, most of my pains disappeared. I went from 5 mg prednisone every other day, a week with nothing and then back up to 80 mg every day. This week, I have reduced that to 60 mg per day and will taper more again in the following weeks. I have noticed that my digestion is not normal and a lot of foods that I eat seem to go right on through. I am hungry and eating way too much but not gaining weight. I actually lost 5 lbs during that one week where it was hard for me to even chew.

The last couple of days, I have been developing a pain in my left hip and leg. It was so bad this morning that I needed to have my son put the sock on my left foot. I could not lift my foot up to my knee without twisting my hip and getting a sharp jolt. The thought is that this is also a result of GvHD.

I will be interested in what my INR is when I get it checked tomorrow. It was so high last week that I did not take warfarin for 5 days. I have noticed some bruising so some blood IS leaking out.

On a positive front, I saw my eye Dr this morning and got a clean bill of health. I go in every 6 months now to avoid any complications from GvHD in my eyes. My eyes are a little dry so I use eye drops, but they are clear and my eyesight is not changing.

I have resigned myself to being out from work for another couple of months until we see where this is leading. We may need to try some more medications and address the iron build-up as well.

Atom Subscribe Added (2008-03-19 12:06)

Since my posts have become less frequent and I figured out how to do this, I have added an Atom Subscribe feed to this blog. You will note the link down on the right side where it says "Subscribe to Posts". Click on the "Atom" link and it should open a dialog helping you to set it up further.

[1]Atom is similar to RSS and is supported by many of the same RSS readers. It works fine for me with my Macintosh Mail program and the Safari browser. There is actually a Subscribe to this Page menu item under bookmarks in FireFox as well. If it all works well, you should get the blog posts as soon as I enter them on this blog.

1. http://en.wikipedia.org/wiki/Atom_%28standard%29

Anonymous (2008-03-20 09:38:00)

We hope you improve. Will keep you in our prayers. Big Brother

Horton Hears a Who (2008-03-23 07:36)

On a whim last night, my son (home from college) and I saw a movie based on the Dr. Seuss book, "Horton Hears a Who". We went just to be entertained by this animated film, but came away talking about what meaning might be made from the script. In the movie, Horton, an elephant, discovers very small people living on a speck on a clover flower. He hears the very small voice of the Mayor of Whoville, but cannot see the residents. He carries the flower around the jungle, telling the other animals, but no one else believes him. As he rumbles around, he causes all kinds of problems (earthquakes, high winds, darkness) on the flower and in Whoville. The mayor likewise tells his town about talking with Horton, but again no one believes. They experience the effects of Horton, but don't hear him or believe that he exists.

Anyway, we thought there was symbolism in the movie about faith in God as well as listening to hear what God has to say. This morning, I woke up thinking more about this, reminding me of a CD that one of our church "Angels" gave me when I was in the hospital last May for my BMT. The CD is named "Be Still and Know [that I am God]" by Maranatha Music. As I listened again to the CD, it gave me great peace to know that He is in control. He will deliver us from all our troubles.

When I got up, I did a search on [1]Google and found a number of different "theological" interpretations of this movie and other related Dr. Seuss books. Some relate to [2]abortion where the little Whoville people are the unborn that are not recognized by the animals of the jungle.

Happy Easter! He is Risen!

1. <http://www.google.com/search?hl=en&q=Seuss+horton+hear+who+theology&btnG=Google+Search>

2. <http://www.theologyonline.com/forums/showthread.php?t=47141>

Joyce (2008-03-24 15:14:00)

Neat! Joyce

patrick (2008-04-09 17:32:00)

it makes sense that godly truth should be best expressed through children's books, in light of what Jesus said about becoming like children... Shel Silverstein's another author that hides a lot of meaning in simple children's books

First Phlebotomy (2008-03-27 12:45)

After getting 93 units of packed red blood cells over 2+ years, the ferritin (iron) level in my body increased to unhealthy levels. The Dr has finally decided to address this and ordered [1]phlebotomies every two weeks for the near future. We are not sure how long that will be seeing how long it was accumulating. I had my first one this morning. It is just like giving blood, except that they have to discard it. Seems like a paraphrase of an old joke is appropriate: It is better to have a lateral phlebotomy than a frontal lobotomy. (The original joke referred to a "bottle in front of me".

Interestingly, my phlebotomy was in the [2]Apherisis lab where my brother donated his stem cells last May. In fact, I sat in the same chair next to the machine which filtered stem cells out of his blood over two days. It will be a full year on May 9th since that grand contribution to extending my life on this earth.

I also saw the Dr on Tuesday. My INR was down within range so my current level of warfarin will continue (2.5mg on Monday and 1.25mg every other day. Also I will continue my taper of prednisone (now 40mg per day tapering to 40mg every other day over the next month). My next Dr appt is on April 22nd though I will have another INR test on April 9 and another phlebotomy on April 10.

1. <http://en.wikipedia.org/wiki/Phlebotomy>

2. <http://en.wikipedia.org/wiki/Apheresis>

Anonymous (2008-03-27 21:40:00)

It seems ironic that you needed transfusions to stay alive and now your are having blood taken out to stay at a healthy iron level. We continue to pray for you that your health will continue to improve.

Your little sister

3.4 April

Second Phlebotomy (2008-04-10 13:35)

I just got back from my second phlebotomy this morning. The blood certainly comes out faster than it went in before, only took 30 minutes for the whole appt. My hemoglobin was at 17.1 this morning and per the Dr's orders, they drained 500 ml. After a couple of Oreo cookies and some juice, I walked out not feeling too much worse for the wear.

After thinking about the 93 units of blood that I had transfused between June 2005 and last Fall, I decided to stop by and visit the [1]Masonic Day Hospital where I received most of that blood. This is between the Philips Wangesteen Building where I have my BMT appointments and the Fairview University Hospital where I actually had the BMT. I believe that most of the nurses that helped me over those two years were there today and I had a great visit. For any of them reading this, I again thanks you for all of your help and kindness. They were all very professional and experts in their jobs.

After having lunch with a friend, I stopped by the [2]Express Bike Shop in St. Paul, not too far east of the University. I donated four bicycles to their Back Door program ([3]Youth Express) and encourage you to do the same. I had nine bicycles in my garage and needed to clean them out. Some neighbor kids took a couple and my son brought his to the university campus. That leaves two, one of which I need to work on. Now I just need to clean up the rest of the stuff including two broken snow blowers. Luckily, we did not get the 26 inches of snow that they got north of here last weekend. Real Spring seems slow in coming.

Update: Just saw this on evening news after posting earlier this afternoon:
[4]Masons give \$65M to UMinn for cancer research

1. <http://www.med.umn.edu/hot/masons/masonshistory.html>

2. <http://www.exbike.com/donations/>

3. <http://www.youthexpress.net/>

4. <http://minnesota.publicradio.org/display/web/2008/04/10/umgif/>

GET SMASHED (2008-04-22 15:37)

What do I mean by the title this time? Well, it is actually a useful mnemonic for remembering the causes of acute [1]pancreatitis which the Dr thinks I might have. Steroids or autoimmune causes are most likely the problem. Actually, I am not sure if this would be chronic or acute pancreatitis since I have not had any pains except for cramps. My strange diarrhea has persisted for the last month and when I described how the nasty stuff looked and smelled, the Dr immediately related it to fat [2]malabsorption. The Dr ordered a couple more blood tests to measure my amylase and lipase levels. I also got a prescription of Viokase 16 tablets which contains 16,000 units lipase, 60,000 units protease and 60,000 units amylase. I have to take 3 of these before each meal and one before a snack.

I also had another phlebotomy this afternoon. My hemoglobin was somewhat lower at 14.9 where two weeks ago it was 17.1. My platelets are still low at 81 so the phlebotomies do not seem to be helping that. The Dr told me to start taking multi-vitamins (without iron) that might affect my INR which was 1.48 today. I will have to get the INR checked again next week. My case is still strange as the Dr said he used me (unnamed) as an illustration in a recent lecture to all U of MN medical students.

The next big thing will be another bone marrow biopsy on May 9, the anniversary of my bone marrow transplant and also my 60th birthday. I see the Dr again on May 13th to get the results.

1. <http://en.wikipedia.org/wiki/Pancreatitis>

2. <http://en.wikipedia.org/wiki/Malabsorption>

3.5 May

One year milestone (2008-05-16 12:41)

I should have posted this a week ago, but wanted to see the results first. I had a bone marrow biopsy on May 9 which was the anniversary of my transplant last year plus also my 60th birthday. I also had a phlebotomy on Friday to reduce my iron buildup. Over the weekend, my sinus drainage got worse and I had a slight fever Saturday night. Tylenol took care of the fever but I also continued with sinus drainage, a cough and some wheezing. I saw the Dr on Tuesday afternoon at which time he said that the biopsy was all clear, but that I had a touch of pneumonia. I am now on Azithromycin as well as my other medications.

The Viokase that was prescribed for my pancreatitis has cleared up my diarrhea. Dr is not sure how long I will have to take it. It is like all the other medicines that I am on. We will taper off the meds and see if any symptoms come back. I have now reduced my prednisone down to 30mg every other day.

My blood counts remain about the same with only low platelets being a problem. My INR (blood clotting) was a little low, but is affected by the multivitamin and antibiotics that I am taking. I am having more problems with dry eyes which seem to be getting worse. Overall, it is chronic graft versus host disease that continues to cause my problems and will for the rest of my life.

Through all of this, I continue get around and am enjoying life. I attended a two day workshop at the University, taking just a couple of hours off for my Dr appointment on Tuesday. My son and I also went to a Twins game on Monday night when I didn't realize that I had pneumonia. Last night, I took a short bike ride and hope to extend that some each day. Both my son and daughter will be around for the Summer as we need to help my wife recover from a knee replacement surgery planned for June 20.

3.6 June

Knee Surgery (2008-06-20 12:07)

Sorry but it has a month since I last posted. This is indicative of the fact that I am feeling good and not dwelling on my MPD which now really affects my life very little. I just have to remember to take all my medicines and try to avoid any infectious situations due to my compromised immune system. I had a Dr appt on Tuesday where he said I can consider going back to work, probably part-time at first. I have a phlebotomy every two weeks to reduce my iron levels and an INR test every 2 - 4 weeks to check my blood clotting. My blood counts are improving with the platelets now up to 107.

I may never have knee surgery due to my history of blood clots, but my wife has beat me to it. I write this while she is in surgery for a right knee replacement. She is getting it done over the Summer so she can recover to teach school in the Fall. I will post status on her recovery.

We spent 4 nights over last weekend at a resort in Bemidji. The week before we spent 3 days in Boston (Cambridge) for my daughter's graduation from Harvard. She has now moved back to MN and I helped her move into an apartment yesterday. It has been a little hectic around the house with all her stuff and her 2 cats dueling with our two cats. My son is home from college for the Summer as well, though he is still enrolled in a chemistry class. Somehow, he manages to get to that 8am class, four days a week.

Sadly, my mother-in-law died on May 24th. The funeral was at our church on May 28th after which we drove to Decorah, IA for the burial service. My father-in-law died 30 years ago and they are buried in the cemetery of his last parish. She lived near us for the last 14 years. It is sad to think of her leaving us after having such a gusto for life during her 94 years. It is now a big effort to deal with the estate and all of her collections of dishes, dolls and furniture.

3.7 July

Taper Continues (2008-07-24 21:20)

Another month plus a few days have gone by since I last posted. Not much is changing on the health front. I continue to get my INR (blood clotting) checked monthly and get phlebotomies every 2 weeks. I just had one this afternoon. I saw my doctor on Tuesday and all blood tests are ok. Platelet count is still low, but hemoglobin is over 14. All medications are the same with only another reduction in the prednisone, now at 15 mg every other day, down from 20 mg. I continue on the Viokase before every meal and notice the effect if I miss taking it. My digestion of fats is affected and I experience diarrhea within 24 hrs. I am fortunate that I feel pretty good though realize that my immune system is still compromised.

When I am too active, my right knee complains due to arthritis. I am a little jealous of my wife's recent knee replacement surgery though she has gone through a tough month of recovery and therapy. On days without prednisone, I experience more fatigue. This morning I forced myself up at 6:30 for a breakfast Macintosh user meeting. That coupled with the phlebotomy, no prednisone plus too much spaghetti meant I needed a nap this evening.

But God is good. I am very fortunate to be able to complain a little after 4 years.

3.8 September

Steady as it goes (2008-09-02 22:27)

Six weeks have gone by since I last posted and my health situation is steady. I continue to get my INR (blood clotting) checked monthly and get phlebotomies every 2 weeks. I have another on Thursday. I saw my doctor today and all blood tests are ok. The blood test from last month confirmed that my bone marrow graft is still 100 % and the common JAK2 test is still negative, both great news. To check my iron levels, I will get an MRI of my liver next week. (Maybe the MRI magnetic field will suck the iron out !>) Actually, there is a new technique that can measure the iron levels stored in the liver. The Dr feels we need to check to minimize the number of additional phlebotomies that I need to reduce the iron.

Platelet count is still low at 107, but hemoglobin is over 14. All medications are the same with only another reduction in the prednisone, now at 10 mg every other day, down from 15 mg. I continue on the Viokase before every meal and notice the effect if I miss taking it. My digestion of fats is affected and I experience diarrhea within 24 hrs. I am fortunate that I feel pretty good though realize that my immune system is still compromised.

When I am too active, like mowing the lawn this morning, my right knee complains due to arthritis. On days without prednisone (like today as well), I experience more fatigue. Today, I was up at 7:30 am and then took a nap after mowing the lawn. I spent three hours with my Dr appt this afternoon and then took a 3 hr nap this evening.

Keep looking up!

Anonymous (2008-09-17 22:31:00)

Glad you are "hanging in there."

Ken Brandt

3.9 November

18 Months & NATT (2008-11-12 22:44)

Sorry for the 2 month delay in posting, but I figured that now I have reached a major milestone, 18 months since my BMT, I should update this blog. I had my milestone checkup with my Dr yesterday, but no great changes. Last month, I reduced my prednisone medication to 5 mg every other day and today reduced again to 2.5 mg. I have been having more joint pain which may be a result. When I cut out the prednisone completely in March, I could hardly walk, so will be watching what happens now.

I am still having phlebotomies every two weeks to reduce my iron levels. An MRI of my liver last month showed that my liver is loaded with iron. My blood ferritin level was also 4074, where 150-300 is normal. It will take another 3 years at this rate to reduce my iron levels to normal. A [1]Google search on iron overload shows that it causes fatigue and joint pain as well. This somewhat explains why I have been taking so many naps and my joint pain as well. Hopefully, the other complications of iron overload don't occur.

Last month, I also dropped the protonix and fluconazole medications, but after my complaints of heartburn to the Dr yesterday, I am back on the protonix at half the dose. I also tried to reduce the Viokase, but learned I still need it. It replaces the enzymes that my Pancreas is not producing. I actually need to take higher levels since I had more

oily diarrhea in the past month.

During October, I attended a local conference call [2]"Stop the Clot" sponsored by the National Alliance for Thrombosis & Thrombophilia (NATT). I also attended a local support group last week. You may remember that 4 years ago, I was hospitalized for the first time with pulmonary embolism (PE), three blot clots in my lungs. I had a couple more episodes in 2005. I was very fortunate since 25 % of PE results in sudden death. I heartily recommend that you check out this web site and learn to recognize the symptoms.

Overall, I am very fortunate to have made it this far and have relatively minor problems. God has been watching over me and must have some purpose still in store for me, maybe just as an example for all of you.

1. <http://www.google.com/search?client=safari&rls=en-us&q=iron+overload+fatigue&ie=UTF-8&oe=UTF-8>
2. <http://stoptheclot.org/>

Anonymous (2008-11-17 12:55:00)
Glad you are "maintaining."

Ken Brandt

3.10 December

More GvHD (2008-12-10 23:48)

Just as I had about tapered off of prednisone, GvHD hit me again. I was on 2.5 mg every other day with a plan to drop off completely this week. But over the last month, I gradually started to feel more fatigue, nausea, loss of appetite, cramps, joint aches and breathlessness. I scheduled a Dr appointment for Monday where I discovered my Hemoglobin (Hgb) was down to 11.9 the lowest it has been for 14 months. Good news was that my platelets are up to 144, the highest it has been since my BMT 19 months ago. Before then my problems were too high platelets and too low Hgb. Normal range for platelets is 150-300 so that is not a problem now.

I also had a range of other tests: chest x-ray (ok), EKG (?), echo cardiogram (?), nose swab (?) and stool sample (ok). There was blood in my urine indicating hemolysis of my red blood cells and subsequent low Hgb. I saw the Dr again today and more blood tests were taken. I see him again on Tuesday. I wasn't supposed to see him for another month, but that was not to be.

In the meantime, I am back up on prednisone to 60 mg every day. After all the sleep I have been getting (13 hrs of last 24), I expect I will now be up until the wee hours of the morning. High doses of prednisone are known to do that until I run out of gas and crash.

Though I am anxious to get back to work, the last several weeks have shown that I was not ready. The Dr has indicated that we will review that possibility in May next year. By then, there may not be any jobs available though now I get at least one call a week.

As inspiration in this time of trouble, I was listening to CD titled "Be Still and Know" (Maranatha Music) which an 'angel' from our church gave me while I was in the hospital after my BMT. The CD has a track "My Beloved" which is narrated with a deep male voice symbolizing God. It goes "Our relationship is based on my faithfulness. Your faith may wax and wane, but my faithfulness endures forever. I will never let you go. So put your trust in me. In every situation remember these words. 'Don't be afraid! Just believe.' I know the plans I have for you. Plans to prosper

you, not to harm you. Plans to give you hope in the future. But this will only happen if you put your hope in me, and live according to my word. Don't be afraid, just believe. That is your responsibility in our relationship. Believe that my love for you is unending. Believe and trust in my goodness. And when you get discouraged, quickly turn to me. Call out to me for help and I will deliver you from trouble. My faithfulness will be your shield and your fortress. I will fill you with joy and peace as you trust in me. So that you will overflow with hope by the power of my spirit. So don't be afraid! Just believe. ... When you hope in me, you will not be disappointed. ... Don't be afraid, just believe."

Anonymous (2008-12-11 13:22:00)

I am glad the doctors seem to be dealing with this. Hope things can get under control again.
Ken Brandt

Beverly (2008-12-12 07:13:00)

Joel, you are in our thoughts and prayers and we certainly hope you feel better soon!
Bev, Bob, Steve, and Liz

Code Brown (2008-12-22 08:23)

I am writing this from the hospital where I was admitted early Saturday, December 20th. This is titled "Code Brown" for the term they use here for diarrhea patients. I had three bouts with it at home before my wife called the ambulance at 6am. It continued every 1/2 hour until about 11am when they put in an anal catheter to catch the fluids into a bag. I had good relief from all the mess until it started to back up in about 24 hrs. Then I started wearing disposable diapers and now 50 hrs later it has just about cleared up.

Last week, I had three Dr appointments, many blood tests, an ultrasound of my abdomen and a complete torso CT scan. I had to drink a barium solution with the CT scan and had diarrhea from the solution before and after the scan. The current focus of study is of my liver, possibly complications of the iron buildup. I may have to have a liver biopsy to check for cirrhosis. My liver functions (blood test) are out of range. I still have a lot of fluid buildup in my abdomen and around my lungs making it a little difficult to breath.

Since I started writing this about 4 hours ago, I have seen at least 3 more Drs. Current thought is that I will go home after lunch and followup with some more out-patient tests tomorrow and see the Dr on Friday. I will post here at least once more this week and more if anything develops.

Well, it looks like I will be home for Christmas anyway. Remember the meaning of of Christmas and keep Christ in it.

Merry Christmas!

Anonymous (2008-12-24 08:51:00)

Glad you are feeling better and that you will be home for Christmas. Sorry to hear about all of those tests and hope they won't be too bad. MBH

Home again (2008-12-23 21:29)

I am home again and feeling somewhat better. My daughter had to pick me up at the hospital yesterday because my wife was heading to another emergency room to meet my son arriving with similar diarrhea problems. Not sure if we had some of the same bug or something, but he has recovered a lot faster than me. I still have loose stools, but can comfortably make it to the bathroom without messing up. I also ate a 6 inch Subway sandwich this evening so

my appetite is back. I am still retaining fluid but on [1]LASIX (furosemide) which seems to be helping. I am also taking [2]Levaquin as an antibiotic to counter any bacterial infection that I might have.

It does not look like I will have a liver biopsy, but will have a number of other tests over the next three weeks. The main ones are an MRCP, an MRV, an EGD and extended 24 hr stool sample. The [3]MRCP (Magnetic resonance cholangiopancreatography) is an MRI to visualise the biliary and pancreatic ducts and should tell us more about the functioning of the liver and pancreas. An [4]MRV (Magnetic Resonance Venogram) is an MRI of liver and other abdomen veins. The [5]EGD (Esophagogastroduodenoscopy) will check for esophageal varicose veins and take biopsies to check for GvHD in my upper GI track. The EGD will not happen until January 13th and is the one I feel will be most unpleasant but may mean the most. The MRCP and MRV are on December 30.

I will back in the BMT Clinic on Friday (26th) with the stool sample and another blood test. If anything changes then I will post, otherwise it will probably be next year before I report again.

Remember "the reason for the season" is Christ. Keep him in Christmas and have a Happy New Year.

1. <http://www.rxlist.com/lasix-drug.htm>
2. <http://www.levaquin.com/levaquin/>
3. http://en.wikipedia.org/wiki/Magnetic_resonance_cholangiopancreatography
4. <http://jeffersonxray.vascularomain.com/images/uploaded/jeffersonx/MagneticResonanceVenography.pdf>
5. <http://en.wikipedia.org/wiki/Esophagogastroduodenoscopy>

Anonymous (2008-12-24 14:30:00)

Glad you are home. Hope the tests go well.

Ken Brandt

Anonymous (2008-12-24 20:13:00)

We are so happy that you are home for Christmas, Joel - You are in our thoughts and prayers, and we are wishing you all the best!

Love, Bev, Bob, Steve, and Liz

Liver Analysis (2008-12-31 16:25)

I was in to the clinic yesterday for more tests and spent 7 hours there. It was a snowy day, one of our cars is disabled, so my son drove me down and my wife picked me up. I met first with a liver specialist who reviewed my case and ordered a liver biopsy and [1]paracentesis to treat my [2]ascites (fluid buildup in my peritoneal cavity). They will also analyze the fluid extracted and relieve the pressure temporarily. No schedule yet on these tests. He mentioned that I have no evidence of hepatitis and my stool sample tests were all negative.

After a small lunch, I had a blood test which showed my liver function tests were still elevated, but other blood counts were ok. Instead of going back on Bactrim, I had a [3]Pentamidine nebulizer treatment at the office to prevent microbial lung infections. I also have to collect 24 hour urine sample before my appointment next week. I have also switched from the warfarin to Lovenox for blood clotting prevention. This way I can stop Lovenox for a day prior to the invasive tests that I still need to have and avoid excessive bleeding.

After that I walked over to the hospital MRI lab for my MRCP (see last post), but had problems keeping my pants up as I walked. I look like a pregnant man with all the ascites fluid and need to find my old suspenders to hold

up my pants. Anyway the MRCP took about a hour, requiring drinking of more contrast solution and an IV of other stuff. They took at least 800 pictures and I must have held my breath about 30 times. They were supposed to do an MRV as well, but said that may be done another day after review of the MRCP.

Though I had diarrhea over the weekend, it let up Monday night and is still ok today. I was grateful I did not have to deal with that yesterday as well though I carried around supplies if I needed to clean up. What a relief, but I suspect there is more to come.

I will try to post again next Wed after my next appointment.

Happy New Year

1. <http://en.wikipedia.org/wiki/Paracentesis>

2. <http://en.wikipedia.org/wiki/Ascites>

3. <http://en.wikipedia.org/wiki/Pentamidine>

4. 2009

4.1 January

Liver Biopsy (2009-01-07 22:34)

I had my liver biopsy today as well as paracentesis to relieve the fluid buildup. I started out with a BMT Clinic appointment where I also brought in a 24 hour urine sample that the lab will test. My regular blood counts were normal with my hemoglobin now back up to 14.4. The Dr thought he heard some irregular heart beat and ordered an immediate EKG, but no problems were found. They also monitored my EKG during the biopsy.

It took a total of 5 hours for the procedures including 2 hrs of prep and 2 hrs of monitoring afterward. It was really nothing to fear compared to the many bone marrow biopsies that I have had. They started with a quick ultrasound to decide where to poke the needles and selected both on the right side (where the liver is of course). They drained off 4 liters of fluid which weighs about 8 pounds before getting a couple of liver samples. I had a couple local lidocaine injections to numb the areas where the needles were inserted and had some other IV sedative for the biopsy itself. But I was able to see the needles on the ultrasound screen during the action and mostly felt the one as it entered the liver.

Because of the sedative, my daughter drove me to the appointment and my son picked me up. I am feeling much lighter, easier to breathe and generally a whole lot more comfortable. Hopefully, the other fluid in my legs and around my lungs will also dissapate as well. I should learn more about the testing of the fluid and liver samples next week.

Anonymous (2009-01-15 09:11:00)

Thank you for the update. Glad to hear that there is something they can do for these conditions. Sorry that you are having to go through it. MBH

Cirrhosis Confirmed (2009-01-14 10:04)

Yesterday was a long day of medical tests and appointments. I started out at the BMT lab at 8am with blood tests and an antibiotic IV of Ceftriaxone , prior to my scheduled endoscopy (EGD) at 9am. My wife had dropped me off at 7:30 am, since I could not drive my self after the EGD . There was a lot of delay and the EGD did not start until about 11:30. Even before they would start they needed to confirm with a family member who would pick me up afterwards. Since I was supposed to see the liver specialist at 11am that was delayed as well.

Anyway the actual endoscopy went ok . The Dr strapped a mouth guard around my head while the nurse administered a sedative through my IV. Before I knew it, I was recovering with a minor throat irritation. The report of the exam highlighted some recent bleeding at the [1]pylorus, between the stomach and duodenum and a [2]hiatus hernia, though neither appeared serious. Some biopsy samples were taken, but need to be tested.

After the EGD, they pushed me in a wheelchair over to the liver Dr at about 12:30. I then saw my BMT Dr at about 3pm. Everyone seemed to be running late, but I got through it all. By the time my son got me home at 4pm, I was hungry and needed to catch up on all my pills.

Because of the bleeding and hernia, I have stopped taking blood thinners (Coumadin and Lovenox) and will double my dose of Protonix for acid reflux. Recent blood tests had indicated that my original blood clotting problems had been "cured" by the BMT anyway.

The most concerting prognosis from the liver biopsy last week was that there is scarring or [3]cirrhosis of the liver most likely due to the iron buildup discovered before or a complication of the GvHD . The analysis of the Ascites fluid showed no infections or evidence of any tumors. Changes in treatment include a new medicine, [4] Spironolactone , to help reduce the fluid retention and stopping of potassium which is not needed with this mew med. We will see if the Ascites returns and if I need additional drainage of the fluid. Since my blood counts are good again, I will restart the phlebotomies tomorrow and continue every two weeks, possibly for another 3 years. My next appointments with my BMT and liver Drs is scheduled for Feb 10.

1. <http://en.wikipedia.org/wiki/Pylorus>
2. http://en.wikipedia.org/wiki/Hiatus_hernia
3. <http://en.wikipedia.org/wiki/Cirrhosis>
4. <http://en.wikipedia.org/wiki/Spironolactone>

Anonymous (2009-01-15 10:33:00)

Hope it is not too serious. Sorry you are going through this.

Ken Brandt

Anonymous (2009-01-17 09:50:00)

Hi, Joel – We are sorry to hear about this diagnosis, and are hoping and praying that the new medication is successful. Bev, Bob, Steve, and Liz

Anonymous (2009-01-23 19:06:00)

Greetings - So sorry that you've had such troubles but glad to hear that the BMT is working well. It's good they discovered the liver trouble so they can work on it and get it better. Hope you're more comfortable with the fluid situation and that things are calming down and you're feeling stronger. We think of you and send healing prayers each day, Judy and Paul in North Attleboro

4.2 February

More diarrhea (2009-02-11 03:54)

I had my scheduled appts with the BMT Dr and the liver specialist yesterday, but not before having to go in last week. A week ago on Feb 2, I developed diarrhea again, though not as bad as before Christmas. I suffered for 3 days without leaving the house before calling the clinic on Thursday. On Friday, I brought in a stool sample and had an IV to replenish fluids. The diarrhea had let up by Friday, came back on the weekend but has been ok since Monday.

At the appts yesterday, the results of the stool sample were negative for viruses and I received my now monthly Pentamidine

nebulizer treatment for bacterial infections (instead of the Bactrim). My fluid retention has reduced and I have lost 20 lbs since December. Bloods counts are good with the exception of the liver functions which seem to be improving some. I also had a methylprednisolone IV which will be repeated every week for 5 more weeks in an attempt to knock out this GvHD which is suspect for the diarrhea. The regular prednisone tablets have been tapered more to

just 30mg per day. This extra steroid is the probable reason that I am writing this at 3:30am though I was out of the house for almost 12 hrs yesterday. I also took a side trip to St Paul, had dinner and attended at a [1]NATT meeting in the evening without coming home in between.

The local NATT [2]Stop the Clot meeting last night featured presentations by [3]Sanofi-Aventis (makers of Lovenox) and [4]Sigvaris. The first presentation stressed that March will be [5]DVT Awareness month and that more people die of DVT/PE each year than from breast cancer and AIDS combined. This is important to me since I had at least 5 pulmonary embolisms 4 years ago and by the odds should not be on this earth today.

Sigvaris makes support stockings which are important to the prevention of DVT. These are commonly referred to as [6]TED hose like they give you in the hospital for knee surgery. But I learned that "TEDs are for beds" and not for general long term preventive use, at least for those that you take home from the hospital. Sigvaris makes specific socks that fit and look better for everyday use. They are constructed to provide different pressures dependent on your needs and variable pressures with more at the ankle than at the knee or thigh. A good guide to how the venous system works, their products and what you can do can be found [7]here.

1. <http://www.stoptheclot.org/>
2. http://www.stoptheclot.org/mn/feb_2009_group_meeting.htm
3. <http://www.sanofi-aventis.us/live/us/en/index.jsp>
4. <http://www.sigvaris.com/>
5. <http://www.clotcare.com/clotcare/dvtawarenessmonth.aspx>
6. <http://lifecenter.ric.org/content/3000/index.html?topic=2&subtopic=324>
7. [http://www.sigvarisusa.com/prod_web/NorthAmerica.nsf/vw_mf/PDFs/\\$FILE/PatientBrochure.pdf](http://www.sigvarisusa.com/prod_web/NorthAmerica.nsf/vw_mf/PDFs/$FILE/PatientBrochure.pdf)

Anonymous (2009-02-14 19:46:00)
Hope they can knock down the GvHD.

Ken Brandt

Hemochromatosis (2009-02-18 02:38)

I was back to the

BMT

Clinic yesterday for my weekly dose of [1]

Methylprednisolone

, kind of booster IV steroid to knock out the

GvHD

. It may be working since I have not had any diarrhea the past week though I was already feeling better before my first dose on Feb 10. My prednisone dosage was also reduced from 30mg per day to alternating between 30 and 20mg each day. Since I had both the regular dose and the IV booster, I am again writing this in the middle of the night.

I also had a phlebotomy last Thursday, so my hemoglobin,

hematocrit

and red blood cell count were still down. Other counts were ok , though liver enzymes are raised, but coming down.

The Dr told me that I have a gene that may predispose me to [2]

Hemochromatosis

, a condition that affects the absorption of iron. While the main cause for my iron overload and liver/pancreas problems is still thought to be all the blood transfusions, this may be a factor to contend with as well. This gene is hereditary so may have been passed down to my children and may affect others in my family tree.

While I was at the clinic, I also requested that the records department send an update on my medical history over the past couple of months to the long term disability (LTD) insurance company. They are doing a review of my LTD payments for the 2 year anniversary of my BMT in May. (I also requested a copy of the records for my own file since I don't see all of the details through my normal Dr appointments.) LTD payments are about 57 % of my last paycheck, but dependent upon whether I am still considered disabled. A portion of this payment is actually through Social Security.

1. <http://en.wikipedia.org/wiki/Methylprednisolone>
2. <http://en.wikipedia.org/wiki/Haemochromatosis>

W.Pat (2009-02-18 21:42:00)

Foods containing calcium such as cottage cheese, yogurt, carrots, etc are great for slowing down iron absorption.

Too much iron in the liver is worse than booze.

Drinks that have tannins work very well also. Black tea and my favorite, green tea are very helpful. Most herb teas do not contain tannins.

Vitamin C enhances the absorption of iron. It is wise only to consume a moderate amount and not take Vitamin C tablets. Vitamin C has been known to precipitate heart palpitations in those with hemochromatosis.

The ingestion of black tea has been shown to decrease the absorption of iron. African tea which is becoming popular may contain iron so too much should not be consumed.

Patients with hemochromatosis should not take supplements unless there are documented deficiencies.

In severe HH the disorder manifests as potentially life threatening conditions such as septicemia, cirrhosis of the liver, liver cancer, diabetes, heart failure and heart arrhythmias.

Hemochromatosis sufferers should drink lots of water every day to keep the blood thin for easier phlebotomies and to keep the kidneys nice and flushed out.

For people who are diagnosed and treated early, normal life spans are possible. If left untreated, HH will lead to critical organ damage and most likely death.

You can find lots of real life tips from Pat at his blog:

[Http://ironoverload.info](http://ironoverload.info)

4.3 March

To Pee Or Not To Pee (2009-03-23 19:04)

Seems like one of my challenges now is to balance my fluid levels and subsequently my weight. Three months ago, I weighed 239 lbs with a lot of fluid buildup. With treatments including diuretics like Lasix , I was down to 198 lbs on March 10. Unfortunately, my blood pressure was also down to 99/63 sitting and 77/44 standing and I was faint and light-headed. I got IV fluids and dropped the Lasix and blood pressure medicine. Then in the next week, I gained ten lbs back. After switching back to Lasix , I spent last weekend running to the bathroom. I actually urinated 20 times within a 24 hr period on Sunday and every 20 minutes during the first hours after taking the Lasix . Today, my weight was down near 190 lbs so the clinic told me to stop the Lasix again until Wed. I think this is all complicated by my diet and salt intake. So I need to monitor my weight every day and find a level of Lasix that will be just enough.

On my iron level issue, my last ferritin test was unbelievable at 11,000. Dr says it was inaccurate because of my liver so will test again next month. The last reasonable level measured was about 4000, still about 10 times the normal level. My blood iron saturation level was 86 % where normal is between 20 and 55 %.

I just bought "The Hemochromatosis Cookbook" from the [1]Iron Disorders Institute. The book and the website are good sources of info on iron retention problems and dietary solutions. I am trying to figure out what foods are best to eat since some are a source of iron and others inhibit iron absorption.

1. <http://www.irondisorders.org/>

Phlebotomies (2009-03-28 13:10)

I started having phlebotomies a year ago to reduce my iron level. I have been having them every two weeks except when my medical status would not allow. The count so far is 23. I may need 93 of them to match the number of blood transfusions from which I accumulated the iron. This is a rough estimate since the transfusions were packed red blood cells and the phlebs are whole blood. With at least 70 to go, it would take me another 3 years to get my iron back to normal.

Since others people having phlebs have tolerated them every week or even twice a week, I asked my Dr if I could get them more frequently. He agreed and Thursday I had another with only a week since the previous one. Everything went well. My hematocrit had recovered to 44 in the one week from the 45 level before the previous one. The hematocrit is checked before the phleb but not after. The threshold level to proceed is 38. My blood pressure dropped only a few points to 116/66 after the phleb. So I am now scheduled for phlebs every Thursday. If I can sustain this rate, I may be back in normal range within 18 months.

On the fluid front, I have not taken any Lasix since Monday. My weight has been steady at about 196 lbs and if it goes over 200, I will take another Lasix. Otherwise, I am feeling fine though tire easily and don't have the the physical strength that I used to.

Anonymous (2009-03-31 18:09:00)

Hope you can continue to tolerate the phlebs and that your iron rate continues to go down.

Ken Brandt

4.4 April

Diabetes? (2009-04-23 00:06)

Just when I start feeling better, something new comes up. This time it is my glucose level, 274 mg/dL last week though even higher at 335 before that. 60 to 99 is considered normal. So next week I have an appointment with the Diabetes Clinic to get that checked out further.

On the plus side, my liver functions seem to be improving. My alkaline phosphatase is down to 161 U/L from a high of 587 in February. ALT (47) and AST (77) are essentially normal.

I have another phlebotomy today (Thursday) and will be interested in what my hematocrit will be. This is the 6th week in a row and my hematocrit has been dropping each time. Last week it was down to 41.4 %, I felt light-headed afterward and had to wait about 30 minutes before leaving the clinic. It was 45.6 a month ago and 38 is the lower limit for proceeding with the phlebotomy. I may have to skip a week sometime to let my red blood cell count recover.

I am proceeding with further taper on the prednisone and am on hold for the Fluconazole. I have been on Fluconazole for fungal infections since back in 2007. I was off it for a few months last Fall before I had the bad bout of diarrhea. Not sure how that is related.

The Dr thought I could probably go back to work until I reminded him that this is the third cycle that I have reduced my prednisone and I am still not to the level I was at in November when everything went crazy. He agreed that we probably have a few more months to go before knowing what the minimum level I need. I was down to 2.5mg every other day and am still alternating between 15 and 20mg each day now.

Anyway, your prayers are appreciated as I weather the new complications.

Anonymous (2009-04-23 12:33:00)

Wow! Lots of things to deal with.

You are in our prayers.

Ken Brandt

4.5 May

Diabetes Testing (2009-05-02 21:03)

I had an appointment with the Diabetes Clinic on Thursday afternoon after I had my phlebotomy in the morning. A physician assistant (PA) reviewed my lab history over the past 4 years and gave me an [1]A1C test. This test is kind of an average of the blood glucose level over the past 120 days, the average life of a red blood cell. My A1C level was 5.9 % while my glucose level that day was 163 mg/dL which doesn't quite correlate. Seven percent is supposed to correlate with 150 mg/dL. I picked up a One-Touch blood glucose tester for home use and since have seen a range of 103 before breakfast yesterday to 252 just before dinner today. I will monitor it for a couple of weeks and then the PA will determine what is next. It could be Type II diabetes, but almost certainly elevated due to the high levels of prednisone that I have been taking for the last 2 years. We discussed possible medicines to use in lieu of insulin

shots.

My hematocrit has started recovering after the phlebotomies, 42.6 this week after 40.8 last week. Next week I see the liver specialist on Tuesday and have my 2-yr bone marrow biopsy on Friday. This is the 11th biopsy which involves sticking a big needle into my hip bone. Saturday is actually my 2-yr re-birthday since the BMT as well as being my actual birthday, 61 yrs ago. On May 12, I meet again with my BMT doctor and review the biopsy results. I will report next after that appointment.

1. <http://diabetes.about.com/od/symptomsdiagnosis/a/HbA1c.htm>

Anonymous (2009-05-06 01:24:00)

What a miserable process! Hope there is some good news in the future.

Ken Brandt

Anonymous (2009-05-16 18:19:00)

Joel:

Let us know about your biopsy and other tests.

Keeping you in prayer.

Jim

Two-year Rebirthday (2009-05-19 08:47)

Actually, it was 2 yrs and 10 days ago on May 9th that I had my bone marrow transplant. May 9th is also my real birthday, 61 years ago on Mother's Day. My transplant was actually a stem cell transplant and happened over a two day period starting on May 8th. You can read about those days starting on the [1]May 1 post. This is really my second rebirth day since I accepted Jesus Christ as my personal savior about 45 years ago. That was at the Blessed Hope Bible Camp named after the Bible verse: [2]Titus 2:13 "Looking for that blessed hope, and the glorious appearing of the great God and our Saviour Jesus Christ."

Back to today, I officially was told last week that I have Type II Diabetes. I am now testing my blood glucose 4 times a day, before meals and before going to bed. I take 12 units of insulin in the morning just after testing my glucose level. After 5 days, I still have not seen any effect from the insulin, but have a diabetes clinic appointment this afternoon to get further instructions.

I am not sure of the cause, but my toes are numb. It makes my right foot feel like I have a sock bunched up in the toe of my shoe. It feels the same with different socks and different shoes. I saw my orthopedist last week about the arthritis in my knees. He thought maybe the numbness was due to swelling in my knees pressing on nerves to my feet so I now have an EMG scheduled for June 2. It may also be from the diabetes. I was investigating getting the knee replacement that I had scheduled in Nov 2004, but my BMT doctor advises against it. If my arthritis gets to bad, I can probably get cortisone shots.

Actually the prednisone that I am taking helps the inflammation. [3]A year ago when I was almost off of prednisone, my arthritis really flaired up. I am staying on a constant dose of prednisone (alternating between 20 and 10mg each day) over the next six weeks until my next BMT appointment.

My disability insurance just reviewed my case and extended my disability status for another period. One of these days, I plan to post a summary of the past 5 years though you can read all the details in the past postings on

this blog. See the sidebar on the right.

1. http://myelo.us/2007_05_01_archive.html
2. http://www.biblegateway.com/passage/?book_id=63&chapter=2&version=9
3. <http://myelo.us/2008/03/regression.html>

Anonymous (2009-05-21 22:15:49)

Sorry to hear about the diabetes. Hope the toe issue gets resolved.

Ken Brandt

4.6 June

Code Brown - Rota Virus (2009-06-05 11:31)

Just like my bout with diarrhea before Christmas, I am back in the hospital again. On Monday afternoon, I started feeling very hot and sweaty though I had not exerted myself much and had no fever. We barbecued some bratwurst but before eating I lost my appetite and felt nauseous. A short time later, I had my first run to the bathroom with diarrhea. After about 8 more episodes, the later ones with vomiting, I was getting severely dehydrated. I lost 10 lbs since the morning even though I had a good breakfast and lunch. During the night I tried to drink more water, but by morning I could not sit on the edge of the bed because I was too light-headed. I even dropped a cup of water, breaking it on the floor.

My wife called the

BMT

clinic and then 911. The paramedics came and took me to the hospital emergency room while giving me an IV on the way. All I had on was my disposable diaper, but at least I was still warm. After a brief stay in the emergency room, they got me up to the intensive care unit (ICU) where they put me on more IVs. To increase the flow they inserted a central line (with 3

lumens

) into my jugular vein and at one point were pumping 2 liters of fluid per hour into me. I still had 2 other IVs inserted by the paramedics and ER staff. In the space of one day, my weight

fluctuated

from 208 lbs down to 198 lbs and up to 223 lbs, just due to losing or adding fluid. Back in December, my weight had been up to 235 lbs before we brought it down to around 198 through

paracentesis

plus diuretics.

A big complication of the dehydration was that my blood pressure dropped severely and my kidney function was decreased. My

BP

was down in the 60s/40s where normally it is the 120s/70s. Of course, my kidneys did not really have much fluid to remove, but

Drs

132

were concerned that the

[1]

creatinine

level was elevated. In addition, they discovered a heart problem called

[2]

PAC

, (

premature atrial contractions) though not life threatening and not related to this situation. My white cell count was elevated indicating an infection while my platelets dropped. I skipped my phlebotomy yesterday if for no other reason they have withdrawn enough with blood samples over the past four days. All of my blood counts are now back to normal.

Anyway, one of the tests showed the [3]

Rotavirus

, which

is the leading single cause of [4]

severe diarrhea

among infants and young children. I am now on a couple of medications to fight the virus and supply lost minerals plus a full liquid, lactose-free diet. They allowed me a regular diet yesterday until the diarrhea came back last night. Now I just heard they are taking me off everything by mouth except for medicines and ice chips. They want my gut to rest and heal.

For a while I felt like I was tied to the bed. I had 5 leads for EKG monitoring wrapped around my chest with IVs in both arms and the central line in my neck, all getting tangled together. One line was tied to a special instrument that monitored my central venous pressure. That was mounted on the wall so I could not walk with it to the bathroom. I had to use the commode by the bed. At least now I am down to just the central line in my neck which is used for one IV and blood tests. I can get up and walk around the room and take my "coat rack" (IV stand) with me to the bathroom. I still get poked 4 times a day for insulin shots though.

They don't let me out of the room and any hospital staff that comes in wear disposable gowns, masks and gloves. They are very cautious about spreading this contagious virus to others who have compromised immune systems in this ward. My wife also had a minor bout of diarrhea on Tuesday after me. She also learned yesterday that a student at the grade school where she teaches has the Swine flu. Luckily, it was not one of her students, but we have to be extra cautious if she gets any symptoms.

I probably will not be home until Sunday at the earliest if I can make it a day without the diarrhea.

1. <http://en.wikipedia.org/wiki/Creatinine>

2. http://en.wikipedia.org/wiki/Premature_atrial_contraction

3. <http://en.wikipedia.org/wiki/Rotavirus>

4. <http://en.wikipedia.org/wiki/Diarrhea>

Rotavirus Continues (2009-06-07 10:42)

It is now Sunday morning and 5 days since I was admitted to the hospital for dehydration from diarrhea last Monday night. Drs say that there is still traces of the Rotavirus in my stools which are still very soft, but not very frequent.

They also say that my intestinal mucosa needs to heal so I am on a NPO diet (Nil Per Os - Latin: Nothing by Mouth), no food or water except to swallow my pills. They pump 250ml of IV into me each hour and I run to the bathroom almost hourly to pee it out. Seems like a never ending cycle similar to what came first, the chicken or the egg. My weight is back to almost what it was before all this started so actually the benefit of the IVs is for me to filter out the 5 % Dextrose for nutrition.

I feel fine and my blood counts and blood pressure are back to normal as well. I took two walks around the 4 th floor yesterday. Maybe I will go to other floors or try to make an escape later today. Currently looks like I won't go home until Tuesday because they want to see how I react to a limited diet for a few days first. I will post at least a short status report each day. If nothing else, it is something to do to cut the monotony of this place.

This morning I watched a TV church show where the sermon was about Jonah and the whale, Made me wonder what the "reason for my affliction" is. There is something symbolic at least about being "in the belly" of the whale, but three days have come and past; I am still here. I need to ponder this some more and pray that I will be "vomited out upon dry land". (KJV version of Jonah 1 & 2 is quoted.)

Liquid Diet (2009-06-08 11:34)

Never thought I would be glad to be on a clear liquid diet, but it is a big step up from the NPO. I had chicken broth, jello, flavored ice and apple juice a few hours ago. Drs will see how this goes today and maybe I can upgrade to a full liquid diet tomorrow. Then I can have a few soups, cream of "cereals", puddings, yogurt, etc. The IVs was turned down to 20 ml/hr last night, but I still had to get up every 90 minutes during the night. I must still be saturated. On a positive note, my kidneys are certainly working efficiently. During the day, the IV rate is turned back up to 250 ml/hr.

I have been on some medicine named [1]Carimune, which is taken orally to get right to the source of my problem. The drug company does not show an oral version so I asked my Dr if this was experimental. It is a common variation that the pharmacist mixes up. Cost is \$500 for 7.5 oz dose. At four doses per day over 3 days, the total cost is \$6000. Certainly glad I have insurance.

I took several walks yesterday, one with my wife and one all by myself. I went down to the ground floor and played the piano near the back waiting room for 30 minutes. The piano was a little out of tune and I am a little rusty. Luckily, there were few people around. I don't think I will try that today with all the people around.

I spend most of the day on my iBook laptop with one eye on the TV. I have been watching the Food Network, building up my appetite for a trip to Famous Dave's for BBQ and beans

Thought now is I will be here for a few more days until the loose stools clear up completely and I can survive without IVs.

1. <http://www.cslbehring.com/s1/cs/enco/1151517258413/page/1151517258397/ProductListByCategory.htm>

Anonymous (2009-06-09 09:39:10)

It is too bad you have to stay in the hospital so long. Hope you can go home soon and can eat a normal diet.

Our prayers are with you.

Brother Jim

BRAT Diet (2009-06-09 09:51)

Well, it's another day and I get to eat additional foods. I have escalated to the BRAT level diet. No, not bratwurst, but bananas, rice, applesauce and toast with jelly in addition to the clear liquids that I was on yesterday. Seems like a smorgasbord in comparison!

I had a little scare yesterday when I thought there was blood in my stool. They took a test sample and said that it was just red dye from the berry gelatin that I ate earlier. I am pretty much back on my regular medications though some are still through IV. I don't take the Viokase since I am not eating any fats yet. My blood counts are a little low but not a concern. As expected my hematocrit was 35.7 % where it would have to be over 38 % for a phlebotomy. Hemoglobin was 12.2 g/ dL where 13.3 to 17.7 is considered normal. Platelets were 101 where 150 to 450 is the normal range. Before my BMT , my platelet count was over 1000 and after it was down around 50 for many months.

After taking a shower yesterday, I was free of my IV for a while and took a walk through the skyway over to the Masonic Day Hospital. That was the location of most of my 90 blood transfusions prior to the BMT . Unfortunately , I didn't see many familiar faces since they have reduced staff over the last three years. I will continue to explore some more today.

Now just waiting for my bananas and toast to come. I think I will pass on the red dye gelatin (pun intended).

ozzie (2009-06-09 18:37:50)

Hi Uncle Joel,

Sorry to hear you are still in the hospital. Rotavirus can be a nasty infection. I hope you can get out soon now that you are eating again. Platelets always drop whenever anyone is in the hospital for a few days. Kind of strange, but something about the hospital environment makes platelets go down. We will be praying for you that you will be home soon and feeling better.

Love,
Mark

Heading Home (2009-06-11 10:01)

The Drs were here this morning and said that I can go home after lunch. I had to see a dietician and have the IV removed from my jugular vein. I had a little scare after they removed the IV. It seemed like the solvent used to clean the bandage glue off my skin made me light-headed, flushed & hot and cough repeatedly. I called the nurse back, laid down for a while and everything cleared up

I will be on a restricted diet for a few weeks: no fats or lactose. My blood counts are coming back to normal and I have had several normal bowel movements. I am not scheduled to see the BMT Dr again until June 30, but may get back on phlebotomies before then.

I have been developing some numbness in my toes and had to cancel an appt with a neurologist last week. So I need to reschedule that appt and one for my orthopedist. Question is whether the numbness is related to my knee arthritis or the diabetes.

It may be a couple of weeks before my next post, but remember that you can sign up for automatic notifica-

tion by using the "Atom" link on the lower right of this page. This has several options to keep updated on changes.

Back to normal (2009-06-16 20:45)

I have been home from the hospital for 5 days and everything is back to normal, at least the way it was before my bout with the Rotavirus. We even ate out at the Old Country Buffet tonight.

I had a short Dr appt this morning to get labs done and all blood counts were normal. Hgb was 15.4 and Hct was 45.3 % so I can get back to my phlebotomies on Thursday. Platelet count was 167 and white cells was 10.9, both right in the normal range. Only my glucose level was high at 136, but that was right after breakfast. Before it was 91 and good.

I have an EGD endoscopy scheduled for Friday and an EMG of my legs scheduled for Monday. On Tuesday, I see the diabetes Dr again. Maybe I will find out if the numbness in my toes is due to the diabetes.

4.7 July

High Cholesterol (2009-07-30 09:08)

As a further complication in my medical situation, I now have high cholesterol. Probably have had it for some time because I just got tested relative to my diabetes. Some of my original MPD meds suppressed it. Anyway, my total cholesterol is 252 mg/dl where [1] recommended level is less than 200. So now, I have a new medicine, [2] Simvastatin, to take once a day. I had to drop my Fluconazole because of serious interaction with the statin. So I keep the same number of pills per day, about 20 with the Viokase which I take with meals. I am now totally confused as to what I can eat and need to plan my diet better.

On a positive light, my ferritin (iron) level is 2618, down from as high as 11,000. The normal range is 20 to 300 so I have a way to go. I had another phlebotomy this morning in a continuing effort to lower the iron in my body. In contrast, my wife has been to the same clinic to get an iron transfusion since her iron is too low.

I have another appointment with my liver doctor next week so should learn more about how I cope with the diet issues between iron overload, pancreatitis, diabetes and high cholesterol.

1. <http://www.mayoclinic.com/health/cholesterol-levels/CL00001>

2. <http://members.kaiserpermanente.org/kpweb/drugency/drugdetails.do?drugID=238251&name=Simvastatin+20+mg+Tab&index=true>

4.8 August

Lower levels (2009-08-27 18:54)

I have good news that both my cholesterol and iron levels are down. The Simvastatin has taken effect and my cholesterol has dropped from 252 a month ago to 139 this week. There may be some side effects since I seem to

have more joint pain.

My ferritin has dropped almost 400 points in the last month, from 2618 to 2234. At this rate it might be down to normal in 5 months though I am not sure it is a linear process. My hematocrit was only 38.8 this morning, just barely high enough for my weekly phlebotomy. It was 40.4 last week so I might have to skip a week occasionally for my blood counts to recover.

On the negative side, I have developed [1]Purpura, purple discolorations that are caused by bleeding underneath the skin. The doctor says that the prednisone causes thinning of the skin and I must scrape the area where a spot occurs. There is no pain and the spots disappear in about a week.

It will be 2 months until my next doctor appointment if all goes well. Other than phlebotomies, I need to schedule vaccinations for Hepatitis B. I probably will not be posting in the meantime. Remember that you can subscribe to be notified of updates; see the lower right margin.

1. <http://en.wikipedia.org/wiki/Purpura>

4.9 October

Steady State (2009-10-29 17:09)

It seems like I have reached a steady state in my health status. My lab results are about the same over the past several months with the exception of my ferritin iron level. Two months have elapsed since my last report since that is the time between Dr appointments with the BMT Clinic. I did see the neurologist last week for the numbness in my feet and will see the hepatologist for my liver next week.

I still have phlebotomies every Thursday morning as I did today. The Ambulatory Care Unit measures my hematocrit only to make sure it is above 38 percent. Last week it was 40.6, but was 38.4 on Monday when I had blood drawn at the BMT Clinic. This morning it was back up to 41.9. This may just be variation in the accuracy and techniques used to measure it.

The phlebotomies are having a beneficial effect since my ferritin level is down to 1556. It was 2234 in August and 2618 in July. I actually skipped a week in Sept so it still appears to be dropping about 100 ng/mL per week. At this rate, maybe I will be over this problem in 3 to 4 more months.

My BMT Dr is studying my case further relative to why my iron levels caused cirrhosis of the liver. An [1]HFE gene which causes [2]Haemochromatosis was discovered last February. Interestingly, the HFE test was done on my pre-BMT blood which was saved for purposes like this. The Dr said he has presented my case to other hematologists and thinking about to writing a paper including me as a co-author.

My long term disability (LTD) insurance company is requesting an update on my medical history over the past six months to determine if they will continue the LTD payments. One these days I may have to find a new job. My past employer (who still provides health and life insurance) just laid off 350 people so I doubt that there will be a job for me to go back to. I continue to keep up on information technology through user groups, conferences, on-line webinars and self study. I could possibly take early retirement, but insurance would be the biggest obstacle.

1. http://en.wikipedia.org/wiki/HFE_%28gene%29

2. <http://en.wikipedia.org/wiki/Haemochromatosis>

4.10 November

ICD (2009-11-23 18:39)

[1]ICD is the common abbreviation for The International Statistical Classification of Diseases and Related Health Problems. I have seen these codes before on forms that my BMT doctor has submitted to my disability insurance company but just figured out what they stand for. Full details of all the codes can be found at the [2]ICD Data web site.

In particular, three codes that are used for me are:

Primary - Myeloproliferative Disease [3]238.79

Secondary - Graft versus Host Disease [4]279.50

Other - Iron Overload/Hemochromatosis [5]275.0

If you are interested in looking up other diseases, look at the [6]ICD Index.

1. <http://en.wikipedia.org/wiki/ICD>

2. <http://www.icd9data.com/>

3. <http://www.icd9data.com/2010/Volume1/140-239/235-238/238/default.htm>

4. <http://www.icd9data.com/2010/Volume1/240-279/270-279/279/default.htm>

5. <http://www.icd9data.com/2010/Volume1/240-279/270-279/275/default.htm>

6. <http://www.icd9data.com/2010/Volume2/default.htm>

4.11 December

Iron Levels Reduced (2009-12-29 19:09)

I am on a schedule of Dr. appointments every two months, but still have a monthly treatment of Pentamidine nebulizer for my lungs. I had my Dr appt last week and the nebulizer today. Most importantly, I got the results of my blood tests from last week and my ferritin level was down to 970ng/ml. Normal is at most 200 and it was 1556 two months ago. That's a drop of 586 in 8 weeks or 76 ng/ml per week. This is a little slower than it was earlier when it was dropping about 100 points per week. I can look for my weekly phlebotomies for a few more months anyway.

The Dr has also reduced my prednisone to 15 mg every other day. It was 20 mg and will reduce to 10 mg next month. We will see how I fare at the lower levels. Last year about this time I was down to 2.5 mg every other day when I was hospitalized with a bad bout of diarrhea and my prednisone was jumped back to 60 mg per day. Hopefully, I can get off the prednisone and maybe the insulin as well.

Anonymous (2010-01-05 18:56:51)

Seems like things are going better. Hope this continues.

Ken Brandt

Anonymous (2010-01-05 18:58:11)

Things seem a little better. Hope things continue to improve.

Ken

5. 2010

5.1 February

Routine Status (2010-02-26 17:08)

It has been 2 months since my last status since things have been pretty routine. I continue to have Phlebotomies every week though now on Thursday afternoons instead of the morning. This gives me time in the morning to babysit my new grandson (born Jan 10) and then take my nap later in the afternoon. Otherwise, having the Phlebotomy in the morning wasted most of the day. I take a nap every afternoon since I am also up until 1:30 or 2:00am every night watching the new baby.

I also saw my BMT Dr on Tuesday this week, a full 9 weeks since I saw him last. My ferritin level is down another 495 points to 475. The rate of reduction is slowing, now at 55 ng/ml per week instead of 76 in the previous 2 months. The slowing rate seems natural since the iron is less concentrated, less is taken out with the same volume of blood. Normal levels are [1]12-300 ng/ml for males so I may only have another 4 weeks to be back in the normal range.

I also continue to have the Pentamidine nebulizer treatment every month. A few weeks ago I had a Hepatitis B vaccination and need a few followup shots as well. I just stopped taking the Levaquin antibiotic so need to be cautious of any signs of bacterial infections. I was on Levaquin for 8 months after my BMT, then off for most of 2008 and back on it since my hospitalization in Dec 2008.

1. <http://www.nlm.nih.gov/medlineplus/ency/article/003490.htm>

Anonymous (2010-02-26 19:19:04)
Glad "hanging in there."
Ken Brandt

5.2 April

Out of blood? (2010-04-22 22:52)

Well, I got my ferritin down to 284 ng/ml this week, but still need more phlebotomies to get down further to 50. Doctor's new order is to let blood every two weeks, but it is getting slower. Over the last 8 weeks the rate of reduction has dropped to 24 ng/ml per week. It was a 55 drop per week during the previous 8 weeks and 76 before that. Assuming an average drop of 5 % per time, it will take me another 34 times or over year to get down to the target 50 ng/ml. The rate is dropping at an ever lower difference since it is .95x.95x.95...the more I have taken out the less is taken out. A point of comparison is that the average daily consumption (and elimination) of iron is 50 mg per week, I have about 2500 mg in my body and I have been having 24 mg per week removed.

Then on top of this, my hematocrit of 37.3 % was too low to take blood today. It has to be at least 38 %. My blood pressure was 94/57 which is low as well. **Maybe I am running out of blood!** Actually, my hematocrit was 39.3 on Tuesday at the Dr office so it may just be a variation in measurement or maybe I drank more before my appt this morning than I did on Tuesday. I have another phlebotomy scheduled for next week so will see how everything holds

up.

I also had a special T-cell test this week with a reported Absolute CD4 of 682 which is supposedly good. This means that I no longer need the Pentamidine nebulizer treatment this month or hopefully in the future. Because I do not fluid retention problems, I get to reduce my Spironolactone pills to one each day. Still taking 9 different pills a day plus an insulin injection. I have a liver Dr appt on May 11 and will see what he thinks about all these changes.

Anonymous (2010-04-28 18:25:49)

Glad you can reduce at least one treatment and medication.

Ken Brandt

Anonymous (2010-05-07 21:52:14)

I guess having fewer treatments and pills is good. Glad you have retained your sense of humor.

Ken Brandt

5.3 August

Delayed update (2010-08-28 21:01)

Just realized that it has been 4 months since my last update. I should have posted at least 2 months ago. In the meantime, I have seen my BMT Dr twice and my liver Dr, diabetes Dr, eye Dr and GP Dr once each.

I have also had 9 phlebotomies after reducing the schedule to every 2 weeks. My ferritin level was 134 ng/ml on June 29 and then 67 last Tuesday. It dropped faster than I thought it would. Since my target is 50, I probably have reached that level with my phlebotomy yesterday. My BMT Dr has ordered another phlebotomy in 4 weeks and will check my ferritin again at my next appointment in 2 months. Since I have Hemochromatosis, I have to watch my iron intake and may have to have periodic phlebotomies for the rest of my life. After 85 phlebotomies so far, I guess I will keep eating my steaks (iron) and bear the needle some more.

I had an abdominal ultrasound in May after seeing my liver Dr. They still see the liver damage from the iron though everything else looked ok. In June, I saw my local clinic Dr since I was having pain in my nipples. My woman Dr examined my breasts and said that I had no lumps or evidence of breast cancer. At least, I didn't need a mammogram!

Also in June, I saw my diabetes Dr who measured my glucose A1C at 5.7. This compares to glucose of 126 mg/dl which is about what I measure each morning. I am still taking insulin shots each morning as well.

In mid-July, I had another bout of diarrhea and went into the BMT clinic with a stool sample. They found evidence of the [1]Adenovirus which is common in young children, I possibly picked it up from my 7 month old grandson. I also had

conjunctivitis in my eyes, possibly a complication of the virus. The eye problems persisted for about a month, so I saw my eye Dr who said the adenovirus can cause these problems which at last seem to be clearing up. Unfortunately, she also found evidence of

cataracts starting in both eyes. This is a complication of long-term use of prednisone of which I still take 10 mg every other day.

Finally, I am still taking 10 different medications with only one change in the last couple of months. My insurance company informed me that the FDA had dropped their approval of Viokase and [2]Creon was prescribed instead. This provides a substitute for my lack of pancreatic enzymes to digest fats.

1. <http://kidshealth.org/parent/infections/lung/adenovirus.html>
2. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0000279>

Anonymous (2010-09-12 15:50:09)

Sorry to hear about the cataracts. I admire how you continue to take things in stride.

Marge

5.4 December

Belated Update (2010-12-18 22:25)

Seems like I am in a cycle of updating this blog every 4 months. I just had a couple of Dr appointments last week and remembered that it had been a while, but surprised that it had been that long. I see my BMT Dr every two months and my liver Dr about every 6 months. But when I saw my liver Dr last month, he ordered another abdominal ultrasound and another appointment which I had last week. The ultrasound showed basically the same thing as last May, though there are some abnormal lymph nodes, [1]Lymphadenopathy. Both Drs don't seem to be excited about it though. Just another disease to add to my list.

My ferritin and iron levels are remaining steady at 41-42 over the last two months. Normal ferritin levels are 20-300. My last phlebotomy was on September 23 and it looks like I won't need another. I supposedly have Hemochromatosis, but so far my iron levels are steady.

Other problems that I still cope with are sensitive breasts, dry eyes & mouth, fragile skin, pain in my joints and neuropathy in my feet. My toes are always numb and it feels like I have a sock stuck in the toes of my shoes. I still check my blood glucose and take insulin shots each morning for my diabetes. I also take Creon pancreatic enzymes to aid in digestion and spironolactone & lasix to avoid fluid buildup. Finally, I am still on 10 mg of prednisone every other day. Better living through chemicals.

Other than that, I see my eye Dr next week, my BMT Dr in 2 months and my liver Dr in 3 months unless something comes up in between.

I think back over the past 6 years since I was first hospitalized and the 3 1/2 years since my BMT and am thankful to be alive today. I enjoy the time I spend babysitting my 11 month old grandson and being able to take a nap when ever I need to. God has kept me around for a purpose and though I could never work at a regular job, I enjoy life and doing what I can do from the comfort of my home.

Merry Christmas & Happy New Year

1. <http://en.wikipedia.org/wiki/Lymphadenopathy>
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6. 2011

6.1 May

Hodgkin's Lymphoma (2011-05-19 20:32)

A lot has happened in the last 5 months and I am going to try and catch up. Key development was a diagnosis of Hodgkin's Lymphoma on May 19th.

I was hospitalized for 9 days starting Feb 8 due to a bad bout of diarrhea. After about 12 hours and about as many trips to the bathroom, I was so dehydrated that I could hardly stand. My wife called 911 and I was taken to the emergency room and then checked into the hospital. Turned out it was some bug that cleaned out my whole GI tract. I was on liquid only diet for days to allow healing and the a BRAT diet (Bananas, Rice, Applesauce and Toast. I was never so glad to get out of the hospital and stopped on the way home for a Big Mac.

Again on March 15, I had a night of diarrhea again though not as bad as the previous time. I was able to walk and my wife was going to drive, but then called 911 again for an ambulance to the emergency room. Thankfully, after some fluids for my dehydration, I did not have to stay at the hospital. Unfortunately, I got stuck with the ambulance bill which I am still disputing.

Then on April 20, I woke up with weird, rapid heartbeats. I have had short episodes in the past that would come and go, but only observed once when I was in the emergency room for something else. This time it didn't stop and after an hour I had my wife call the doctor. I had enough strength to walk so she drove me to the emergency room where they diagnosed it as [1]Atrial Fibrillation. I was checked into the hospital and monitored by EKG and had an echocardiogram. The next day I had a TEE ([2]Transesophageal Echocardiogram) to check for any blood clots in my atrium. Since no clots, I had a Cardioversion, a procedure that shocked my heart into normal rhythm. I walked out of the hospital feeling normal in a couple of hours. The next day, I noticed the outline of the shock pad on my chest. Only ongoing treatment so far was that I went back on Coumadin blood thinner to avoid possible clots.

During these months my Alkaline Phosphatase was increasing, indicating something was changing with my liver. Doctors increased my Prednisone from 20mg every other day until I was back up to 40mg every day. An MRI of my abdomen was scheduled for May 3 to check out the cause.

I had been suffering from a sinus infection for 4 weeks when I was put on a 10 day dose of Augmentin on April 28. By May 7, I was feeling well enough to attend an all day tech conference, Mother's Day and especially on May 9, my 63rd birthday lunch with my sisters and cousin. It was 4 years ago that I had my BMT on my birthday.

While I had some temperature fluctuations with the sinus infection, on Wednesday, May 11, I started having shivers and sweats at night. On Thursday, I was very tired and on Friday morning decided I had to get into the doctor. In the meantime, the results of the MRI had indicated some suspicious lymph nodes near my liver. After initial checkup at the BMT Clinic, they checked me into the nearby hospital. Because I had been on Coumadin, they could not take a biopsy of my liver and lymph nodes until my INR clotting rating dropped to at least 1.5. They did all kinds of other tests - blood, urine, stool, Xrays, CT scans while monitoring my condition. I continued with the temperature fluctuations from below normal to as high as 103.2. Tylenol was effective and I learned to anticipate it coming on to address before it got that high again.

So on Thursday, May 19th, my INR was low enough to do the biopsies of both my liver and the lymph node.

They did this with the use of a CT scanner, using a live CT images to guide the needles to their target. I had to lay on my stomach for two hours while worked through my back. They would alternate between getting a CT image of where the needle was and pushing it in a little further. Took many iterations in and out. I was sedated, but saw some of the procedure on the monitor. The result was that the lymph node showed I have Hodgkin's Lymphoma which just happens to have temperature fluctuations as a symptom.

Before treatment, I had to have more tests to set a baseline and prove that I was healthy enough to proceed. On Friday, I had two bone marrow biopsies, one on each side. They were checking to see how my BMT was holding up and whether there was any trace of Hodgkin's in my marrow. I also had a Pulmonary Function Test and a full torso CT scan that showed a few more enlarged lymph nodes.

On Saturday, I had a [3]PICC line inserted in my left upper arm. The PICC line goes into my arm, up over my shoulder and ends in the superior vena cava entrance to my heart. This line was required since smaller peripheral veins cannot handle the chemotherapy which was started at 7pm. The regimen used was [4]ABVD, commonly used for Hodgkin's treatment. My main reaction to the chemo was severe chills afterward, to the point that my teeth were chattering. A dose of Demerol took care of the chills, but left me with the sweats. I slept well then and had a good Sunday.

On Monday, I had training for flushing the PICC line plus advanced diabetes management. Before all of this, I would check my glucose level before breakfast and take an injection of Lantus. While in the hospital, they checked before every meal and give insulin based on glucose level plus what carbs I had just eaten. I now have to do both at home as well. After my final training, they discharged me with a stop at the pharmacy to get a whole lot of additional medications to take at home.

On Tuesday, I had a followup appt with the BMT Clinic to get an injection of [5]Neupogen which should stimulate blood cell production to counteract the chemo effects. While there, I complained about the PICC line extensions added so that I could reach and flush them out. I had these lines hanging down to my wrist and had to keep them netted up on my arm. Doctor decided that I should have a [6]portacath installed. That will happen on Thursday, May 26, but they removed the PICC line immediately.

All in all, I am back home, sleeping in my own bed, typing this on my Mac computer and not feeling to much worse for the wear. I walked through the valley of the shadow of death with the BMT and have had four good years. While I have a few more complications now, life is good. Thank you, God!

1. http://en.wikipedia.org/wiki/Atrial_fibrillation

2. http://my.clevelandclinic.org/services/transesophageal_echoecardiography_tee/hic_transesophageal_echoecardiogram_tee.aspx

3. http://en.wikipedia.org/wiki/Peripherally_inserted_central_catheter

4. <http://en.wikipedia.org/wiki/ABVD>

5. <http://en.wikipedia.org/wiki/Filgrastim>

6. [http://en.wikipedia.org/wiki/Port_\(medical\)](http://en.wikipedia.org/wiki/Port_(medical))

Anonymous (2011-05-25 15:10:15)

As you are aware, Wanda and I have been praying for you through all of this.

We will keep you in our prayers.

Jeremiah 17:17

"YOU (GOD) are my hope in the day of disaster."

Many are going through disasters.

You have your own personal ones.

We are thankful God is in control.

If we are believers in Jesus, we have avoided the ultimate disaster.
May God be your strength and hope.

Brother Jim

PowerPort Implanted (2011-05-26 16:02)

I was in for out-patient surgery today and had a [1]Bard PowerPort implanted in my right chest. As I mentioned in previous post, the PICC line I had was too much trouble to maintain for the 6 months that I will need chemo. My wife drove me to the hospital where they started about 8 AM in an outpatient room with all the vital tests to prove I could continue. At 9 AM, they moved me into an operating room where they prepared me for the surgery. Interestingly, they transferred me from the gurney to the operating table using a hover pad, an air mattress with many holes in the bottom. They inflated it with air and just floated me from one to the other.

The procedure went well though I don't remember much since I was sedated. I now have an incision about 2 inches where they placed the port with catheter under the skin and a little incision about 4 inches higher where they inserted the catheter into my right jugular vein, No stitches - all held together with superglue. The catheter continues over to my left where it ends in my superior vena cava, just like the PICC line did. The port is a duo version so that it can support two needles at once and will be used for all future blood draws or any infusions included the chemotherapy. My first use will be blood tests again on May 31 with chemo planned for June 3. There is nothing that I need to do at home to maintain it.

I was back to my out-patient room by 11 AM, had some lunch and my son picked me up at 12:30 PM. Home now and feeling good. Just bothered a bit by dry eyes, a little blurry vision and my first eye floater in about a year. Hope that clears up.

1. <http://www.bardaccess.com/port-powerport-duo-mri.php>

Anonymous (2011-05-30 20:36:03)

Hi, Joel - I'm so glad the procedure to put the PowerPort in place went well, and that you are home now. You are in our thoughts and prayers, and we're just glad to know that you are home and doing well!

Bev, Bob, Steve, and Liz

6.2 June

Blood counts back up (2011-06-03 06:24)

I have had 2 clinic appointments this week and can report that I am feeling much better. I was dragging on Tuesday morning but perked up after my appt. My white cell and platelet counts were down so I had another appt on Thursday where both were going back up. Did not need a platelet transfusion as I had feared.

I still have a lot of bruising from all the needle pricks at the hospital and subsequent injections that I give myself. I check my blood glucose 4 times a day and give myself an insulin shot at least 4 times. I also need a daily injection of Lovenox to thin my blood following the Atrial Fibrillation last month. Hopefully, I can get back on Coumadin soon.

The incision from my dual port is healing well, but the superglue still hinders its use. Hopefully, the glue will continue to come off so that the ports can be used for my second round of chemo on Monday.

In the meantime, I am gaining strength. I have worked in the yard and garage, shopped for groceries, recycled fluorescent light bulbs, fixing stuff around the house and generally doing everything I could a couple of months ago. My son has been great in getting the lawn mowed and helping with any heavy lifting.

Your prayers are valued as I have the next round of chemo.

Chemo #2 (2011-06-06 17:07)

I had my second round of chemo this morning and am feeling fine. Only slept 4 hours last night and needed a nap this afternoon. The last of the superglue came off my incision with a little encouragement last night. I was there at 8:30 am and started with premeds, Benedryl and Tylenol and vital signs. They used the new ports for which I was glad are dual ported. The first try could flush but not withdraw blood so they put heparin in and used the second port which worked well. They later were able to clear the first port later. The infusion of the four drugs, [1]ABVD, took about 2 hours. We stayed a little while to see if I would have any reaction like the first time, but lucked out and we were back home by 4:30 pm. It was good to have my wife along for support, but I should be able to drive myself next time.

The new meds are affecting my sleep, averaging about 4 hrs at night with a one hr nap during the day. I am up before my wife and working around the house. I pretty much have the routine of testing my blood, counting carbs and giving my insulin and Lovenox injections. Have to take a couple of extra drugs at home over the next three days.

Keep looking up!

1. <http://en.wikipedia.org/wiki/ABVD>

Hair & Mouth (2011-06-11 19:07)

Well, the chemo is finally taking it toll on my hair. Every time I brush more comes out. Four years ago only the dark hairs fell out and I was left with wispy grey hairs, but I never lost it all or shaved it off. Just waiting to see how it looks.

My other complication is mouth sores primarily on my tongue and front lip. My sister recommended a combination of 1 Tbsp molasses and 1/2 an orange. I tried that last night but didn't taste too good and not sure how to take it. Today, my neighbor mentioned [1]Tea Tree Oil which seems to be an Australian cure for [2]everything. This afternoon I tried a [3]mouthwash of the stuff and will see if it helps tonight.

Otherwise, I seem to be doing fine. I will back to the clinic on Tues to check how my blood counts are holding up.

1. http://en.wikipedia.org/wiki/Tea_tree_oil
 2. <http://www.teatreeoiluses.com/tea-tree-oil-uses-human.htm>
 3. http://www.ehow.com/how_5666355_make-mouthwash-tea-tree-oil.html
-

Afib, Colitis & dehydration (2011-06-25 11:09)

I was scheduled for a clinic appt on June 14th, but had to go to the ER at 5am. I woke up with more atrial fibrillation but by the time I made it to the ER, it had disappeared. I was also having loose stools so they gave me fluids. My clinic appt was postponed until the next day when the Dr said that that I had chemo induced [1]colitis. My white cell count was also low so I got shots of [2]Neupogen. I had a hard time sleeping since the Neupogen stimulates cell growth and pain in the bones. I was into the clinic again on Thurs and Fri to get fluids and more Neupogen. My white cell count recovered and on Monday when I went in again, I felt a lot better.

All this time they are using my new dual Power-port to take blood and give fluids. On Monday, since I was in and out with just a blood test and no fluids, we forgot that I still had the IV lumen connected to the port. It wasn't until about 3:30pm when I realized this tube hanging under my shirt. Luckily, I was able to get back to the clinic before it closed to have the lumen removed so they could also flush the port with heparin.

This week, I have been feeling pretty good since my next chemo was delayed until Wed, June 29. I see the Dr on Tues to check blood counts again and confirm the chemo appt. We will see what the next week brings.

1. <http://en.wikipedia.org/wiki/Colitis>
 2. <http://en.wikipedia.org/wiki/Filgrastim>
-

6.3 July

Chemo is Working (2011-07-29 13:29)

Since my last posting, I have had 3 more chemo treatments with the 5th one on Wed July 27. Only had one bad day during the month on July 19th when I had to get an IV of fluids while at the clinic for a scheduled appointment. Seems like I got dehydrated from the previous days of high temps and humidity. We had water in our basement from about 8" of rain during the previous weekend and were setting up the garage for a sale. I must have overdone it and was really weak and tired by the Tuesday appointment.

Anyway, on Tuesday this week, July 26, I had a [1]PET-CT scan before my BMT clinic checkup for my chemo session scheduled on Wednesday. While at my chemo treatment, my BMT Dr stopped by and confirmed that the PET Scan showed no evidence of active cancer cells where the original biopsies indicated or elsewhere from my "eyes to thighs". He said that almost all patients who have this good of a PET scan after only 2 cycles of chemo (4 treatments) fully recover from Hodgkins. My sister went through this same process and experience with her Hodgkins and is cancer free today. I still need to go through 4 more cycles of chemo to make sure the stuff is killed for good. Thankfully, my reaction to the chemo and followup drugs has been good. I am essentially feeling as well as I have in the past 4 years since my BMT.

Praise the Lord. He must have more for me to do here on earth.

1. <http://www.petscaninfo.com/zportal/portals/pat/cancer>
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7. 2014

7.1 June

(2014-06-11 20:10)

Belated status.

I just got a comment on this blog that I have neglected for almost 3 years. Anyone still checking in may have thought that I died. But Praise the Lord, I am still around and feeling better than I have since 10 years ago when I was first hospitalized with pulmonary embolism. Let me summary the past three years.

My chemo for Hodgkins was successful and in January ~~2014~~²⁰¹², I was finally able to wean off of taking any prednisone. In fact, the day after I took the last prednisone, I went into insulin shock (hypoglycemia) while watching the evening news. My wife called the paramedics who gave me a shot of glucose to raise my blood sugar. That was the last day that I took insulin. I monitored my blood sugar for a month and was assured that I no longer had diabetes.

I was supposed to have my right knee replaced in 2004 and could not because of my other medical problems. After 8 years of delay, my left knee was bad as well and I had both knees replaced in March 2012. My cardiologist had recommended heart ablation for my atrial fibrillation but I had to delay that until March of 2013 due to the knee surgery. Since then I have just been taking Sotolol and warfarin with no further signs of fibrillation. I have a PET or CT scan every six months to check for any further problems. I fully expect to have my gall bladder removed next since I had a small attack last Fall and the CT scan in May showed growing gall stones. All blood test show normal levels.

So I may not post again but encourage all who read to have faith. I did walk through the valley of the shadow of death and God has been with me the whole way.

8. 2015

8.1 March

(2015-03-01 16:37)

It has been about 9 months since my last post because my health has been pretty good. I just had another CT scan on Monday and appointment with my Dr on Tuesday. Scan was good and no sign of Hodgkins returning. But my iron levels were a little high so I am having a phlebotomy tomorrow. First one since Sept 2010 so I hope it doesn't become a habit. I have a followup appointment in May to check my iron levels again.

I also saw my cardiologist on Friday. He said my EKG was fine. I showed my AliveCor EKG history from my iPhone app. I have had a few rapid heart rates of around 130 bpm but he said it was just regular sinus rhythm and was not concerned. My next appointment with him is in a year.

9. 2016

9.1 May

Thyroid Nodules and Iron Levels (2016-05-22 08:29)

It has been another year since my last post and I am feeling great. I have had CT scans every 6 months, but will no longer need them. It has been 5 years since I had Hodgkins and Dr says I am still clear of any cancer.

Over the last month I have had 5 medical appointments. My last scare was a biopsy of a couple nodules on my thyroid which turned out to be benign. Then the CT scans and Dr followup. But my iron levels are still high due to hemochromatosis and I had another phlebotomy this week. Additional are scheduled every month until I get my iron levels under control.

It has now been 9 years since I had the BMT and over 11 years since my first bout with blood problems. Praise God that I am have endured and doing fine today.

10. 2017

Ten year anniversary of my BMT (2017-05-10 10:55)

Ten years ago on May 9-10, 2007, I received a stem cell transplant from my brother. This is called a bone marrow transplant (BMT) though they just filtered stem cells from my brother's blood and infuse them into me. It took two sessions since there were not enough stem cells in the first infusion. May 9th just happened to be my 59th birthday. My brother was 70, old for this procedure but was a perfect match.

Thanks to the excellent staff on the University of Minnesota Medical Center and Fairview Hospital in Minneapolis and the grace of God, I am feeling great today. UMMC conducted the world's first BMT back in 1968. Prior to the BMT, I suffered for 2 1/2 years with myeloproliferative disease (MPD) and antiphospholipid syndrome (APS) also known as Hughe's Syndrome. My MPD was an unclassified version and possibly combined with myelodysplastic syndrome (MDS) and autoimmune hemolytic anemia.

Simply it meant that my bone marrow was producing defective red blood cells and too many platelets and I had over 90 units of blood (packed red cells) infused prior to the BMT. Interestingly, after I recovered from the BMT, I had too much iron in my body and had an equivalent number of phlebotomies. In the process, I had 12 bone marrow biopsies (BMBs) where each time they stuck a large needle into my hip bones to remove a 5 cm long 3mm diameter sample of my bone marrow plus three samples of blood. Along with all the infusions and blood tests, I have been a human pin cushion.

Prior to the BMT, I had to undergo radiation and chemotherapy over 5 day period that essentially wiped out my immune system. I literally went through "the valley of the shadow of death" (Psalms 23) and God was with me. Four years later, I had chemotherapy for Hodgkins Lymphoma over a 5 month period that progressively weakened me, but never wiped me out like the pre-BMT.

After the BMT, I suffered from Graft vs Host Disease (GvHD) where my new stem cells fought with my original immune system. Periodic BMBs monitored the progress of stem cell replacement in my bones. It was January 2008 before the engraftment was essentially 100 %. My GvHD lasted to at least February of 2009.

In May of 2011, I was diagnosed with Hodgkins Lymphoma and had 5 months of chemotherapy. I was supposed to have 6 months of chemo but after 2 months a PET scan showed that the cancer was gone. They kept up the chemo every two weeks during which I progressively got weaker and weaker. I finally asked the doctor why I still needed the chemo and they stopped it.

I also developed other complications from the medications. I was on Prednisone until January of 2012 and developed diabetes. The day after I took my last Prednisone, I went into insulin shock (hypoglycemia) and my wife had to call the paramedics. That was the last time I gave myself an insulin shot though I checked my glucose levels for several months afterwards.

I was supposed to have knee replacement surgery in November 2004, but failed the preop physical and was admitted to Unity Hospital for pulmonary embolism, three blood clots in my lungs. That's when they discovered by blood and bone marrow problems. Well, after 8 years of waiting I finally had both knees replaced in March 2012.

In April 2013, I had heart ablation for atrial fibrillation and in January 2017 I had cataract surgery. I have also had a few scares with my thyroid, but biopsies of lymph nodules last year and just last month show no return of

cancer.

As I posted in this blog on April 4, 2006:

The song "Amazing Grace", written by John Newton in the late 1700's. It was interesting to learn that the song has been modified over the years and that the original words had a special meaning to me.

Yes, when this flesh and heart shall fail,
And mortal life shall cease;
I shall possess, within the veil,
A life of joy and peace.
The earth shall soon dissolve like snow,
The sun forbear to shine;
But God, who call'd me here below,
Will be forever mine.



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