

2004 WG Journal

**Beginnings are scary, ends are usually sad,
but it is the middle that counts.**

from Hope Floats

January 1

Another blood draw and if all goes well the boys are off to the shooting range. We are getting ready for the upcoming cribbage tournament. Racheal's truck is *almost* ready to be hauled to the dump...to get weighed...so we can get a title for it.

January 6

Over Christmas vacation Ben got out on the shooting range three times. He is entertaining us with magic shows, lifting weights to build muscle mass (lost due to prednisone and inactivity), and riding his dirt bike whenever possible (still not in the dirt).

Days are going by with minimal nausea, but some vomiting and fatigue are thrown in here and there. All in all life is good...we weren't sure Ben would ever feel this 'normal' again. We don't know how long it will last but we are grateful for every minute of it. A cancer survivor explained the emotional recovery process this way:

The emotional recovery from cancer, for my wife and for me, was as great as the physical one. It took a long time to recover from the emotional trauma of having one's life suddenly upturned. Eventually we became re-absorbed into "normal" life, and moved past the daily fear of recurrence. Our focus now is to hold fast the major life lessons that many survivors cling to: Don't waste time. Don't take your body for granted. Cherish life, and your loved ones. Live every year as if it is your last. Best of luck in your journey.....<Reprinted with permission. [See Rick's story.](#)>

Since Ben's last Cytoxan treatment he is becoming anemic again and his WBC is lower than it should be. He continues to have those bothersome-to-him and scary-to-me night twitches. Then there's the blood pressure.

It is fluctuating from the high-end-normal to low-enough-to make-him-dizzy. At least four different fellows, the primary nephrologist and the head nephrologist are making blood pressure medication decisions. Lately it has been frequent consultations by phone between monthly clinic appointments.

Ben has not been an ordinary case. I need to be reassured that everyone has consulted about 'the plan' and understands his seizure history. I can't sleep at night if the suggestion is to peel away several meds simultaneously since it took weeks to stabilize him last time his blood pressure was out of control. My fear of Sept. 10 isn't buried very deep.

I was at our local ER with my grama last month for her broken hip. I saw one of the EMTs that was at our house the day Ben had his seizure. I'm not even sure of his name, but he did an outstanding job dealing with the situation that day. It surprised me that three months later just seeing the EMT again instantly brought back *ALL* of the emotions I experienced that day. My adrenaline rushed, I flushed and felt prickly all over, as my heart raced and I had difficulty breathing. Physically I recovered quickly and was able to thank him but the intensity of those recalled emotions stayed with me for days.

Hopefully those scary days will remain behind us and things are stable enough with Ben that updates will be needed less often. Drop me a note if it seems like it has been too long between updates!

January 7

Today was supposed to have been the monthly combined clinic plus a bone scan at the University Hospital. Due to the dangerous road conditions we opted for a phone consultation. Dr. Eddy outlined new blood pressure parameters and gave me a detailed plan that should see us through the next couple of weeks.

January 14

Ben is happy to report 20/20 vision after this week's eye exam. Yesterday Neurology named Ben's night twitches. I'm pretty sure *myokymia* means the twitching rippling muscle type of movement and *myoclonus* is the larger startle type that usually happens when falling asleep or waking up. The resident and attending doctors confirmed what the nurse practitioner said, that Ben is looking at two years of medication based on the severity of the September seizure. The Trileptal could be causing the nausea so other meds are being considered for down the road.

January 20

We got our money's worth at a local cribbage tournament recently, each playing twelve games in 6 hours. Ben scored in the top third of the group of 70 but just missed getting into the qualifying round. He didn't mind; he had enough cribbage for the weekend. He had a friend bring his dirt bike over for three nights. I briefly lifted my 'don't do it in the dirt' ban and they rode and rode and rode. They both wiped out and would be happy to tell you their sensational stories. Ben still takes medicine four times a day and monitors vitals twice a day. The medicine is down to 20 pills a day. Things are still day to day but right now there are more good days than bad.

January 26

Last week's Cytoxan IV treatment was uneventful other than some fluid retention and a small increase in blood pressure. In a few weeks, we expect Ben to move to a different medication called Methotrexate. Hopefully he has had his last Cytoxan IV for this flare...YEA!!! The home med routine is more manageable with 12 different meds given up to three times a day. Now we are impatiently waiting for Ben's lymphocyte count and bone density to return to normal.

Be kind for everyone you meet is fighting a hard battle.

Plato

'How does Ben feel?'



February 2

Today we were at the doctor's office twice before 10:15am. Ben had his blood drawn which is supposed to measure the low point of his WBC. Then he needed to see the on call doctor because of a sinus infection. We will see Rheumatology and Nephrology on Wednesday for a check up and to set up the Methotrexate (MTX) schedule.

February 6

After yesterday's visit Ben needs 3 shots a week: two epo and one MTX. He'll probably still average a poke a week to check his blood counts. He said he would rather have his blood sucked

than an injection going in. But at least he doesn't have to have the monthly IV. I told Ben I would tell him a joke for each shot but now I need to come up with some. Please post appropriate JOKES on our guestbook! There is some other fine tuning of meds going on and it always takes awhile for the new schedule to become routine. The bone scan, a story in itself, came back as we thought it would but hoped it wouldn't. He is at high risk of fractures...he has osteoporosis! That should resolve over time if the disease activity remains at bay so the Prednisone can be reduced. At this point I think he will be lucky to be on his dirt bike by June.

February 11

We made it through Ben's 13th birthday without any piercings. He had a friend over the same night he took his first MTX shot (Feb. 9). Ben was either pretty confident that he'd feel fine or that his friend wouldn't mind dumping the bucket. In the end, I dumped the bucket. With his hematocrit dropping we are checking for internal bleeding. He still has that stubborn sinus infection. And now I can't blame the nausea on the Trileptal because he is waking up with it even though he is given his anti-nausea med an hour before he gets up.

People are asking the details for the upcoming benefit for Ben; this is what I know. On Valentine's Day a co-worker of Todd's is hosting a VFW sponsored dinner at the Eagles (5-7pm, donation at the door). The Shifty Sailors have been invited to sing. They are a local group of guys that sing sea shanties. My doctor, Ben's doctor and an old friend are part of the group so it would be really fun to have them there. We are extremely appreciative and thankful for every bit of support.

February 18

It was fun to see everyone at Ben's benefit, many thanks for coming. The food was delicious, the music was wonderful and the financial help is greatly appreciated.

It looks like the MTX isn't going to give Ben any more nausea than he is already having. That is a relief! We keep whittling away at his blood pressure medication as his pressures go low enough to make him dizzy. We are finally seeing what we were told in September: it is more difficult to get his blood pressure under control than to keep it under control. We are giving Ben his anti-nausea medication daily and plan to do that for a few weeks before going another round at unraveling the cause of the nausea. He still has break through retchiness but generally has more good hours than bad.

February 23

For the first time since September, we managed to spend the weekend camping at Ft. Casey. The weather was gorgeous. The kids had a great time infiltrating ball games that were being played. Thanks to the anti-nausea med, Ben felt fine all weekend! What a joy to see him being an ordinary kid. At home Ben's current passion is billiards. Things get loud with two male pool sports in the family. I spent the weekend watching his blood pressure like a hawk since it was creeping up as meds taper.

Did I already say Ben is doing his own shots? Ben's next blood draw and Nephrology clinic will be March 8. We are optimistically hoping to see his total WBC within normal range and his lymphocyte count gaining toward the magic number of 750 (necessary for gardening and dirt bike approval).

Confine yourself to the present.

Marcus Aurelius

March 3

As far as Ben goes things are calm at the moment. We are still dealing with Ben's retchiness and blood pressure issues but try to remember how much better things are now. We'll know how the

MTX is working after blood work next Monday. My adrenaline is long gone so I'm are relying on faith, friends and inspirational quotes to help stave off the pity party.

Things are moving at a slug's pace getting the defective flooring replaced. The girls' rooms are getting Hydro-Seal 75 and Pergo from DIY Flooring. Things have been stacked and shuffled since September and I'm starting to get cranky about it.

As if we didn't have anything else to occupy our time, we finally decided to put together the wooden kayak kit that we bought 'used' 18 months ago. Ben says he won't go in it! No surprise since in his younger days Mr. Paranoia practically needed a life jacket to ride on the ferry.

March 9

It was a record setting sunny day in Seattle and we were attempting to stay cheerful while stuck in a waiting room for Hours. Our attitudes quickly came around when we saw the blood test results indicating that it shouldn't be much longer before Ben can get his dirt bike in the dirt. (Assuming his lymphocyte count follows the current trend and expecting no catastrophes.) There was some minor tweaking of immunosuppression and blood pressure meds.

On the home front we are continuing our emotional and financial roller coaster ride. 'Where are we going and what am I doing in this hand basket?' Last Friday the installers finally came to prep the basement floor (YEA!) and that day our furnace started blowing smoke through the ducts (&*\$%! The floor is on hold until we have a heat source. Ben will be utilizing the pool table in the living room, and the girls will be enjoying our mild maritime climate from their carport bedroom longer than expected.

March 14

We have heat again! Ben's only hardship right now is the nausea but even that is better, down to several times a week for a few hours at a time.

March 23

Ben has been extra retchy and has a cold. He is postponing his blood draw until next week to make sure he has his best shot at getting those counts in the dirt bike range. They may need to cut the MTX dose another 10% to get him in the 'normal' range; time will tell.

The last few weeks have been unbelievably stressful. The short version is the floor is done...glued with blood, sweat and tears.

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In doing her health final on kidney transplants Racheal found this excellent transplant story and resource list: <http://www.johnfmartin.net/resources.htm>

Another very useful page showed donor compatibility. The chart below is from that page. We were happy to find out that the Rh factor is not an issue but disappointed to see that Ben's blood type is the most limiting.

KIDNEY COMPATIBILITY CHART

used with permission

[From 'A Patient's Guide to Kidney Transplant Surgery Presented by the USC Kidney Transplant Program'](#)

Blood Type	Can receive kidney from:	Generally can donate a kidney to:
O (Ben's type, O+)	O	O, A, B, AB
A	A, O	A, AB
B	B, O	B, AB
AB	O, A, B, AB	AB

March 28

Ben is sick with a virus; the sore throat, runny nose, tickly cough one. So far no complications. We are able to cut back to monitoring Ben's blood pressure once a day but trials without Zofran aren't working (anti-nausea med). The girls slept inside last night. ...in their beds....in their rooms! I can just hear them now...'back when I was a kid, I had to walk 5 miles to school in the snow and sleep in the carport.' <grin>

Confine yourself to the present.

Marcus Aurelius

April 5

We had a rip roaring celebration of Racheal's 16th birthday, spring and general health. It sure was wonderful to see everyone. Despite the crowd Ben had a good time. We've given up on the attempt at eliminating the anti-nausea medication in order to enjoy spring break with minimal nausea and emesis basin dumping. We won't know until next Monday if Ben's lymphocyte count is up to the magic number of 750 (and we do know that his bones are fragile), but we decided to give into his begging campaign and approved a two night dirt bike trip.

April 12

Easter weekend brought several days of high blood pressure for Ben. This means keeping our suitcases by the door while we monitor and give the medication we have on hand for 'spikes'. We were waiting to see today's blood count thinking his hematocrit might be extra high causing the pressures to be higher (it wasn't). So we are increasing his Enalapril. We are also holding his Epo injections for now even though this doesn't appear to be the culprit of the higher pressures. It might be that he is recovering from the Cytoxan and won't need the Epo to keep his hematocrit normal. But then it may be that his kidney isn't producing enough Epo on its own and he'll wind up doing Epo permanently. His WBC is shifting around. Some levels are higher and some lower but over all Rheumatology says they are pretty much the same as last month. Still not good enough for unlimited riding but obviously they don't care about that as much as we do because they aren't reducing the Methotrexate dose.

April 14

Dr. Emery decided Ben's counts are close enough to the goal so he can garden!!! I doubt she will ever say dirt biking is a good thing. She has said she has had to put the pieces back together too many times. So we can attempt to relax about the microscopic fungi. Neurology wants to keep with twice a day anti-seizure meds and the anti-nausea med at least until next September (one year seizure free). Ben's risk factors are higher than some with seizure disorders because of the small blood vessels in the brain that can be affected by Wegener's and the length of that whopper of a seizure he had. I am attempting to follow my own advice and 'confine myself to the present.' We see the combined clinic people May 8.

April 19

Calgon take me away! A group of people are unhappy about Ben checking the mail on his dirt bike. But worse they are mad about the occasional shooting that goes on here. That fact that we ARE already compromising doesn't phase their position. The reason I am posting it here is I feel it is WG related. There are so many things Ben can't do because of this disease, but these are things Ben CAN do and people are fighting to take them away. To top off my day, Ben's lymphocyte count came back about 30% lower than last week meaning we have to take away gardening and dirt bike riding...

For those of you that still want to know more about this nasty disease check out Bruce's WG site: <http://www.wegenersgranulomatosis.net/> I think it has everything I need to know all in one place. It could keep me busy for the rest of my life; I wish would have had it 8 months ago.

April 20

Ben had a blood draw today to check how the increase in his blood pressure med was affecting his potassium and creatinine. They were fine. His lymphocyte count was down almost 30% from last week so NO STIRRING UP DIRT. It is a giant loss after only 6 days of thinking it was ok. Which means most of that time it probably really wasn't ok! His hematocrit was up from 39 to 42 without any Epo shots so maybe his kidney is producing the Epo on its own. It also means he has the energy to mess around in the dirt that is off limits. Eight months of restriction is taking its toll on his cheerfulness.

April 28

Ben's WBC seems so be heading back in the right direction. His Rheumatologist wants his lymphocyte count at least 700 and his neutrophil count at least 1000. Over all WBC should be 5,000-10,000 but the other counts are more important. He was stable enough to be able to go fishing for a week starting opening day. He is at Lake Roosevelt with Grandma, Grandpa, Uncle Ron, Aunt Lori and JR. I hear the fish are big, 19", and fat. I jump every time the phone rings but so far everything has been fine.

"Life is not a journey to the grave with the intention of arriving safely in a pretty and well preserved body, but rather to skid in broadside, thoroughly used up, totally wore out, and loudly proclaiming - wow - What a ride!"

May 3

Ben looked great when he came home from Lake Roosevelt. All smiles and tan. It was time for him to have a fantastic vacation catching long, fat fish. Since Racheal has her driver's license he wants her to take him to a nearby lake every night. She isn't very interested. We'll find out on Wednesday if his WBC are back in the normal range. While Ben was away, one of his hens got killed and his mother duck left a nest of 15 eggs. He is contemplating building a new chicken coup, incubating some duck eggs, and planting tomatoes, cucumbers and sunflowers...after his WBC are where they need to be.

May 4

Ben just totally surprised me by driving up to the house in his Scout, Tweety. He got the battery in, the tire pumped up, figured out the shifting pattern...I have no idea what all he did but he had a huge grin on when he drove by my office window! I am happy we have it now even though I wonder if we are the reason for county's junk vehicle law.

May 6

We saw Dr. Emery and Dr. Eddy yesterday. We were also treated to a surprise visit by Jordan. What a nice man. Bone density and growth hormones were discussed as issues that that may need to be dealt with in the fall. We finally got someone to officially read Ben's bone density

results and were told that walking is ok but running could cause a compression fracture. Even though he was given really good news, PERMISSION TO GET IN THE DIRT, he has to be very, very careful. It is difficult for him not to press the limits and difficult for me to say no yet again.

More good news is Ben is not required to inject Epo right now. His hematocrit was at 39.1 and they target 33-36 on Epo. He is tolerating the Enalapril which keeps his blood pressure reasonable and protects his kidneys from the protein he is passing in urine. Jordan said Ben's kidney function isn't great but it is good enough to use Methotrexate. If his creatinine creeps up close to 2, his kidneys will definitely wear out at some point in the future making a transplant necessary. The only thing we can do to keep Ben's kidneys in good shape is control blood pressure, watch protein in his urine and keep the Wegener's inactive. Obviously all of that is not in our control. Every day that Ben keeps own kidney function, improvements in medications and treatments are made. The crude estimate is his function is about 65%. Yesterday his creatinine was 1.3.

May 12

Ben is enjoying the dirt....but he scares me. So far he has a bunch of stitches on his shin and some deep bruises on his thigh gained through his intense enjoyment. Wegener's wise things are stable. Things are still stressful around here but it is because of the administration resignations at the school district affecting people we admire and respect, our kids' school and Todd's work. Meetings, meetings, meetings.

May 21

Thankfully the only new thing to report is Ben does not need his anti-nausea medication right now. The main ongoing concern is Ben's osteoporosis. Despite (or because of?) taking a pile of meds every day he feels 'normal' and wants to do normal boy things. This week I agreed that he can kick start his bike if it is warm. We are constantly negotiating to find a balance we can both be comfortable with. I told him at the beginning of this I would not put him in a plastic bubble. Now I am thinking in order for both of us to survive I may need to wrap him in bubble wrap.

**The pupil that is not required to do what he cannot do
never does what he can do.**

John Stuart Mill



June 1

For now Ben is the happiest boy alive. He is 'dad' to Drover, a ten week old Jack Russell from Posey Canyon kennel in Leavenworth.

June 9

This week Ben's blood work checked out okay. As far as kidney function goes he appears to be holding his own, right around 65%. His total WBC and RBC are good. His hematocrit has dropped to very low-normal but no Epo injections have been ordered yet. His sed rate and potassium are on the high side. His lymphocyte count is borderline for doing dirt activities. He keeping busy training his puppy, riding his dirt bike, driving his Scout and tending his garden. Tonight he went to the movies with a friend.

June 14

The last week of school has arrived along with sunshine. We are having a problem in the potty training department but otherwise are very happy with the new addition to our family. Ben had a couple incidents with his Scout over the weekend.

June 21

Todd, Ben and Amanda spent Father's Day in Cle Elum checking out the dirt bike trails. Next we head to Pasco for Todd's conference. Ben has been fighting off a sinus infection and a bad attitude. His blood pressure has been hopping around and the more concerned he gets, the higher the reading goes. His seizure med is at the bottom end of the therapeutic range. Since he seems stable and is nearing the one year point, the neurologist agreed to leave the dose alone. We've only been living with this disease 11 months. It seems like forever.

The ongoing crisis with our school district is not helping our stress levels (Todd's work and the kids' school). It is difficult to determine where prudence ends and paranoia begins. I wouldn't doubt if someone from our artsy community uses the fodder for a novel. *When life hands you lemons, ask for tequila and salt.*

June 30

The end of the month found us in Pasco. While Todd attended a transportation conference, the kids spent hours in the pool. The highlight of the trip was meeting another family who has a 13 year old son with WG. Ben *seems* absolutely fine and normal. People, including us, are able forget that this disease is lurking in the background. On the surface that seems good but it gets him unnecessarily exposed to illnesses and we've forgotten to bring his pills when we are out and about. Ben is having blood work done next week so we'll have a better idea of where things stand. In the meantime he is monitoring his blood pressure, taking his pills, giving his injections, watching his diet and avoiding spine jarring activities. Drover is a sweetheart. Not potty trained yet but he still makes us laugh.

"It's not the load that breaks you down, it's the way you carry it."

July 11

Ben had a combined clinic visit and an ophthalmology check last week. His eyes are fine despite the steroids. It's been almost a year since Ben's diagnosis and he is stable on MTX, folic acid, Prednisone, Prevacid, Enalapril, Trileptal, and Zofran. He still has large amounts of blood and protein in his urine from kidney damage. He has about 65% function. He didn't grow for 11 months but just as they were talking about growth hormones, he grew a 1/2". I've noticed more prominent veins in his arms and chest. The rheumatologist believes Ben could have two blood clots from his old dialysis catheters (one on the right and one on the left shoulder). So back we go to the hospital for an ultra sound. Since my dad's phlebitis I hear clot and think brain and lung, stroke and death. It makes me more tolerant of those fights Ben picks with his sisters!

An axle has been found for the Scout so it should be running soon. Drover had his first puppy class. Ben's cousin is visiting from Montana. Ben and Amanda have one more week of swimming lessons. We are still spending too many hours in meetings, and now it is time to figure out how we will be involved in the fair without sheep.

July 19

No news on Ben's health...that's good news. We are trying to sort out where the best place would be for an inexpensive family vacation. So many options.

July 20

Another post already! Thanks to the generosity of a friend offering a cut rate deal on motor home rental, we are heading to Mt. Rushmore. Finally! Yes, Drover is coming along. As if that isn't the trip of a life time itself, Ben and Todd have much bigger news. It feels as if we won the lottery.

Ben was accepted for a "Hunt of a Lifetime" through a program by that name that operates similarly to Make-A-Wish but offers hunting and fishing dreams. As it stands now Ben AND Todd will be heading to Manitoba for moose hunt this fall. Hearts are racing and hands are shaking already. I'm sure you haven't forgotten the reason that Ben qualifies for a hunt like this

July 21

Went to Children's for the ultra sound today. We were relieved that there were no obvious clots. They'll keep an eye on the veins and order an echo cardiogram if there is any change. When we arrived home there were two boxes from Cabela's. This trip is starting to feel real to me now. It is such a thrill to be a part of this experience.

Hunt of a Lifetime outfitted Ben for the cold weather from head to toe including binoculars. There have been many phone calls with the man who donated the hunt and the coordinator at Hunt of a Lifetime. Lea Meadow Outfitters has exclusive rights to this area in Northern Manitoba, only accessible by float plane. The success rate is 75%. Besides moose Todd and Ben can hunt black bear and wolf and fish for northern pike and walleye. From camp (tents) they will get to and from the hunting grounds by boat. It is about 20 degrees at night, 50 degrees during the day. If successful, the majority of the meat is left for Split Lake First Nations elders. In turn, the Split Lake Band does not hunt the area. If the hunter makes a hit but can't find the bull, there are no second chances.

Todd has been the one making the arrangements so he knows all the details. Email him if you have questions!

August 7

We went on a spur of the moment trip to South Dakota! We decided to go and left about 50 hours later for 16 days in a rented motor home. The trip was great; I'll post more on that later. Ben is doing fine. His blood pressure is actually low but not too low. He is due for another blood draw that we hope will confirm that things are going well. One shot a week, meds three times a day, monitoring blood pressure daily, monthly blood draws, visits to Children's about once a month...SO much better than this time last year.

August 18

Ben is doing pretty well. Things aren't perfect but I can't help but think about this time last year which puts in all in perspective. Ben has started throwing up weekly and doesn't seem connected to his MTX injection. He had been off of his Zofran (anti-nausea med) and feeling good for about a month. Blood results came back stable so treatment appears to be on track. My guess is five more months of MTX injections and then a decision will need to be made about further treatment. We expect a bone scan soon to see if his bones are still deteriorating. All Ben is thinking about is his moose hunt (see below). It is about 30 days until they leave for that. We are still trying to make the most of every minute.

Our whirl wind trip to South Dakota went like this...

THURSDAY: picked up rented motor home and stayed in Marysville

FRIDAY: stopped at Deception Falls on Steven's Pass, Dry Falls, Grand Coulee Dam, swam at Lake Roosevelt, stayed at Lake Roosevelt, Lincoln WA

SATURDAY: Toured around, swam and dove for hours from the boat, went to the light show at Grand Coulee Dam, stayed a second night at my brother's property

SUNDAY: Drove to West Glacier and found my niece, stayed at West Glacier, MT

MONDAY: Rafted the Middle Fork of the Flathead River, toured Glacier National Park, stayed a second night at West Glacier campground

TUESDAY: Drove to Whitehall stopping at Museum of America in Polson, MT. Stayed at my sister's house in Whitehall, MT

WEDNESDAY: Drove to the Battle of Little Big Horn, Visited Big Horn County Museum, stayed in Hardin, MT

THURSDAY: Toured Battle of Little Big Horn some more, drove to Deadwood, SD, and walked around town, stayed in Sturgis, SD

FRIDAY: Shopped in Sturgis, toured two Black Hills national cemeteries, toured Big Thunder Gold mine, visited Mount Rushmore, camped at Keystone, SD

SATURDAY: Toured Crazy Horse Monument, saw Buffalo herd at Custer State Park, visited Mammoth site at Hot Springs, SD, drove through Badlands National Park, made it as far east as Wall Drug Store, then headed west and pulled into rest stop at 11:30pm Sheridan, WY

SUNDAY: Saw lots of wildlife in the Big Horn National Forest in WY, visited Buff Bill Dam Visitor Center before entering Yellowstone at east entrance, toured Yellowstone Canyon and Mammoth Hot Springs, camped at Norris Campground

MONDAY: Toured geysers from Norris Basin to Old Faithful, Gibbon Falls and Paint pots, camped in Yellowstone a second night

TUESDAY: Headed back to Whitehall stopping at Ennis earthquake area and Virginia City. Visited Dave, stayed in Whitehall again

WEDNESDAY - THURSDAY: stayed in Whitehall two more nights

FRIDAY: Drove from Whitehall - home. Took about 15 hours. We traveled over 3600 miles in 15 days stopping at about 30 major tourist locations

August 31

Ben has an neurology clinic appointment at Children's in 10 days. He has been feeling great and has been busy swimming and fishing every possible minute. The moose hunt is coming together and is going to be over before we know it. Flight arrangements were made yesterday. Todd and Ben will fly out September 19 and arrive back September 30. The gun has not been sent from the factory yet. The donations to make this possible are staggering.

"The important thing is not to stop questioning."

Albert Einstein

September 1

We rafted on the middle fork of the Flathead river just outside of Glacier National Park. My niece was our guide. She refused to let me do the 'scenic float!'

September 3

Drover and I wish we were going along for the HOAL. The gun should be here by the 16th one way or another. Oh, the anxiety of waiting!

September 5

The hunting location is Freeman Lake, Manitoba. They will leave from Thompson.

September 12

The man handling the gun for Ben (Crow a sheriff in Texas) is overnight shipping the gun on Tuesday. The gun dealer on the island here is expecting it and will let Todd and Ben know as soon as it arrives. I expect them to go through a couple boxes of shells on Friday and Saturday. One thing they don't want is a wounded bull moose!

Ben has been asking about getting back into the sheep business. Thanks to some wonderful friends that is going to be a possibility next summer. These folks will be loaning us some of their fantastic sheep next summer. It is perfect for us because Ben's health is too time consuming and unpredictable to breed sheep the way we did before. THANK YOU Don and Linda!

Another thank you we want to make is to the Bunyon Buster Log Show at our county fair. They auctioned off some firewood and gave the proceeds to our family. Receiving this gift was such a welcome surprise. Besides the financial help, it means a lot to us that people understand that Ben's illness isn't over. Today he looks and feels good while on this methotrexate treatment and it is possible to forget the time bomb he is sitting on. But he still needs to avoid common illnesses, excess dust, spine jarring activities, sodium... I am thankful for each moment with Ben but fear isn't buried very deep. Last year at this time we were in intensive care with him just waking up from an induced coma.

September 14

Todd and Ben meet the shuttle a mile from home at 4:55am Sunday morning. Anyone want to place bets about how much sleep Todd gets Saturday night?

Ben's blood work came back fine. His WBC was 6.9. His creatinine came back at 1.3, a jump from 1.2. No reason to panic but I don't like it climbing. His potassium and phosphorus have been running a little high but this time they were within the normal range which means his kidneys have been able to clear that ok. Yesterday Ben's blood pressure was 90/60 so he had some potato chips and a quart of water and it was normal by bedtime. Apparently there is a national shortage of MTX, the immunosuppressant. THAT is making me really nervous. So far it has meant is hours on the phone with pharmacy, multiple trips to the pharmacy, delays in filling the prescription and filling it differently (10ml vial instead of two 2ml vials, no preservatives so you have to throw away whatever is left in the vile). Ben has enough MTX to head out on his trip so he is happy.

September 16

THE GUN HAS ARRIVED! It turns out to be a 7mm Savage with a composite stock, blued barrel and a muzzle brake. They will be sighting it in this afternoon.

September 20

Todd and Ben left yesterday morning. They hit a snag in Vancouver. Check out the HOAL page for more details.

September 30

They're back!

You just have to let it go. Catch and release.

quote from Kyle Cook, avid fisherman who has a son with rapid aging disorder

October 1

Still recovering from the trip. What an amazing adventure. Ben's blood pressure was only high one day during the trip and that was the night he got his moose.

October 6

Had an appointment with Rheumatology and Nephrology today. They also threw in a routine blood

draw and an echocardiogram to see how the high blood pressure has affected Ben's heart. The good news is we don't have to go back until January! Ben is tapering his prednisone from 5mg a day to 5mg every other day. He still has more casts and blood in his urine than he should have if his disease is inactive. But he feels good and his blood levels don't indicate inflammation so it might just be residual inflammation but it shouldn't last this long....no one has an answer. The decision to taper off of the anti-seizure can be postponed until January. So things are as calm as they ever get around here. Still glowing from the hunting adventure.

October 8

The kids got their flu shots today! It is still Very Important to protect Ben from colds and flu that can stress his immune system and set back the progress that has been made in his recovery.

October 16

Opening day of deer season. Ben went off island, where we have black tail, to Walla Walla to hunt white tail and mule deer. Last year he did not get to hunt much because of the Cytoxan. Ben's creatinine came back at 1.2 and everything else blood wise seems to be doing ok. He is looking and feeling great.

October 18

Ben connected with a buck. A long way from the truck but it was worth it according to him.

October 27

Ben left on the 25th to fish the Yakima River with my dad before heading to Naches for his elk hunt. I got scary news today that there is a national shortage of injectable Methotrexate. I spoke with a nurse at Children's who was reassuring but it doesn't totally remove the fear simmering around the edges of my consciousness.

The measure of success is not whether you have a tough problem to deal with, but whether it's the same problem you had last year.

John Foster Dulles

November 1

No word from the hunters but they have to drive an hour out of the way to call. Ben has a scan set up for January to determine the state of his osteoporosis.

November 9

The boys are home from their elk hunt, empty handed but a great vacation. Ben's blood pressure remains stable. He seems to be doing okay with 5mg of prednisone every other day. Most days he looks and feels great. If he throws up, it is usually due to his weekly methotrexate injection. We are still discussing the seizure med taper.

November 17

It has been a rough week. Ben had an odd cycle of vomiting that didn't seem related to his MTX. He lost four pounds in five days. Along with that he came down with a cold that included a cough, that turned into bronchitis, and congestion, that turned into a blocked sinus. His low grade fever has meant four trips to the doctor, sinus and chest x-rays, multiple blood draws, steroid nose drops and antibiotics. It remains essential to keep Ben away from seemingly minor illnesses. Thanks for helping us!

November 22

After 12 days of being sick Ben still has a fever and nausea. He is still on the antibiotic and steroid nasal spray. He lost 5 pounds in 4 days and is having problems staying hydrated. I've been silently worrying that this could be disease activity and on Friday Ben's pediatrician said that outloud. Ben's amylase level is elevated that could indicate pancreatitis, but then I was reading "in kidney disease, the kidneys are not as efficient at removing amylase from the blood. Amylase rises

in the blood, but stays at normal levels in the urine." I'm taking Ben to see Dr. Emery at Children's tomorrow so hopefully she'll have some ideas on where to go from here.

November 23

Dr. Emery thoroughly examined Ben then ordered a pulmonary function test (PFT), sinus and chest x-rays and lab work including checking his c. anca level. The nurse had to give the PFT examiner two Tootsie Rolls to test Ben on his lunch hour. Dr. Emery is suspicious of a flare but is going to wait to increase his prednisone and MTX until Ben has finished this course of antibiotics. Dr. Wallace is on this weekend at Children's which makes me very happy because Dr. Emery, Dr. Wagner and nurse Teri are all out of town for the holiday.

November 25

We talked with a Rheumatologist at Children's who wanted to change antibiotics. Once I said he was allergic to penicillin he decided to leave well enough alone for now. Ben is going from 5mg of prednisone every other day to 20mg a day. Hopefully he feels better soon.

November 29

The doctor decided to put Ben on Bactrim twice a day for two weeks. Ben's fever is lower but he is still waking up with dry heaves and carrying around a barf bucket during the day...feeling miserable. One of his sinuses is still sore, he is hacking up green stuff. He is definitely bruising easily. Still waiting to hear the anca and PR3 levels.

If we are facing the right direction, all we have to do is keep walking.

December 1

Still puking. There was a mention yesterday of the possibility of draining Ben's sinuses.

December 2

Dr. Wagner spoke with someone at Children's Oncology unit and we are trying a new anti-nausea plan. It is hard to tell if the Zofran was doing anything. Ben only had 8mg this morning (instead of 8mg three times a day) and he vomited a couple times, once after trying the new Benadryl/Raglin combo. If this doesn't work, there are one or two other things to try. Dr. Emery is working to get an appointment with the ENT people to see if Ben needs that sinus drained. Sleep is hard to come by right now. Healthy visitors are most welcome to entertain Ben.

December 7

None of the anti-nausea options worked any better than Zofran. We aren't positive that it is working either. Ben had his gall bladder ultra sound today. It looked good. He hasn't been to school since November 9 so his math teacher is giving him lessons at home now.

December 8

Today's blood work looked 'Benish.' Everything following his normal trend except his Amylase level is still elevated. We are off to see the ENT folks at Children's tomorrow.

December 9

They squeezed us in to the ENT clinic and then squeezed Ben in for a sinus CT scan which meant several hours of waiting around. The news was tentatively good. The doctor thought it looked more like regular sinusitis than active WG disease. He suggested surgery to open up his sinuses that will allow him to breath better plus allow the medicine to get where it is supposed to go. He would biopsy if he does surgery to open up his sinuses. I'm pretty sure Dr. Emery would like to see that tissue to make sure she shouldn't beef up his immunosuppression.

December 14

Sinus surgery is scheduled for January 12. The ENT doctor said he can't promise that will resolve his fever or puking but it will be beneficial in resolving the blockage issues. If the sinus surgery

doesn't stop Ben's puking, Dr. W would like to schedule a scoping procedure to look at the opening of Ben's pancreas. He has two out of three of the symptoms for pancreatitis. It all sounds so far away.

Yesterday I met with the head of special ed to discuss home/hospital instruction and getting a 504 Plan in place to deal with educational issues. There are no students in the district who have gone through anything remotely similar so there is no rubric for the district to follow and no one to offer support for us.

December 14 pm

Ben's sinus surgery has already been rescheduled to January 19. I was able to talk to a Special Services fellow at Educational Service District (ESD) 189 about what is allowed in a 504 plan. I thought it was nice of him to say now is the time to be getting this done. He directed me to a booklet that explains the purpose of a 504 plan and some of the types of accommodations (email me if you want a copy of it).

December 17

Yesterday was a 'good' day. He was up and around all day, feeling better than he has for awhile but far from perfect, helping me get ready for the WIA (school) cookie exchange. He wanted us to host it so he could have all the left over cookies! While I was at Amanda's banjo lesson, Ben's friend from a district 25 miles away, called to say he had been poked in the eye at school and needed a doctor's attention. His mom wasn't home, I wasn't home, no one they called was home, so Todd took care of it. It worked out for Ben and his friend because they got to eat cookies and spend the night together. Dr. Wagner has left a message for internist, Dr. Christie, at Children's to discuss the next step.

December 22

There have been more good days than bad recently. Ben still throws up but it has been more like every other day rather than daily. The next step is to check out Ben's pancreas with a scope during his sinus surgery if he is still having symptoms on January 19. If nothing shows up with the scope, they are discussing synthetic marijuana. When The anca level finally came back and it indicated that all of this probably was not a flare. A suggestion was offered that it may be RSV. That explains the congestion but not the vomiting. We are all looking forward to Christmas.