

January 2

Happy 2008! Ben has a virus involving coughing, congestion, clogged ears, and bloody noses when he blows his nose. He sounds awful. He actually initiated the process of contacting his wonderful ENT nurse practitioner by email to get his back to back Z-Packs faxed to the pharmacy.

His second set of blood work came back with his creatinine even higher (1.7); however, his BUN was down from 33 to 30. These tests were done so nephrology will have the information when Ben sees them on Jan. 9. Between the creeping toxin levels and the edema, something is not good.

School starts tomorrow for Rach, Ben, Amanda, and me. Todd has to work on school vacations except for holidays. We are checking into some new cross country skiing locations. Let me know if you have a favorite spot!

January 9

Ben saw his doctors today. They believe that the rise in his CRP and creatinine levels were from the virus he had. Any strain on his system causes symptoms that wouldn't occur to someone without the damage and vasculitis that he has. They redrew his blood just to confirm their thinking.

At this point, aside from a flare, they are most concerned about heart disease. He has too many risk factors: vasculitis, high creatinine, high blood pressure, and high cholesterol. Anemia and his calcium/phosphorus balance are likely to become problems as his kidney function drops. But no one is saying transplant in the near future so that is a relief. We thought maybe it might be like a gas tank where the second half seems to go so much faster than the first half!

Ben decided he wants to interview the two rheumatologists that Dr. Emery recommended. That will be interesting. Hopefully Ben will do the talking.

January 18

Things are going well. Ben mentioned getting a job today which means he feels well enough to do that AND feels confident enough that his health is stable. I said school comes first. He said I'm not getting one *right now*. I guess he thought I was rushing him.

You'll see Racheal driving around in her newest pick-up. She is passing her old Ford Ranger to us because she bought a 4x4 version. Amanda said the new one is *much* cooler. Ben is still fighting for a bigger engine in the Scout. I think he needs that job to pay for the gas if he gets a bigger engine. Plus he is saving money to go to Yellowstone with a buddy.

Transplant Article

<http://www.abc.net.au:80/news/stories/2008/01/24/2146032.htm>

February 2

Ben is counting down the days until his birthday. He plans to buy some fancy fly fishing stuff. This birthday puts Ben 365 days from leaving the safety net of Children's. Our calendar is filling up with appointments as we consult with adult primary care providers

and rheumatologists. The plan is to ask whoever Ben chooses to recommend ENT and GI docs. Ben is going to try to stay with his nephrologist for awhile but his adult office is in Kirkland. I am envisioning each specialist in a different county. I hope it isn't so!

Ben is also making plans to get his wisdom teeth out. That is scary because the inflammation caused by the removal could trigger his autoimmune system to attack itself again. Since he is stable and off chemo and steroids, we have to set our fears aside and go for it. Our insurance will cover about half of the bill; the oral surgeon requires cash up front for the other half. Didn't we just go through this with Racheal???

February 13

Ben met his new PCP, Anne, yesterday. She is a local nurse practitioner and used to working with people with chronic health conditions. She gave us her opinion on the two places we are checking out rheumatologists and suggested that we talk to every nurse we know to get their opinions. She also said that Ben might want to consider using a higher dose antibiotic because the bacteria on the island have become very resistant. As we are coming from experience with a doc who never gave Ben antibiotics when he needed them, it was an interesting contrast. So one new doc down and five to go.

Ben is driving us nuts wanting us to quiz him for his mid-terms. It was much better when he and Rach were in the same classes so she wanted to study, too. For those of you interested in what I am doing at work, here is one part of it...<http://www.sw.wednet.edu/sites/hs/hsfalcontut/>

February 28

Ben met with the oral surgeon today who took one look at his extensive history and quickly wrote out a referral to Children's Hospital. He recommended that Ben gets his teeth removed and spend the night there. Who knows how long that will take to schedule? We are hoping that it will be considered a medical procedure rather than a dental procedure which will give us significantly better insurance coverage.

Monday Ben will consult with a new rheumatologist. We think we have everything in order.

March 3

Ben met with a new rheumatologist today. He liked him and the facility enough to give it a try without checking out guy at the University of Washington. Todd's mom uses this same clinic for her rheumatologic disease and I've felt that she has received appropriate and thorough care. Now the decision is whether to wait until Children's refuses to see him anymore or to make the transition gracefully now. Leaving that knowledge base and comfort during a crisis behind is frightening.

This clinic houses an ENT, GI, and has recently added a nephrologist which are all departments Ben needs to see at least every three months. It sounds like their records, at least lab reports, are readily accessible to all departments if the labs are done onsite. They will have them done STAT if Ben arrives an hour before his appointment so he won't have to wait for a call with the results. All of that sounds good. Plus there is a walk in clinic which could very possibly take the place of many ER trips.

This rheumatologist, Dr. Slack, made a referral to his clinic's nephrologist so that will likely be the next consult. We are still waiting to hear about the dental referral that the oral surgeon make asking for Children's to handle Ben's wisdom teeth.

March 6

The dentist from Children's accepted the oral surgeon's referral and set up a consult for May. We were told the actual procedure could be a scheduled couple weeks after that appointment. Ben will probably want to wait until after finals.

He'll be taking Marine Biology, English 104 (Research), Health & Wellness, Kayaking, and Political Science. He is complaining about his credit load but I think he'll be fine if he stays well (and focused).

March 19

Ben has had a nasty virus. It looked like he was trying to swallow one of those throwing stars or something the way he winced. He is finally out of bed and looking better.

March 31

Still trying to make the new primary care provider understand that Ben can be very sick without looking very sick. He still has a fever and possible sinus infection. We can either convince this doc to listen, find another doc, or try to get someone's attention at the ER. Such a bad system!

Ben's regular appointment with nephrology and rheumatology at Children's got canceled so he will only see nephrology in May, the day we go in for the "transitioning to adult care" workshop. I think they should have let him attend the workshop before kicking him out of care.

April 13

No news is good news...Ben finally decided to take the antibiotics for the nasty virus he had that settled in his sinuses (as they always do but we keep hoping it won't). It required a quadruple dose of the big stuff so far but he is improving.

He has several appointments at Children's coming up. The wisdom teeth visit, the transition panel, nephrology, ENT, and ophthalmology are all scheduled within a week of each other. We'll keep the cribbage board handy.

Ben's blew out reverse in the Scout. It is back on the road now, but he has plans to change things. He found a Blazer with a 4.3l engine that needs rebuilding. The Scout body is going to end up on the Blazer frame. The only downfall I've heard is that it is an automatic.

I'm still hearing talk about him going to Yellowstone on a fishing trip this summer. I hope he gets to go. My favorite place on earth is a toss of of Yellowstone and Glacier National Park. I love them so much that I am reluctant to explore else where!

April 29

It turned out to be "three strikes and you're out" for new primary care provider Ben was trying. I'm sure we'll be happier, and she will, too! I did a bunch of calling around and was surprised to find a practitioner who has an opening, took patients under 18, AND had experience with patients diagnosed with Wegener's. She our last try with on island care for Ben, but based on our phone conversation she seems to "get it."


Ben has his kayak rescue and roll class next weekend. It just snowed last weekend!

Luckily they'll provide him with a farmer john wetsuit. And he should really get his sinuses good and flushed when he tips the kayak over and over.

The engine for Ben's Scout is in the going back together phase. Apparently the Blazer frame doesn't have to be shortened like they originally thought. Ben has a good teacher...Todd won second place at the state school bus mechanic's competition!

Ben is on his fourth round of back to back antibiotics and still having problems. Luckily, he'll be seen in the sinus clinic next week. They mentioned another surgery before but didn't want to rock the boat while he was doing so well (he has had 16 vomit free months). The big problem with vasculitis is that the correcting the damage caused from the disease can cause another flare. Knowing that doesn't tend to make for a good night's sleep.

May 6

 All good news today from Children's. Ben's eyes are perfect; they will continue to check them every six months. He had a sinus CT which showed a clogged ethmoid and maxillary sinus. But since Ben has had eight courses of antibiotics since the flu triggered this, and he is free of pain and fevers this might be as good as it gets. Surgery was offered, but we elected to just keep that on hold for now. We confirmed the treatment protocol of antibiotics at the first sign of any congestion (now with a different antibiotic to attempt to avoid resistance). The best news of all is that Ronna (our favorite ENT contact) will continue to see Ben until he is 21!

May 14

We enjoyed the Nephrology Transition Panel yesterday. We listened to a myriad of presenters from career counselors to transplant specialists. Then the kids and parents broke out into separate groups for question and answer periods.

Ben had an appointment with his nephrologist as well. He put Ben on Lovastatin because his LDL was still too high especially considering all the other risk factors he has for cardiovascular disease. That brings Ben up to seven daily prescriptions which is still half of what he took in the early days.

A funny thing that happened...the nephrology fellow asked Ben what he has been doing. Ben responded "lotsa school." She thought Ben said "law school." Her eyes were really big as she enjoyed the company of our genius...until we got the miscommunication straightened out. The attending and fellow were very entertaining. They joked about Ben using a pressure washer to clean his sinuses. The doc said when the water starts spurting out of Ben's tear ducts, he would know to turn the pressure down a bit. Maybe you had to be there...

We'll get lab results in a week or so. Hopefully his creatinine is holding at 1.8. It has crept up over the last year but that is supposedly due to Ben's increased muscle mass post puberty (not actual decline of the kidneys). I believe Ben is within a quarter inch of one of his life goals...being taller than his big sister.

June 1



We've been playing Bocce ball and learned that we all have the best time if Ben and his Grandpa Joe are on the same team (they can mourn together when they are behind and congratulate each other when they are ahead without driving the rest of us nuts).

Ben's kidney function appears to be holding its own. His blood work is "Ben-ish" (not normal but normal for him). His creatinine was 1.7; BUN 22. He was cleared to start his Lovastatin and will need a fasting blood draw soon to make sure it is working.

He has two weeks until summer vacation starts...and Racheal graduates from community college with a transfer degree. It doesn't feel like summer; we try to keep the furnace off after mid-April, but that isn't working this year. But the grass is growing like crazy and the slugs are out so the warm weather must be on the way.

July 14

Ben was pretty happy to finish his first year of community college with straight A's from his five classes. But then he took the SAT and isn't feeling as confident about admission at his college of choice. He was told that UW and Seattle U would be his best bet for the mechanical engineering he wants. Unfortunately, even though he expects to have his transfer degree, it looks like he will need an extra year to take the prerequisites required for that major. We are going to some meetings at UW this week to start the process of sorting it all out.

We are realizing that Ben probably won't have a chance to go to Yellowstone next August when he will likely be setting up housekeeping away from home so we decided he gets his graduation present this August...a boys only fly fishing trip to Slough Creek in the Northeast corner of Yellowstone...wolf and bear territory.

Amanda goes to camp this week. She had fun at her first tennis tournament last weekend. Racheal is busy working at Lind's Pharmacy specializing in their photo department. Crabbing opened last weekend so we are getting our fill of crab with Ben at the helm. Todd and Ben went fishing on the east side of the mountains with my brother and his friend. They came home with a plethora of stories.

August 6

Today was Ben's wisdom teeth extraction. They poked and dug around in both arms, four spots, before finally getting a good IV in. I don't know what the problem was since he shouldn't have been dehydrated and they are certainly experienced. They told us to expect an hour but then had him for an hour and a half so we were plenty nervous. According to the Very Nice surgeon things went fine. I think Ben got the point that if he wants to recover and enjoy his trip to Yellowstone, he better take it easy the next few days. So he is watching his action movies with his frozen peas and the infratonic.

We've been rehashing the idea of going to the Cleveland Clinic Center for Vasculitis for Ben to see WG specialist Dr. Langford. And we started the special needs trust process but aren't sure now is the time to afford that. We could actually commit to something if I could find work. I found 20 jobs to apply for this week which is surprising when the last two day's headlines were about major corporate lay-offs.

August 7

Ben is doing great. He was tying flies most of the day and took a couple naps. 🐟 He needed only minimal pain meds and says it only hurts when he talks.

There was a scheduling snafu that had to be straightened out today. Now his farewell visit with Dr. Emery is September 4 which is bad because it is the first day of school but at least Ben will be in the state! After that Ben will be with the adult rheumatologist at the Everett Clinic. If that doesn't work the plan is to go to the U of WA.

Since we are very happy with his primary care provider it makes the other transitions a bit less scary. His PCP agreed to manage most of the prescriptions following the specialists recommendations. It sure makes it easier to get hard copies and refills if it can all be done in one place.

August 11

Days like today make me wonder if I did the right thing by getting out of bed. Todd showed me how to use his new fax machine at work which is sort of funny because he despises office machinery. Apparently I found that so exhausting I had to come home and take a several hour nap.

Ben had mentioned that one of his extraction sites was tender. He saw a local dentist who declared a partial dry socket, removed some stitches, and filled the hole with clove flavored packing. He needs to go back in a couple days.

It is too hot and all our fans came up missing after Amanda's bedroom flooded when my tub leaked above it this winter. I finally broke down and bought a new fan even though I know the old fans are somewhere around here in a safe spot. I stuck my new sturdy, metal, fan in the window sill, and it promptly smashed onto the tile floor and jammed one of the blades through the wire shroud. Luckily we live near Ace. I think I'll just get a replacement real quick. But I buy the cheapest fan this time.

On the way home we stop at the coffee shop to buy a gift certificate. I didn't even get myself an iced mocha! When I tried to drive away, the car wouldn't start...cranking slow like it hadn't been charging. Amanda pushed me off to the side of the parking lot, and we were preparing to walk the mile home. A kind jumper-cable bearing man helped us get started again, and we got home with the fan, the gift certificate, and the car.

But when we plugged in the new fan, it didn't work!

I have four interviews this week; I'm praying this day was an isolated incident.

August 26

Happy Anniversary Mom and Dad! 🍷

The boys made it home from Yellowstone despite the fact that the keys were temporarily lost on the trail at dusk in bear country. It sounds like there were enough fish and fun times to make good memories. They even took some pictures for me!

Todd thinks it will be two more weeks before Ben's Scout is back on the road. Amanda has one more tennis tournament before she will be a sophomore. The photo machine at Lind's was broke down for two days so Racheal had an unexpected vacation.


I had three interviews yesterday and one today. I must look better on paper than in person. I am applying for jobs even when I know I'm not exactly qualified so for the most part I don't take it too hard and try to just be thankful for the interview experience.

September 9

Ben made his schedule changes today so he'll have American Government, Kayaking, Spanish, Interpersonal Communications, and Learning Into Action. I'm disappointed that he dropped Geology but he didn't need the elective. This has been the most expensive quarter yet for books...over \$500. He hates this "turning 18 now you're an adult" thing but he has made a couple of his own appointments and we are doing his mail order meds together for now.

I was offered a part time job with the Senior Center as Activity Coordinator for Time Together (adult respite). They agreed to wait for my answer until I hear back from the hospital where I interviewed for Assistant to Recruiter in the Human Resources department (full time with benefits).

September 10

 **I went from having no job to having three jobs! The Senior Center activity coordinator position will be Tuesdays and Fridays. Evening clerk at the community college will be Mondays through Thursdays. And I'll do some data entry for [Dinners in a Flash](#). No medical benefits but quite a lot of flexibility.**

October 2

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I knew it had been awhile since I posted but I didn't realize it had been THIS long. Ben's Scout was on the road for about three days when it started "ticking." Apparently, it had a blocked oil passage which meant stripping it back to the block and starting the rebuild over. Ben said he'll have even more power now since the cylinders were bored again. At least he'll have plenty to talk about when he does his presentation for his senior project.

Ben is gearing up for hunting season. He can do his online Interpersonal Communications work in advance. His Geology and American Government teacher's are familiar with the hunting routine.

Things appear stable on the WG front. We just have to be extra vigilant...never knowing if a bloody nose or a cold are "normal" or a disaster...we use a lot of Purell.

November 17

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Ben met with his new rheumatologist today. He said Ben looks GREAT! His blood work was Ben-ish which means good for Ben. The doctor also emphasized that doing the sinus rinse is critical. Ben used to have combined clinic appointments where he would see

rheumatology and nephrology the same day. Now he has to have separate appointments, but if he is not having any problems he can alternate between the two specialties.

Now it is time to register for winter classes. Ben is looking at Ethics, Physics, and Precalc 2.

December 15


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Ben is doing an internship at his uncle John's work this week. He has his classes lined up for winter in Oak Harbor: physics, pre-calc 2 and ethics. He plans to stay up there Monday through Thursday. We'll miss him, but poor Drover! He listens for the Scout to come in the driveway every day and loves to snuggle with Ben at night.

I'm enjoying my time off from the college. I even took a basket making class at the craft store!

December 22

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 **We have 13" of snow as of this morning and only went in the ditch one time so far. Ben wasn't able to finish his internship due to the weather so he'll have to finish that up winter quarter. His physics class was canceled so he needs to find a replacement for that.**

For all of you out there with sinus issues...Costco is selling a kit (Neilmed or Ocean Spray) that makes it easy to take care of things when you are away from home.

For those of you not familiar with Section 125...we are using a Flexible Spending Account the first time. We put in a certain amount of money every month then send in receipts for expenses like medical co-pays and the company reimburses us with our own pre-tax dollars. The biggest downfall, aside from the paper work, is if we overestimated our contribution, we lose whatever is left at the end of the year. I'm not sure if you can only sign up as a benefit through an employer or if it is something that can set up independently.

Ben will see nephrology Feb. 4; other than than achy joints and the usual ongoing WG related stuff, all is well for now.