

January 5

 Ben passed his driving test. So look out after Feb. 10 at 8:30am when he actually gets his license.  That Y chromosome driving style makes me nervous.

Dr. W called us today to say he spoke to his neurologist buddy who confirmed an autonomic neuropathy diagnosis for Ben. This does not mean that it is true and doesn't change his course of treatment. But it is nice to have a name/reason for the barfing, hot flashes, and tachycardia.

January 11

Ben saw Dr. Emery and Dr. Okamura (Daryl) yesterday. Based on their last conversation, he finalized his decision to stay off of the growth hormones. The decision was made to double his Prevacid dose. Ben has been experiencing more heartburn so it makes sense to me to give the dose morning and night. His Calcitriol dose was also adjusted. Calcitriol is a form of Vitamin D that is prescribed to patients with kidney or parathyroid dysfunction. It helps regulate calcium in the blood and utilize calcium in the diet.

Dr. Emery heard from Dr. Hoffman and the Cleveland Clinic. While Dr. H has never seen autonomic problems associated with WG, he will see Ben if Dr. E refers him. However, we are now in a situation like having an intermittent problem with your car. If you take it in and the mechanic can't hear the funny noise, there isn't much the mechanic can do. So we've decided to put Cleveland on the back burner. If/when the vomiting reoccurs, we'll pursue another opinion. Based on the orthostatic pressures and pulses, Dr. H suggested replacing the prednisone with Florinef steroids which help retain electrolyte and balance fluid shifting and out of the vessels and trying support hose. I'm sure just the suggestion of support hose will make Ben say he feels perfect.

It was a scary night though because Ben's blood pressure was over his safe parameters. Besides slowing killing his kidneys, that brings back the seizure fears. This morning his readings were back in his normal range. Whew. We do still keep emergency anti-seizure medication on hand. But we had let his Isradipine prescription lapse because he hadn't needed it in a couple years. Isradipine is a calcium channel blocker that relaxes the blood vessels so the heart doesn't have to pump as hard. It is fast acting and Ben only takes this as needed.

We got in and out of Seattle before the snow and freezing weather caused all the traffic jams and accidents so we ended the day feeling blessed!

January 16

It's official. I now have three teens. Ben has been able to attend school since winter break...when it isn't canceled because of the weather! For the most part can block out his nausea. He said if he tunes in to it, it is about a 4.

We are getting some of the paperwork in order to go to Cleveland even though we aren't making an appointment. If Ben's health takes a turn, we'll have one less hoop to jump.

When Ben is feeling better, I still try to post once a week to let you all know that. If I get negligent, don't hesitate to email me.

January 26

Todd took Ben to see cardiologist Dr. Salerno today. The GI doctor chose the doctor and set up the appointment, still trying to sort out the weird blood pressures and pulses and nausea and vomiting. Dr. Salerno believes that all this is from autonomic neuropathy not related to the WG and once it gets out of whack it can take years to sort itself out. He said that swimming is the best thing Ben can do because the water pressure helps the vascular system circulate. Unfortunately, I think the days have passed to get a prescription for a pool.

Dr. Salerno's recommendation was that Ben is seeing Adolescent Medicine again. This time to do a biofeedback program. He is also suspicious of Ben's thyroid function so that will be added to his labs next time. Todd said the doctor "was a really nice guy." That is what we have come to expect. We are so spoiled by Ben's medical team at Children's.

Ben saw his naturopath today also. Ben's overall health score (as monitored by German technology) made a big improvement. Dr. J prescribed a different homeopathic drop.

If you don't believe in vibrational medicine, at least rest assured that homeopathics are diluted to a level where the original "medicine" can no longer be detected, so at least it can't hurt to try. If you are interested in vibrational medicine, read on.

We've seen this naturopath off and on for 18 years (unfortunately more off than on because of the cost). He helped Todd with chronic fatigue. He could get Racheal through teething without antibiotics (a minor miracle). Almost 16 years ago, Dr. J stopped Ben's colic by determining that the wheat I was eating was causing Ben's stomach upset (Ben was nursing). I inadvertently tested the theory not realizing red licorice was wheat based. I ate wheat. Ben screamed. I stopped. He stopped. Simple really. If only I would have known five months earlier.

At his first visit in November, Dr. J gave Ben several homeopathics to try to force Ben's body to recognize and rectify what is going on especially in his appendix. He said it is as if his body stored all the bad vibes in his appendix because it isn't a vital organ and it is one that is easy for the body to wall off and forget about...until too much is going on in there and the body can't ignore it any longer. There may be long lingering effects from food poisoning in the past. One of the homeopathics treats *h. pylori*, a stomach bacteria which should have been killed with antibiotics but showed up with Dr. J's tests.

He believes, as does the acupuncturist, that one of Ben's triggers is fungus and mold which we can't get away from in this climate, but he can try to treat homeopathically. The acidophilus helps counteract any candida that is going on. Again right in line with the acupuncturist, Dr. J said Ben's body is reacting to the Prevacid rather than seeing it as a helpful agent for reflux. Same with one of the blood pressure meds. Besides the homeopathics, another treatment is where electronic information is recorded as a mirror image on a metallic strip like on a credit card. Ben wears this card to try to neutralize/harmonize his body's reaction. There is also an element of acupuncture to his treatment involving short, tack-like needles that stay in until they fall out.

It is interesting how alternative medicine practitioners, at least the ones we use, are willing to compliment Western medicine, but most allopathic physicians are reluctant to recognize alternative medicine as viable. There are exceptions. When we last saw the nephrologist, he looked up Ben's supplements in the Children's data base and found out asparagus capsules that Ben has taken are contraindicated for inflammatory kidney

disease. This doctor said he is all for alternative medicine except when the scientific evidence contradicts it.


February 2

After a month of feeling really good, Ben has been nauseated this last week. He has vomited once, but it is enough to worry that a bad spell is heading his way. His rheumatologist mentioned hitting him with a bolus of steroids at the first indication of a problem. But apparently she didn't write down a plan in Ben's chart, and she is on vacation for a week. Ben did see his primary doctor to get a baseline in case he declines. He offered hydration in the office, but Ben doesn't go for that since he is such a hard poke. I asked him for a plan. How do I know when he needs hydration, ER, someone to look at him besides me? He said to use my sixth sense. It isn't very much help because my intuition gets all messed up when Ben is so sick. I just want him fixed...now.

On the school front he is down to just three classes so I am officially homeschooling. I haven't done that in 12 years! He is taking Pre-Calc, Contemporary Problems, and English. I am reluctantly accepting that he will graduate with a Washington State diploma with 19 credits instead of the 29 required by our district. He still has to pass the writing assessment, the WASL, and do a senior project. The WASL is turning out to be a scheduling nightmare. There is no flexibility, but there is no flexibility with appointments that are made months in advance either. And his health is the priority.

We are counting down the hours until the DOL opens its doors on Ben's 16th birthday. I think its 192 hours and 10 minutes right now.

February 10

 Happy Birthday to Ben! We started out the day at the Department of Licensing, arriving before the doors opened. Ben was only somewhat horrified to be met by a giant bouquet of balloons and a giant reception of relatives. The problem was the DOL's computer system was down. We waited around a couple hours before heading home without his license because he had paintball buddies to meet in the afternoon. He isn't TOO disappointed since he managed to talk me into two parties, one tonight on his real birthday and one tomorrow with his friend. Somehow he always negotiates something extra.

February 13

 Ben is now a licensed driver!

Ben felt sick for two days after paintballing. He plays hard and his body rebels. During the game he has to be careful to stay hydrated or off we go to the ER. Afterwards I can expect him to complain that his joints are stiff and achy, especially his ankles. This time he felt like puking for two days. He felt better this morning and was able to go to school today. Luckily, he doesn't paintball real often.

February 21

Ben loves his freedom but constantly tells us his Scout is under powered. Todd just says that wasn't an accident, and Ben is welcome to trade for the '54 GM that has the worn out 454.

Ben is still nauseous after eating but vomiting is rare which is wonderful news from the

standpoint of his esophagus and teeth. He saw an East Indian Ayurvedic MD yesterday who is in the U.S. every four months at the Earth Sanctuary. Ayurvedic medicine is older than acupuncture. Pulses are read to determine which herbs and diet to prescribe. Both acupuncturists Ben has seen have read his pulse so that wasn't anything new to him.

Ben thinks it is "weirder" than acupuncture but was shocked when the practitioner just felt his pulse and said that he had a weak immune system, his body was having problems metabolizing his food, and he is carrying extra toxins. She asked if he was on any prescriptions and/or had any sinus trouble. Everything she said was right on. Ben is willing to take the herbs but the diet is another story. He thinks wheat and refined sugar make him feel better.

February 27

Distance education is a mixed bag.
It's like one of those nasty pit toilets in the middle of nowhere.
You are thrilled to see it when you need it, but it sure does stink.

March 5

Today Ben had a follow up appointment with the ENT nurse practitioner Ronna Smith. He doesn't have a fever or sinus pain but he has been coughing up nasty gunk the last few mornings and is feeling tired and flu-ish today. After she looked him all over, we were surprised to hear that she suspected a sinus infection.


Ronna said as we get older that it is common to have an infection in the sinuses without a fever plus he is still on steroids that might inhibit his body's ability to produce inflammation or fever. Since he is "a repeat offender" she wants to "catch it as early as humanly possible" to avoid that awful cycle he has gotten into before. She gave me permission to be the expert and she will prescribe meds over the phone.

His last CT scan shows his right maxillary sinus as totally blocked off probably from a combination WG damage on top of being extremely small to start with. They could go back in and do more turbinate reduction, rinse his sinuses out, and add a liquid antibiotic to the sinus rinse he does daily.

For now they ordered a double round of Zithromax antibiotics. Dr. Manning (the ENT who has done Ben's sinus surgeries) said it isn't proven but some doctors believe that giving a "Z pack" does something immunologically besides the antibiotic effect.

For now we'll keep the other treatments in the file while we wait and see if this works. More than likely Ben will need his sinuses professionally rinsed every year or so.

March 9

 If you have never had a teenager who has flares of illness, you have probably never experienced the repeated letting go that has to happen. Each time there is a crisis, we bond like super glue. As the Ben feels better, he acts like a regular teen ager, and I act like a regular mother. This cycle has a tendency to hurt both of our feelings because there is a certain pain in the process of pushing away to gain independence.

Most teenagers and parents go through this once. In our case it is at least a quarterly transition. I can't explain it. It isn't a rebellion, but a noticeable withdrawal and attitude difference. Today Ben was leaving for the night, and I put my cheek out for the

usual kiss. He winked at me and said that I was going to have to settle for that...it is time I was weaned off of kisses.

In the back of my mind I added "for now." I am thankful he is feeling as good as he is so helps to balance the sadness of letting go.

March 12

Ben isn't feeling well. He has a headache and his muscles ache. He has a slight fever along with hot flashes and chills. As usual we hope it is "just" the flu. Luckily, he sees his docs and will get a bunch of blood work done on Wednesday.

He decided to take Statistics at the community college. I expect that he will love all of those formulas. After he finishes out this semester, he will be a Running Start student and plans to take the rest of his high school classes as community college credits. We are blessed to have some fabulous teachers available to him. In fact, every teacher I have asked said they are willing to make it work for Ben. He will still have to pass the state high school requirements along with the WASL, writing assessment, and senior project.

March 14

Ben met with his Renal/Rheum team today. It was a good visit in that they were thrilled that the vomiting has calmed down and there is no obvious disease flare. It is always a cold splash of reality though.

Ben's ankles have some edema and his creatinine is rising, bad signs for kidney function. His kidneys are probably having a hard time keeping up with his growth. He's almost 5'9".

His blood pressure has been running on the high side so he is back on 5mg Enalapril. When your systolic pressure is high your heart has to push harder to pump the blood around, and that can damage the heart. So they are thinking about another echo cardiogram earlier than the yearly one.

They debated doing another lung function test and chest x-ray because of the bloody, mucousy stuff he coughed up last week but trusted his (and ENT's) judgment that it came from his sinuses. He'll see this team again in two months.

March 31

There isn't much to report which is a wonderful thing! Ben managed to take most of his meds while I was away (see Other News blog for details of the trip to DC). He confessed that while I was gone he did not take his blood pressure or do his sinus routine (which is the ONLY known thing besides avoiding stress that can help prevent future flares). I guess all that nagging I do really helps. His blood pressure looks a little better with that extra Enalapril and his creatinine level indicates that he is tolerating it. The nausea is nearly non-existent. Between hanging out with friends and school, he is busy and happy.

April 12

Todd and Ben have tried to go dirt bike riding during spring break for the past few years. This year there is so much snow where they usually go (their hunting area) that snowmobiles are still the off road vehicle of choice. So they stayed on the west side of the mountains and got in a couple days of riding before they got rained out. Ben is busy spending the night here and there before school resumes. He sets this incredible pace when he feels well. I'm not sure if it is because he never knows how long it will last or if that is just how he naturally is. It does my heart good to see him being a social butterfly, but I always worry he is over doing it.

April 19

You've heard me talk about these key players but now you can put a face to the name if you want. Ben sees most of these folks every few months....

Rheumatologist

Helen Emery (the captain of the team)

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=901959

Nephrologists

Jordan Symons (doctor who diagnosed Ben)

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=180695

Ikuyo Yamaguchi (Fellow at the time of Ben's diagnosis)

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=443820

Allison Eddy (did Ben's kidney biopsy and still sees him)

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=43752

Daryl Okamura (usual nephrologist these days)

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=915074

Otolaryngology

Scott Manning (has done Ben's sinus surgeries)

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=42457

Ronna Smith (wonderful, fabulous nurse practitioner)

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=292730

Gastroenterology

David Suskind

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=996280

Ophthalmologist

Avery Weiss (I don't think his picture has been updated this decade!)

http://www.seattlechildrens.org/our_services/find_physician/detail.aspx?id=15909

Search for other Children's doctors yourself....

http://www.seattlechildrens.org/our_services/find_physician/default.aspx

Ben is feeling well most of the time. He hasn't eaten much for three days because of nausea but it is hard to tell if it is due to the sinus infection/antibiotics or a random virus or ? He is attending school and being his humorous self.

April 24

Ben saw the eye doctor today who said everything is "groovy." Ben's eyes don't show any damage from the WG or from the prednisone. He continues to get them checked every six months just in case.

May 1

🙄 Ben seems to have his normal school work load with quite a bit of free time to socialize. Now that his bones are back to normal he is trying to get his skate legs back with a group at the park after class. We are in the midst of the typical adjustment period that happens when he is feeling better. Ben thinks I'm not nice to him because I don't let him have everything he wants. Typical teenager.

May 7

Ben saw Ronna Smith his ENT nurse practitioner today. She thinks he is looking great. There is still redness and swelling of one nasal turbinate, but she felt like he looked better overall (inside and out). She wants us to stick to the plan of contacting her with any sinus symptoms since it seems to be working best. She agrees the local "wait and see" approach just doesn't work with WG.

PS The nurse called us into the exam room before we finished our game of cribbage, but I was ahead!

May 11

Today is a good day! 😊



May 17

Ben saw his nephrologist and rheumatologist yesterday. We also met another family that is dealing with vasculitis. We met via the online parent support group and figured out our kids had appointments with the same doctors and the same time on the same day. We love these doctors, but no wonder things are always behind schedule!

We knew going in to this appointment that Ben's cholesterol was high. Prednisone will do it, but he also comes by bad genes on both sides of the family (one grandpa died of atherosclerosis at age 58). Once you add the other risk factors: vasculitis inflammation (cholesterol loves to build up in inflamed areas), high blood pressure (which can enlarge the heart), protein leakage from the kidneys, and chronic kidney disease, he is at high risk for developing cardiovascular disease.

Ben's ankles are a bit edemic and his blood pressure is running a little on the high side. The doctor is giving him two months to make any lifestyle changes regarding his lipid levels, and then they will add medication. Other than finding out "if it tastes good, spit it out," he is feeling great!

May 27

Ben convinced by dad to take him and a friend to Jameson Lake. He's been gone three nights and I haven't heard anything so that is good news. Ben will be surprised when he gets home. I finally bought myself an MP3 player. Now we won't drive each other nuts with our music and talking books. The problem is every one is yelling at me all the time or startling me.

Todd is busy tiling the kitchen, dining, and utility rooms. Labor to have it installed would have been an additional \$6 sq ft (not including any materials). I'm sure he is thinking it would have been worth it about now. It is looking great! Stop in and see if you get out this way. Plus I am still looking for homes for few sunflowers, basil, arugula, and lettuce starts.

June 5

Ben is STILL feeling fine. With the help of a friend, he is installing tweeters and woofers in his Scout. I asked him if he had any mid range "meower" speakers, but I guess they don't because he just looked at me funny.

The floor tile is installed so the stove, fridge, washer, and dryer are all back in place. That means we have to cook and wash again. Too bad. We are all counting down the days to the end of school. Rach is finished tomorrow. I am done Thursday morning. School was extended an extra week for Ben and Amanda because of our hard winter. Happy Birthday, Sandy!

June 18

Ben has a new book about fly fishing locations and is planning all sorts of trips for the summer. It is hard because the intermediate license makes it so he and his friends need to drive separately. Assuming he does not get a ticket, that restriction will be lifted in August. He has the fishing fever though because he got up early this morning and went fishing before going to school.

My transfer degree is done, and I am preparing to begin phase two. My first classes through WSU's distance program (all online) will be Family Stress and Coping and Sociology of Aging. After that I plan to take Juvenile Delinquency. The kids are SO excited about that!

June 29

Ben was thrilled to find out his classes don't start until September 17. That gives him time go to Yellowstone, fish the Elwha River, go dirt bike riding in Naches, hike around Lake Ozette, and take a road trip with his sister. He really makes the most of the time he feels well.

July 7

Ben has found out where the best fishing is in Yellowstone and what flies he needs to tie to catch the big ones. It is the first big trip for us in a tent and Ben is insisting that we camp in Grizzly country because that is where the best fishing is. While we travel from Sun Lakes State Park (WA), to Bannack State Park (MT), to the Grand Tetons, Yellowstone, and then Palouse Falls (WA), Amanda is hoping to get some nice pictures to enter in the fair as her 4-H project. Racheal is planning to help with the driving because she'll have more leg room and control of the radio.

July 11

 We are leaving our coastal 95 degree weather and heading east where they are expecting 105 degrees tomorrow. We are all pretty cranky...but we ARE going to have fun.

Ben had a good appointment today. His rheumatologist ran through the list of symptoms super fast because he feels great. We had the fastest appointment ever...30 minutes (compared to 3 hours sometimes).

His proteinuria has dropped thanks to the Enalapril/Cozaar combo. His blood pressure is great and steady. His creatinine is holding at 1.5 (good considering the damage his kidneys sustained but double "normal" levels).

Two months ago Ben added flax seed oil capsules to his fistful of meds and did his best to follow the dietician's fat reducing recommendations. I was amazed that his cholesterol level dropped 15% putting him at 206. His bad cholesterol is still high (LDL 140) and his good cholesterol is still low (HDL 29), but both are moving in the right direction. His triglyceride level needs to drop at least 50 points to reduce the risk of heart attack and stroke. His nephrologist suggested Cholestin (red yeast) which is the natural version of statin Mevacor.

Cholesterol Info: <http://www.americanheart.org/presenter.jhtml?identifier=4500>

Red Yeast Info: <http://www.medicinenet.com/script/main/art.asp?articlekey=14999>

As soon as we get back from our trip, he is coming off prednisone...for the first time since his diagnosis four years ago (Seafair weekend has a different meaning for our family). Getting rid of the prednisone is a relief and a scare at the same time. No one really knows if that little bit is doing something to keep the inflammation down. He just has to try it and see what happens. Getting off the prednisone will allow his bones to regenerate faster and hopefully allow his cholesterol to drop some more.

His bone scan came back in the low-normal range. It showed 9% improvement in overall bone density since a year ago, but the risk of fractures is still very real. Ben has started calling me over protective. I just follow doctor's orders more than he likes. Come to think of it, I follow most rules more than he likes!

July 24

 We made it!! Running on seven cylinders with a cracked head, blowing streams of black smoke alternating with streams of white smoke that included occasional puffs of black.

We made it despite our lack of air conditioning in record-setting triple digit heat in MT and WY. It was so hot that Yellowstone shut down fishing except between 5am and 1pm because the rivers are hot the fish are dying. The many of the creeks and rivers were pushing 80 degrees which made it the perfect temperature for us to cool off.

http://en.wikipedia.org/wiki/2007_Western_North_American_heat_wave

We'll never forget the long-cuts, the six hour thunder and lightening storm, and the chipmunk in the tipi at Bannack, MT. We enjoyed a self-guided tour of the preserved ghost town and a guided tour of the gold mill that included a ride on a 1931 flat bed pick up, so much so that we hope to be able to attend "Bannack Days" sometime. One of the best surprises of the trip was that a class on cooking with cast iron Dutch ovens was offered during our Bannack stay.

http://www.bannack.org/bannack_days.htm

I wish we could see the elk refuge in Jackson, WY, when the elk are there.

<http://www.fws.gov/nationalelkrefuge/>

At the Grand Tetons, we camped near Colton Bay on Jackson Lake and fished and swam every day. We enjoyed a ranger talk about the park and enjoyed the wild life (moose, bison, pronghorn).

<http://www.nps.gov/grte/>

This was our third time at Yellowstone; I still think it is absolutely awesome, even better in some ways this time because of my geology class. Things had shifted and water levels were down so some thermal areas were not as dramatic. Besides the thermal stuff, I love the rivers, waterfalls, sage brush smell, lodge pole pine, animals (big and small), and rocks. So many pictures to take and so little memory space! I love the Norris Basin, the girls love the Artist's Paint Pots; Ben loves the geyser basins near Old Faithful. Todd loves the huge bull elk. We were a little nervous about going to the Super Volcano visitor center but it wasn't nearly as scary as the Discover Super Volcano movie.

<http://dsc.discovery.com/convergence/supervolcano/supervolcano.html>

Blackfoot Indian Jack Gladstone blew us away with his songs and stories at a campfire presentation one night. During his performance Ben and I saw a shooting star. He has a song with some Navajo Code Talkers speaking in it. His work is an interesting mix of patriotism, ecology, and Indian legend. <http://www.hawkstone.com/>


Ben had expert advice on the best fishing areas so we stayed in the north east corner of the park. As I understand it, it is also the area where you are most likely to see grizzly and wolves. Despite the drought, Ben caught a few nice fish. It was a lot of fun to watch him having so much fun. Mostly we read and swatted bugs while the boys fished, sometimes at camp and sometimes at the river. Occasionally we swam (aka bathed) while they fished.

We ate a lot of ice-cream, learned a lot of trivia, and laughed a lot between the snarls and grumbles from being hot and tired and crowded. One night, Racheal mistook Todd for a moose!

Our last night out (11th night) we stayed with my sister's family. They live about 11 hours away so visits are infrequent, therefore, very special. Thank you to everyone who supported Multi-Media Madness by helping us to raise funds to make this 4-H photo

safari happen!

July 24 part 2

 Ben's blood work came back indicating that it should be ok to go off prednisone. For the first time in four years he will "just" be on maintenance meds (for blood pressure, sinuses, and GERD). Well, I guess that isn't true since he is also still on Amitriptyline for his assumed autonomic nausea. I expect that they will try to wean him off that if the prednisone elimination goes well. Funny that 10 prescriptions plus four OTC things seems minimal.

This is always a hard time for me because Ben got sick July 20, 2003, and July 28th is the anniversary of Ben's diagnosis. Hopefully, this year won't be so hard. A friend is going introduce me to live horse racing!

August 5

[Back to Full Blog](#)


Ben has felt well for nearly seven months. I hope we've found the answer for keeping his nausea/vomiting at bay and that is being super aggressive about treating his sinus problems (using "Rambobiotics" if anything looks remotely suspicious). The longest he's felt well in the last four years was nine months in a row. I try not to count the days as we approach that mark. But as an anxious realist I have to work hard not to.

Ben is spending as much time as possible trout and salmon fishing. He just came home from his trip to the Elwha River. Todd confessed that they slept in late and took naps in the afternoon. They did stay up for the evening bite but the fishing wasn't great. Sounds like cribbage wins were equally distributed.

Today Ben is helping Todd swap the engine in GM to get it ready to sell (fall out from our trip over Teton Pass where we almost had to push the van). If you know of anyone in the market for a custom 1955 first series, give them our number!

August 16

[Back to Full Blog](#)

 It didn't last long. It was only a few days that Ben was legal to haul friends around with him when we got the call. "Dad, bring the stretcher." Todd figured it was the welded axle that broke, but upon examining the situation he decided that Ben abused his u-joint. His little diesel doesn't have much power but does have a lot of torque. Ben didn't help his case for a bigger engine!

August 22

[Back to Full Blog](#)

Todd and Ben headed out today for a four night trip to Naches to ride motorcycles. If they are lucky, they will see some elk, too. It is a squeeze to get everything in the short-bed pickup compared to the luxury of the old van. But at least they shouldn't be stranded on the side of the highway!

Racheal and Amanda are doing a mini camping trip which leaves me the house to myself to get my classes under control. They left the dogs here with me so I'm not exactly by myself like I wish I was!

August 30

[Back to Full Blog](#)

 My Grama G is the best bread maker. I've been trying to learn to make my bread look

and taste like hers for 25 years. All of the kids have participated in the mixing, kneading, rising, and baking process. Ben decided to make some cinnamon bread from the dough Racheal had rising overnight in the fridge. He asked me all sorts of questions...where's the bread pan, how hot should the oven be...and then he grabs the tape measure. Something he has never seen me use when I make bread. He had to measure the width of the rolled out dough to make sure it was the right size for the pan!!!

September 10

[Back to Full Blog](#)

The other night Ben said, "I'm going to go to bed here in a minute." I said, "Here? You haven't slept here all summer." He insisted that he had been home way too much...the night before, a day the week before that, and another night a month ago. He is just finishing up a three night salmon fishing camping trip with his sister on the heels of a several night trout fishing trip with is friend on the Elwha River.

Just a week until his school starts. He is already trying to negotiate out of any chores at home.

September 25

Ben is in his second week of full time community college. He likes his teachers but claims some of the subject matter is boring. As usual he procrastinates until the last minute. Last night he was up until 1am reading and writing his essay for psychology. Then he said the teacher didn't ask for it!



I asked him if he wanted the lecture from me or from his dad about how we want him to get lots of rest in order to have his immune system functioning at its highest level so he will stay well. He said he plans to do his homework that way again because he had a good weekend. I think I should have had his dad give the lecture!

October 8

Ben just experienced his first sinus infection since April. This is wonderful considering the health (or lack of) his sinus cilia. He leaves for hunting in ten days. He has his new boots all broke in, and I'm told his gun is dead on.

We all got flu shots today even though I would have preferred to wait until after Christmas. Getting it this early means the effectiveness might be gone by flu season. But the shots are hard to come by later. Too bad they won't just sell us the loaded syringe so we could do it ourselves later. Todd (aka Mr. Scaredy Cat of Needles) would love that.

We are too close for comfort to the Medicaid cut off (Ben qualifies because of our family size/income, not his diagnosis). I am applying for jobs that look like they will provide secondary insurance for Ben and still give me time with Amanda. That pretty much means with the school district. So far I've had a couple interviews but no offers. Prayers are much appreciated!

October 18

Ben has been trying to reduce his cholesterol with dietary changes to avoid medication. I know he added 1300mg of Costco flaxseed oil twice a day, but I can't figure out what else he did to get these results. His overall level started somewhere around 230 and now he is down to 171! Unfortunately, his HDL dropped as well so more

fish and red wine!

Flu season is in full force. Amanda started it two weeks ago and still has no voice. Todd has feeling awful while he is trying to get ready to go hunting. Ben had a sinus infection that required back to back Z-packs. The day he finished those, he got the flu. Now he has to take two more Z-packs plus probiotics. He is dragging around and even skipped class yesterday.

October 24

[Back to Full Blog](#)

Today was my first day on the job. I am working part-time at the high school in three department: special ed, library, and the career center. I'm sure it will be nice to get off the emotional roller coaster that I was on for the last three months as I searched for work. So far I am still on the roller coaster trying to figure out the insurance piece. Even though I work part time, I am considered the kids' primary insurance provider because my birthday comes before Todd's! It is critical that Ben not have a lapse in insurance so everything has to be filled out and timed just so. The payroll lady told me a good thing...between Todd and I we will have double vision! [coverage she meant]

October 26

[Back to Full Blog](#)

I heard from the boys yesterday. Everyone (Todd, Ben, Joe, Ron, John) is having fun even though no one has shot an elk yet. There were some sightings but not by the people with the right tags. Ben assured me that he is working on his homework. It was good to hear his voice! So good that I didn't even yell at him for not taking his blood pressure machine and his pressurized sinus irrigation on the trip. He is supposed to do both things daily.

October 31

[Back to Full Blog](#)

The boys called yesterday. Ben didn't even say hello...just "are you pulling Drover's tail?" Tail time is Drover's favorite time of day. He will play fight as long as you are willing to grab his tail. I'm only good for five minutes or so. He usually thinks it is tail time when I think it is time to go to bed and read.

It sounds like the weather is warm and there aren't many elk in sight. Todd saw a beautiful 5x5. I asked if he took any pictures and he told me that he didn't but he had his scope on it for at least five minutes. I'm sure the main thing that kept him from shooting it was not wanting to give the game warden his new truck!

November 1

[Back to Full Blog](#)

When the girls and I were in DC this spring, our bus to the city went right by the Walter Reed Medical Center. So the idea was extra meaningful to me when someone suggested making out an extra Christmas card to:



A Recovering American Soldier
c/o Walter Reed Army Medical Center
6900 Georgia Avenue, NW
Washington, D.C. 20307-5001

November 5

[Back to Full Blog](#)

The boys are home. They were disappointed that there were so few elk in the area. I was happy to skip the butcher shop process that normally occurs in my kitchen after they return.

November 9

[Back to Full Blog](#)

It is time for Ben to register for his winter quarter classes. I made some suggestions that he wasn't thrilled about so we'll see what he does. He is looking forward to his LONG winter break. He has about a month off. He is tapering off the amitriptyline to see if he can live without it (or if it is preventing the nausea/vomiting). I am sad that I don't get to see him much. Sometimes we pass on the road when he is coming home from school and I am heading into work.

November 20

[Back to Full Blog](#)

😊 Last year Ben spent the night before Thanksgiving in the hospital. After sitting in a big ferry line we made it home, but he didn't feel much like eating. This year he has requested all his favorite things...pretzel jello, seafood chowder, salami rolls, Dutch Oven Rolls, apple pie...I am happy to make what he wants, but I'm afraid we will have left overs until Christmas because we aren't having our usual large gathering.

Ben is getting his eyes and ears, nose, and throat checked today. In January he sees his rheumatologist and nephrologist again. I don't think he has ANY medical appointments in December. A sign of improvement.

December 2

[Back to Full Blog](#)

Ben has been having bloody noses which could indicate a flare. In Ben's case (so far), bloody noses, vomiting, and urine issues are giant red flags. I noticed that it makes him much for faithful to his sinus regimen. He is already planning his month long winter break and will not be happy if this involves a calendar full of doctors visits. We are waiting for his ENT at Children's to tell us how to proceed.

I have a final for my "Family Stress and Coping" class and then I am taking time off from university courses. I would rather help proofread essays for Racheal and Ben and help Amanda with her high school classes for now. My Study Skills booklet is really coming in handy!

Please email me if you didn't receive a family Christmas letter and would like one.

Christmas Pictures 2007

[Back to Full Blog](#)



December 11

Ben had a local blood draw. His nurse had a difficult time for some reason. He was happy to show her the bruises on both arms a week later. The inflammation markers came back normal, but his BUN and creatinine were both higher than usual. So Rheumatology is happy, and they've passed the information to nephrology. We still aren't sure of the cause of the bloody noses because our house is humid enough. For now we'll go with the blood test results and assume all is well and remission continues.

Ben's poker table supplies arrived yesterday. He plans to build a masterpiece. Ask him about the deal he got on his poker chips!

December 21

We have not received a call from nephrology and will go with "no news is good news" (aka functional denial) for now. While Ben's creatinine and BUN are creeping up, it wasn't a gigantic leap like he experienced with his diagnosis. He sees his Renal/Rheum team on January 9.

At that appointment, we need to talk about Ben moving to adult care. Dr. Emery's top picks were at the U of WA and Everett. The UWMC charges a ton for parking and facilities fees and is farther away BUT it seems like a good idea to have all the most frequented teams in the same building (even though they probably communicate by phone and email).

The animals haven't started lining up two by two yet, but I keep watching for them. The rain has seemed incredible even to a native. We are making Christmas plans to use all of our Dutch Ovens. Please send recipes if you have any good ones!

December 25

 Merry Christmas!

We ended up having a wonderful day despite the transition of having Racheal divide her time between here and her boyfriend's family. For some reason even the non-dyslexics were thinking one thing and saying another. Like when we played dice and I rolled two ones, I hollered "a pair of twos." When we played Tripoley on Ben's new poker table, my dad laid his card down and said "red of hearts." But the funniest thing was when my mom was trying to remember the saying "you snooze, you lose." I could almost see her brain churning, and she was so happy when she thought she came up with it. She said "you sleep, you weep!"

Nephrology called and wants to run more blood work. They don't have the MPO results which is a white blood cell protein that indicates inflammation but also damages the cardiovascular system. And because of the edema Ben is noticing, they want to run some other tests before his appointment.

Interesting MPO article at:

<http://www.sciencedaily.com/releases/2007/07/070703172506.htm>