

## January 12

**Here is the blog!** Sorry for the advertising. I'm not sure I can stand this format but here goes...

I've promised Ben a joke per injection...some days he'll need two! Please pass them on. 😞 Ben told me to tell you that he doesn't consider anything inappropriate.

## January 13

**I learned something new today! I think I've been around the medical field too long. Today on this blogstream website I was surprised to learn a new definition for BM. It stands for 'book mark.'**

**If you go to the BM link, Blogstream will send you an email every time something new is added here. Maybe THAT is the feature that will convince us all that blogging is the way to go. 😊 There is also counter on the page so I'll have an idea of how many people actually read the updates.**

## January 18



**We had a great time sledding over the weekend. To celebrate Amanda's birthday we went over Snoqualmie and Blewitt Pass, spent the night in Leavenworth and came home over Steven's Pass. We had some award winning crashes. Todd sprained his neck but managed to take this picture of me.**

**Last night Ben noticed edema in his ankles. This morning he noticed it in his hands. According to his doctor's scale, he gained TWENTY POUNDS in the last month. Ben said that he didn't think it was that much because first weight was artificially low because he had been sick with the flu. Still it indicates he is packing around a substantial amount of water.**

**So today I had several conversations with different department nurses at Children's. Dr. Eddy said it would be reasonable to head to Emergency if we were nervous. We ARE nervous but we can wait until we hear back about today's blood draw.**

**Dr. W saw Ben at 5pm and took blood and urine samples. The results should be back by 8pm and he will let us know how they look.**

## January 19

Ben was very puffy when we woke up this morning. He had acupuncture and Julie said she didn't think our water was causing the edema problem but that the growth hormone was. She gave him an NAET treatment for it. Dr. W consulted with Dr. Emery. She wanted to see Ben in Seattle.

Somewhere the message of where to go got mixed up so it ended up that Ben was admitted to Emergency before I could get anyone to listen to me and call Dr. Emery. Talk about bureaucracy! When the ER resident finally called Dr. Emery Ben was unadmitted and we went to the clinic. I need to get a 'smart mom' letter like my sister has.

Dr. Emery did a thorough evaluation on Ben, looked at last night's blood work, and consulted with an endocrinologist (luckily Ben met him one time when he was staying at Children's so he is a patient of record).

Dr. Emery's conclusion is that the edema is caused by the growth hormones. Ben will stop them for one week and then try again. The edema should be gone and not return. Hopefully this along with acupuncture will allow him to continue with the growth hormones.

Amazingly we got all that done in a 6 hour round trip. When I got home, there was a message from the water filtration installer explaining that we had large amounts of sodium in our water when the filter was first installed. That couldn't have helped Ben's situation but it should be resolved now.

## January 20

Things were calm today. Hopefully they remain that way as we wait for the edema to resolve over the next week. I am glad that we've re-established contact with Dr. Kletter. So far we've had huge teams working on Ben and it's never hurt to have too many experts putting their heads together.

The sun finally came out so Ben was able to do his geometry project. He is still working on his Scout. The interior looks great. I told him he should just wash the moss off the outside and call it good.

## January 24

Ben reports that his edema is resolving. He will see Dr. W tomorrow to confirm this before re-starting the growth hormones.

We are pondering having him drop online geometry in favor of math at our community college. The teacher is great and I know he would like it so much better than online. But there is the price...

## January 25

Ben is going to resume his growth hormone injections tonight. We decided to go with a half dose for a week to see what his edema does. It is much better but not totally gone.

When we were heading to Children's last time, Ben made me laugh so hard I almost crashed. I promised him an X-box game if he was admitted. We were talking about it on the way down and he said, "I hope they impound me." He didn't know why I was laughing. When I explained, he said that it came from living in a junk yard!

## January 28

The way Ben's growth hormone is packed he has two full does per vial plus some extra. He uses a fancy injection pen for two days and then a regular syringe the third day (or else he has to do two shots with the fancy pen on the third day).

Last night was the regular syringe night, the first one since he resumed the injections. Ben woke me up to ask me how much he should take. It got confusing fast. I thought the vial was 10ml and when he dialed in 3.6 on his fancy injection pen it was giving him 3.6ml.

In the light of day I figured out the vial is 2ml with 10mg of medication suspended in it. Dialing in 3.6 on the fancy pen is actually giving him 3.6mg of the actual growth hormone but I didn't know how many ml it was. Having the right numbers to plug into the ratio really get the dose right. Maybe we can use this for the WASL?

His regular dose will be 72 diabetic units (.72ml) but this week he is doing half doses...which would be 36 diabetic units which is what we had been doing before. Turns out it was an underdose before!

Ben took his college placement test. They made him take English even though he only wanted to take math. Just making sure he could read, I guess. He placed in English 101! After missing 85% of two school years, it really validated all the work we did at home.

## January 31 ~ Edema

Ben's edema is back. He gained about 3 pounds in the last 5 days. This morning I started by calling Dr. W asking if he could consult with the endocrinologist. Dr W was swamped and he couldn't do it today. Dr. W's opinion was we gave it a good try but that we should give it up. I understand where he is coming from, however, I'm not inclined to give up that easily on something that is so important to Ben without the advice of a specialist on human growth hormones.


Since Rheumatology consulted with endocrinology on Jan. 19, I tried calling Dr. Kletter asking if he could see Ben this week. The first available appointment is in May. Next I called Dr. Emery (Rheumatology) and left a message. Since Rheumatology didn't prescribe the hormones, they aren't really the ones to figure out what to do. That would be nephrology since the hormones are prescribed as a result of renal insufficiency.

The nephrology nurse kept posted throughout the day about what was going on. Before the day was out the nephrology nurse called and said the endocrinologist said to continue with the half dose. Based on his experience he believes that the edema will resolve itself. Nephrology will prescribe a diuretic if Ben feels any discomfort or gains 2 pounds or we feel nervous.

Well, we do feel nervous since that horrific seizure happened when we was bloated up with edema when his kidney function was around 10%(too high for dialysis but really too low to function without it). The theory at that time was the water retention caused a

spike in blood pressure in the middle of the night which caused the seizure. These decisions aren't easy.

## February 3 ~ more edema

 Things aren't going as well as we had hoped with Ben's water retention. He lost a couple pounds over a couple days and then gained 2 pounds overnight. So Children's prescribed a diuretic. We'll talk over the plan with nephrology at an appointment on Monday. Otherwise Ben is in great spirits planning his paint ball birthday party for next weekend.

## February 6

Ben had appointment with Nephrology today. We do so much over the phone that I actually like going in and letting them see him for themselves.


Dr. Eddy has been in contact with the growth hormone manufacturer. Edema is an unusual side effect, about 1 in 1000 patients. No one knows why it happens. For some it resolves itself. Ben is going to continue the hormones as long as he is not uncomfortable and it isn't compromising his health.

To do this he is going to increase his hydrochlorothiazide (and trips to the bathroom since this is a diuretic). Since hydrochlorothiazide can be used to treat hypertension, Ben needs to cut back on one of his other blood pressure meds to keep his blood pressure from going too low.


It is a juggling act. The hydrochlorothiazide can make him dump potassium but one of the meds he is on can make it run high. The combination of blood pressure meds that he has been on seems to be the thing that brought his proteinuria down. We'll need to watch to see if it creeps back up. If he vomits or has diarrhea, I have to remember to hold his meds so he doesn't dehydrate.

Assuming increasing the diuretic gets the water off of him, we will raise the hormone dose in a couple steps to see if he can tolerate a full dose. All this so he can be taller than his sister?

## February 9

 Ben met with his college advisor today. They did their business and then traded hunting stories. Ben is very happy at the thought of being in a math class again. It's been 2 1/2 years of private tutoring and online work which make a real class sound like a piece of cake.

## February 10

 Happy Birthday to Ben...my Valentine baby! Ben the paintball party is underway. I told Ben I wanted to give all his friends clean socks as party favors after they get all gross running around in the woods.

## February 15

Ben's weight is back up as high as ever from water retention. His medical bracelet usually dangles around and it is tight on his wrist. The blood and protein in his urine are fine, his blood pressure is good, he feel great. BUT it is still scary because of the brain

swelling component. I spoke with the nephrology nurse this morning and Dr. Eddy authorized another increase in his diuretic. He'll be adding a dose at night so I wonder if he'll need to get up to pee.

The best thing was the moral support. The nurse said something like we want to keep working on this because we want Ben to be successful because we know how important this is to him. That was SO NICE especially because of the lack of support on this issue from his pediatrician.


Ben needs labs done next week to be sure he really is tolerating the diuretic okay. My feelings remain the same...as long as he wants to do the injections and tolerate the side effects AND it is not compromising his health...we will continue.

## February 19

 Ben can lose 2.5 pounds overnight but then it comes back. He is still about 10 pounds over where he started but seems to be hovering right around that same spot.

He is happy as can be. He and his friend, Max, set up airsoft bunkers and had a war. I am not as happy because the 'bullets' are not biodegradable. But it is worth the mess to see him smiling.

## February 21

 The girls informed me that they are going to believe the old wives tale about bad things happening in threes in hopes that our run of bad luck is finished. Over the weekend the stove element caught on fire when Racheal was home alone, the freezing weather caused our furnace to flood the furnace/storage room when it was home alone, then our upstairs shower leaked into the downstairs bathroom. Hopefully the girls are right.

## February 24

 We are supposed to be heading over the mountains to play in the snow. We are delayed in leaving because it snowed here last night! Hopefully the drive is ok.

Ben threw up yesterday but seems fine today. It is impossible, after 5 winters of puking, not to think "here we go again." But thankfully he feels and looks good this morning.

## February 27

I talked with the nephrology nurse today. She said Ben's sodium level is low because of the diuretic. He needs labs done in a week to see where it is at. He cannot safely go any lower. If he is dizzy or has diastolic pressure below 50 before the blood draw, we'll have to make a change immediately. He is staying at a half dose of the growth hormone for now. He is feeling fine and is still carrying a substantial amount of water but is maintaining his weight.

Ben tried out cross country skiing over the weekend. I was surprised that he was so cautious. He is usually such a dare devil. He acted like I was trying to murder him every time we went down a teensy hill. I LOVED it and can't wait to go back.

## March 3

**Ben had a blood draw this morning. I drove it to the hospital hoping to get the results before the weekend because I am worried about his sodium level going too low. He hasn't been feeling well. Lots of muscle aches and low energy. Hopefully it is the ordinary flu, not a reaction to his diuretic.**

**I am nearing the end of my PE classes. This is pretty much what I look like on the treadmill. It looks like Racheal and Ben will be in the same math lab next semester at the community college.**



## **March 6**

**Ben still feels miserable. He is sleeping a bunch and vomiting a little and now has a sore throat. He's barely eating but so far I've coerced him to drink enough to stay hydrated. The nephrology fellow on call said his blood work was normal for him. We had to hold his night blood pressure med because his pressures were 90/58.**

## **March 6**

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**A summary...Ben started growth hormones in January. He gained 10 pounds of fluid in a week. He went off the hormones for a week and resumed at half dose. He was edemic and gaining so the nephrologist had a look at him and prescribed a diuretic. The dose was increased three times. He is now at 50mg in the morning and 25mg at night and he has probably lost about half of the water weight. I can still see it in his hands, feet and face.**

**After increasing the diuretic Ben had a blood draw to check his electrolytes. His sodium level was low. About a week later (March 2), he had a slight fever, no energy, took long naps, vomited. We didn't know if it was low sodium, a flare or the flu. He had his blood rechecked Friday (March 3). We drove the blood to the hospital, it was marked STAT. We never heard from anyone with any results.**


**The next day he was feeling worse and his blood pressure went down to 90/50. We cut out his night dose of diuretic. When we called to confirm this with the nephrology fellow she reported that his sodium level was fine. His urine dipped clear of protein and blood. This is great but also unusual.**

**Sunday Ben developed a sore throat. This is actually sort of good news because it looks like he has a virus. But with Ben it always means a trip to check for strep. This morning he saw Dr. Buysee and LOVED her. She used to be a partner and we hope she comes back. She was concerned that his blood work indicated that he is dehydrated (news I should have had last Friday). Also that his creatinine is higher than it has been since fall of 2003. She called Children's while we waited. They had just reviewed the blood results and left a message on our home phone asking for weights and blood pressures and that Ben get another blood draw next week.**

**It was a long weekend. Ben has added coughing and gagging to his symptom list. He hasn't eaten much in several days. His happiest moment today was when my sister**

brought him his favorite sandwich from his favorite deli.

## March 8

 Ben grew 3/4" since December! There is no telling if it happened because his prednisone was reduced to every other day or if it is because his half dose of growth hormones. Either way he is thrilled.

Last night I thought I a nice hot bath would be relaxing. So I grabbed my nightgown off the hook and headed to the tub. When I got to the tub I realized I had actually grabbed a pink, fuzzy scarf. I like to sit in the tub while it fills up so I hopped in and added a bath fizzy. I ran the water until it went cold. Then I realized I never closed the drain! Maybe I need more than a hot bath?



## March 10

Ben is looking better but is still keeping us up at night. He even walked around for a couple hours today. His acupuncturist thinks his immune system was suppressed by the flu and that the mold in our windowsills is complicating his recovery. At her direction Todd sprayed a fifth of Everclear in our window sills to kill the mold. I was surprised because I've been cleaning them monthly and you couldn't see any mold unless you opened the window. Since we switched from wood to propane, we do get more condensation in the window sills. A trade off, I guess.

## March 13

Over the weekend Todd and built a bumper and trailer hitch for his Scout. And I think he watched 10 movies. Ben doesn't have school this week because of WASL testing. I'm glad he'll have this extra time to recover. He is able to spend most of his day up and around but still sounds terrible and tires easily. His acupuncturist said that mold is hindering his recovery but there isn't much we can do to get away from it in our climate. I debated about starting basil and leeks in the house but decided to go for it. Now I hope I didn't shock them to death by moving them outside without hardening them off.

## March 15

 Due to a serious sore throat and congestion I can't hear very well or speak very loud. Ben is having the same difficulties. However, he solved the problem. We plan to retire from the profit of his invention.



## March 19

**From the Pediatric WG list..."As parents as I am sure you are all aware it seems almost impossible to relax as soon as you do something else crops up."**

**Ben had a CT scan of his sinuses on Friday that showed moderate to severe blockage (due to his damaged sinuses inability to handle mucous from the flu). He showed virtually no symptoms (slight pain and mild fever). The same thing happened in December. He needed two rounds of antibiotics to get rid of his symptoms. In January Children's ordered a follow up CT scan and surgery was mentioned. Dr. Emery wanted him to see Dr. Manning (ENT) but the earliest they could see him was April 3 so here we are.**

**Prior to Friday's scan results his local pediatrician seemed convinced it was what he sees in every other kids who comes in this time of year...allergies to mold and pollen. If we can't get him to understand the disease process, I need to over ride Ben's choice and make him leave his favorite nurse.**

## March 20

**We went to Children's today so Ben could have labs done. Since the ANCA test is lab specific, and that is best marker of disease activity, it makes sense to head down there. His creatinine is back down to 1.2 (this is good). Everything indicates he is getting better from his virus. We won't know the ANCA results for 7-10 days, but it appears he has a mother-of-all sinus infection, not a disease flare. He is four days into antibiotics and feels worse. The rheumatology nurse said it could take several courses of antibiotics to get him better. Seems like a good time to meet our 'local' ENT. If he has any WG experience, he's our man.**

## March 22

**Ben met a new doctor today, Dr. Becker, an ENT. Ben has a penicillin allergy which makes treating his infections trickier. Dr. B prescribed a different antibiotic. It is a broader spectrum drug that covers more than what he was on the past five days. Dr. B looked up Ben's nose with a scope and said he could see scarring.**

**Dr. Becker has not met anyone with WG before but knows one of the consultants and is willing to call him. He seemed to take Ben's diagnosis seriously, so much so that he said he would never do surgery on him and would defer to Dr. Manning at Children's for anything more than a stubborn sinus infection.**

**Right now Ben's main symptoms are fatigue and fever. He isn't blowing any real nasty stuff. If he isn't feeling better in 10 days, he does another round of antibiotics. Hopefully this will be Ben's last cold/flu of the season. This is his third week out of school.**

## **March 26**

**Will I ever remember this stuff?**

**Maxillary (cheek sinuses)**

**Ethmoid (between the eyes, behind the nose)**

**Frontal sinuses (forehead)**

**Sphenoid sinuses (behind the ethmoid sinuses)**

**Sinus tissue damage (ciliary dyskinesias)**

**Small sinuses (hypoplastic sinus)**

## **March 27**

**Day two of vomiting. I wonder (again) if it is connected to his sinus issues. The sinuses behind Ben's eyes are sore and his head hurts making it difficult to sleep. You can imagine things are pretty sullen around here.**

**Ben saw Dr. W and his acupuncturist today. He goes back to acupuncture tomorrow. I drove Ben's blood to Coupeville for STAT processing. Dr. W is going to consult with Dr. Emery once he has the results.**

## **March 28**

**The lab results indicated that we could wait and see...just report how things were going to Dr. W every day. But after Ben vomited two more times yesterday he seemed weaker and his lips were dry so off we went to Children's ER at about 6pm. They gave him 2.5 liters of fluid. He fainted when the nurse wasn't looking but by some miracle I kept his head from hitting the floor from the other side of the bed. He got admitted to the main floor at 6:30am then I got to sleep for 2 hours. Todd will stay with Ben at the hospital tonight so I can go to the first day of spring quarter tomorrow.**

**Ben is under Dr. Emery's care. He is off the antibiotics and growth hormones for now. His blood pressure meds are being held. He is very puffy but is peeing and his creatinine down from 1.5 to 1.3. Following Ben's usual style no one is sure if the vomiting is caused by a flare, another virus, lack of adrenal function, sensitivity to antibiotic, clogged up sinuses...**

**The good news is I am the Champion of Champions at cribbage and gin rummy. Plus I won a facial (including cucumbers on my eyes) and a hand massage playing 21. I lost a couple times and will need to make Ben a foot bath and his favorite muffins.**

**Thanks for your continued prayers and support!**

## **March 29**

**Nothing has been resolved. Ben doesn't look as well as he did last night. He is lethargic,**

his cheeks are flushed and he has a tiny fever. I pinched him as requested for Grandma Cid and he didn't even flinch.

Todd went to Coupeville this morning to get the sinus CT to avoid another dose of radiation. Todd and I passed the marathon baton (the CT scan disk) and I came back to stay with Ben. By the time I got back to the hospital the ENT doc was involved in a 5 hour surgery so he isn't even going to look at the scan today. More than likely it will be when Ben has his appointment with Dr. Manning on April 3.

Ben was about to be discharged this evening when he had the dry heaves. The nurse called the doctors and they agreed to keep him here another night. The nausea drains his energy and prevents him from drinking 'enough.' Enough has been defined as 4oz per hour.

If Ben's fever doesn't climb and if he doesn't actually puke, I expect we'll be out of here before noon tomorrow.

Good news: Dr. Emery tested his Achilles tendons and agreed that it is growing pains. He is thrilled to have evidence of his inch of growth!

## March 30

Dr. Emery was just in and said we are going home. They gave Ben a different type of Zofran that is quick dissolving hoping that will keep the nausea at bay. Wishful thinking probably but worth a try. The other change is bumping his prednisone up to 10mg daily for a couple weeks. The thinking there is that his body could handle day to day adrenal production but it couldn't produce enough for the virus/sinus infection which lead to the puking/dehydration. I hope.

If you want to visit, look for Ben in the camp trailer in the yard. We don't want him in the house breathing dust and paint fumes from our bathroom mini-remodel.

## March 30

Ben attracted this skinny girl friend in his Git-r-done jammy bottoms.



## April 2

 Ben has been taking it easy (for Ben) since coming home. The day we came home we slept until 5pm, woke up for 2 hours and then went back to bed. It usually takes me about a week after a hospital stay to catch up on my rest and adrenaline. Springing forward doesn't help!

We are done with the major dust causing work in the house. My dad, bless his heart, helped me paint, vacuum and mop so Ben can be in the house now. I have the *BEST* friends and family.

So far Ben's fever hasn't returned. He still has dark circles under his eyes (I've read that can be from low kidney function or sinus problems), and he is more tired than normal. Thankfully the retchiness settled down.

## April 7

Todd and Ben saw Dr. Manning who said he wants to do sinus surgery if Ben still has pain in a month. Ben is to use the Rhinocort when he has symptoms, the Bactoban saline three times a day, Neti-pot once a day and as many courses of antibiotics as he needs to get the infection to go away.


Ben is feeling back to his old self. I asked to make his watch chime every hour to remind him to drink.

## April 11

Ben's sinuses are still sore but otherwise he is looking good. The weather has been motivating. He is outside all the time. I am worried his grades are suffering! He went back to school last week after being off for a month.

His sister is getting her wisdom teeth out in two days. I told Ben he needs to be her nurse for all the driving around she does for him!

## April 18

Drover accidentally jumped up and hit his head on Ben's cheekbone. It REALLY hurt Ben's sinuses reminding us that Ben is facing the possibility of another sinus surgery. We should know by next week. It is scary because there is a significant chance of a disease flare activated by the inflammation caused by surgery. We were talking about it this morning when Ben said, "If I have to be on the Cytosan again, I'll just have to lie around, play X-box, and be a potato bug." 

## April 27

Ben has his sinus surgery scheduled for May 26. It is normally an out patient surgery but since Ben is Ben, it will be an overnight deal.

The **BIG NEWS** of the day is...I received a birthday gift that will make it possible for us to attend the WG Symposium in Baltimore in July. We are still in shock. The next step is figuring out the particulars like exactly who will go and how many cases of Clif Bars we'll need.

## May 1

**Ben is hacking up nasty sinus yuck and it makes him want to puke. Plus his sinuses hurt and he has a small fever. Waiting for surgery on May 26 seems like forever. There is no chance of surgery being moved up unless Dr. Emery can force it. Ben will see Dr. Wagner this afternoon and has an appointment for Dr. Becker the ENT to look at him Thursday (if he is still miserable). I just don't want the puking thing to get entrenched, and I'm convinced some of the puking thing is sinus related.**

## May 4

**Ben is congested and throwing up but seems to be holding his own in the hydration department. Children's Rheumatology and Otolaryngology both agree with what is being done locally (500mg Levaquin for 14 days).**

**Between worrying about Ben and being excited about Baltimore I am having a hard time sleeping and studying. 🤓 If you want to check out what we'll be doing go to: [www.wgassociation.org](http://www.wgassociation.org) We will have two days to tour the DC area. Please let us know YOUR favorite must see attraction in Baltimore or Washington DC.**

**Ben is disappointed that the FBI tour is closed for renovations. There is a spy museum that might make up for it.**

## May 8, 2006

Hello from Seattle! After several people telling me how great Ben looked all weekend, Ben was admitted through ER yesterday afternoon. Dehydrated, nauseated, with sinusitis and fluid in several joints. Work is being done to push his sinus surgery date up, hopefully to the day after tomorrow. The Infectious Disease team came by. They are looking to see if they can find a better antibiotic. That will probably mean culturing what the ER doc gets during surgery for now he is being treated with two. The sore joints indicate a flare but his blood work is stable so no one has made the official call. We've seen Dr. Eddy and the Nephrology team and Dr. Stevens from Rheumatology. There was talk of sending him home on the weekly MTX injections.

Ben isn't eating much but knows how to special order what he wants. I got a coupon for a free pizza for testing out the wireless pilot program and he is looking forward to redeeming that on the way home.

## May 9

**Ben threw up yesterday and today. They tried Zofran and a few other anti-nausea drugs that haven't worked in the past. Now Ben is trying a motion sickness patch. They switched his IV antibiotics back to the pill form. Last night the antibiotic IV bag came unhooked and spilled all over Ben's bed and the floor so they weren't sure how much of the dose he got. Since he has been on antibiotics for over a week without helping, the Infections Disease people are wondering if there is some kind of fungus growing in Ben's sinuses.**

**Since it is 8pm and we are still here, I assume we are spending another night. Since we signed the consent and the anesthesiologist came, I assume the surgery is on. I was told that Ben is last on the surgery list and it is 90% sure it will happen. This time around there is a lack of information and/or conflicting information. I know there is discussion on the team level and the nurses tell us what they know as soon as they know it. Everyone has treated Ben (and me) with kindness and respect.**

**Thank you for the phone calls and gifts!**

## May 10

 Based on symptoms seen yesterday the doctor thinks Ben now has Telogen Effluvium. This is different from the Androgenetic Alopecia that Todd suffers from.

Surgery is on for 1pm today and Ben will be staying at least one more night. Doctors orders were to move around before surgery because of low blood pressures (100/30). After large doses of prednisone, Ben's joints are feeling better.

## May 12

We came home from Children's last night after four nights and a sinus surgery. Ben is totally hydrated...8lbs worth. His nose has to heal up before we know if it helps the nausea since it is draining and dripping now. He is taking 5mg of prednisone daily for now. The pathology report from the biopsies will determine whether he needs anything stronger. It could be that his joints were swollen from infection or as a side effect from the Levaquin. Infections Disease recommended that Ben take the antibiotic Moxifloxacin for 21 days. There was discussion about putting him back on a maintenance dose of Bactrim. We are keeping a close eye on blood pressures and tweaking those meds at home.

Dr. Stevens was SO thorough and understanding. It was a comfort to have Dr. Eddy on call even though Ben's kidneys appear stable (65% function, creatinine was 1.5). Children's is dedicated to making parents part of the team which is an enormous emotional boost.

Your support brightens our spirits so much! Coming home to a clean house, a stocked fridge and a meal in the crock pot was incredible. What topped it off for Ben was the pizza Lunchable but for me it was the beautiful flowers!

## May 15

Ben is throwing up and weights 2 lbs less than when he went to ER a week ago because of dehydration. We are measuring and his output is about three times his input so far today. The drainage from his sinus surgery is super gross and would make even a cast-iron-stomached person barf. Because of his renal impairment, I can't wait for obvious signs of dehydration like dizziness and a racing heart. I KNOW he is dehydrated. The question is can he keep something down to get rehydrated or do we need to head back to Children's. It is such a fine line.

## May 16

As of last night we are back at that expensive Seattle "hotel." Ben's orthostatic pressures sent him back to get rehydrated (after vomiting only 4 times). Besides the Rheumatologist, he had consults with ENT and GI today. Ben is scheduled for May 25 to swallow a monitor to check is acid reflux. The right side of Ben's nose/sinus is having more trouble healing. That is his problem side. Since we left Children's Thursday the cultures, biopsies and blood work all came back, and they looked great. That indicates that the sinus problems are all due to previous damage rather an active disease. Still a struggle but no immunosuppression is needed. Ben is convinced that the sinus drainage is causing the vomiting. It is reasonable to hope that once he heals up, everything will be fine.

My guess is we'll head home tomorrow afternoon. Ben said he didn't mind if I go to

my Marine Biology field trip to the Seattle Aquarium tomorrow. He has a pistol shoot at the gun club on Saturday and a paintball party arranged for Sunday. I guess it all boils down to optimism...and a sense of humor.

To save you Googling time...

Telogen Effluvium: hair loss due to stress (Ben)

Androgenetic Alopecia: baldness (Todd)

## May 17

Ben is back home.

## May 18

Ben is feeling pretty good today...a 5-7 on the retchiness scale (0 being perfect). I am making him take it easy. To him that means watching movies, not doing homework.

His right sinus and nostril are still putting out lots of SUPER nasty stuff. He is on strong antibiotics already. Many doctors put their heads together to try to discover the cause of his repeated nausea (ENT, GI, Rheumatology). Ben came home from the hospital with a scopolamine patch, a Zofran prescription that he agreed to try to make the doctors happy, and a plan for an esophageal pH monitoring test next week. See:

[http://www.medicinenet.com/esophageal\\_ph\\_monitoring/article.htm](http://www.medicinenet.com/esophageal_ph_monitoring/article.htm)

The room this time wasn't on the same floor as Tulley's Coffee so I survived on Clif Bars instead. We'll be keeping our fingers crossed that we won't be going back soon. 🙏

## May 21

The scopolamine patch and Zofran aren't helping. Ben is miserable, tired and nauseated with nasty drainage from his nose. I'm dumping barf buckets and making sure our overnight bag is ready for action.

## May 22

Ben was admitted to Children's through ER last night with the usual nausea plus a slight fever and blurry vision. The blurry vision might be a side effect of the scopolamine patch so that's gone.

Ben's attending doc is Rheumatologist Dr. Wallace. She said this 'not vomiting' is not good enough. She is going to do her best to get rid of the nausea before we go home. She has called in ENT, GI and Infectious Disease again. I asked if there was a possibility of getting pH monitoring test done while he is hooked up to the IV. That means skipping 2 morning doses of Prevacid then 24 hours of monitoring. They added IV Clindamycin and upped the sinus flushing to four times per day.

We are in a tiny room on the first floor. People are asking how to help...prayer, meals for here and at home, and a Tulley's Coffee gift card would be my requests. Ben won second place in the pistol shoot Saturday (beating his father) and is saving money for a revolver. Your thoughtfulness of keeping in touch and really caring when you ask how we are is what is most important.

## Later May 22

Ben said he still loved me but he would be very happy if I went to the parents' room

while he played X-Box in the teen area on the second floor. The rooms are right next to each other. He saw them as he was being wheeled to his room on his last visit. Very perceptive!

A team of three ENT's looked up his nose and down his throat with a camera and saw lots of nasty black stuff. They supported the idea of the pH testing because his vocal cords show evidence of reflux. However, it could be damage from vomiting. The fact that my dad has Barrett's esophagus is enough reason to check.

A different GI doctor came by and wants to call in Neurology to revisit the idea of cyclical vomiting and abdominal migraines since I am a migraine sufferer. I was surprised when the Endocrinologist stopped in. It sounded like she was going to have his blood tested in the evening and the morning to check is natural cortisol levels.

I don't ask many questions about 'the plan' because I get tired of conflicting stories. Doctors and nurses generally tell us what we need to know when we need to know it. Another life lesson in learning to 'be.'

## May 23

The Rheumatology social worker came today. It was a real treat to have a conversation with someone who has an inside track of understanding. Ben's social time wasn't as exciting as mine. He saw a nephrologist in the elevator.

A Neurology resident stopped in and examined Ben and then brought the attending back to do her exam (trials of being a patient in a teaching hospital). Ben's neurological exam is normal. The neurologist said they don't think Ben's vomiting cycle fits with the abdominal migraine theory. 🤔

The Neurologists said that some of the metabolic blood work came back in the abnormal range so that angle is being pursued. Lactate is one level that was mentioned. Ben has to fast for some more blood tests.

As far as we know the pH probe is still on the outpatient schedule for Thursday and it appears Ben won't be going home before that.

I had a flash back while Ben was cruising the channels and I saw Reading Rainbow. When Ben was born, Racheal was three. She wanted us to name Ben Levar!

## May 24

Phone calls and visitors are most welcome during this sort of stay where we are biding time...especially if you want to trade hunting stories. If you want to call, dial 206-987-2000 and ask for Ben by name. It really is ok if it isn't a good time. If it isn't, we'll let you know and we'll reconnect later.

Ben kicked me out early this morning, sending me off to school. I can usually tell how he is doing by looking at him, so I had to call him a lot to check in. Ben told me it is the beginning of the 'transition' where he needs to be responsible for his own care. He really was listening when I was talking with the social worker!

While I was away, the pH probe was inserted and his IV was relocated. He likes the forearm site best so he can do homework and work the computer mouse. It usually


takes some from the IV team to insert it there.

Ben is doing great with the tube down his throat. He still feels like puking but he isn't complaining. And he is faithfully logging all his activities including what he eats to compare to the data. The probe should be pulled out around 1pm. The drainage from his nose looks better (less infected), so the assumption is doubling up on the antibiotics was the right thing to do. If Ben tolerates his oral antibiotic tomorrow, it sounds like we will be going home.

His vomiting usually occurs in the fall and lasts through spring. Could it be wood smoke? Mold? Alder pollen? My current theory is that something triggers Ben's mucus production (like a speck of sheetrock dust). His WG damaged cilia can't handle it. This creates stagnant mucus and often a sinus infection. The sinus drainage or the antibiotics used to clear the infection, trigger his vomiting. Once the vomiting gets started, it won't stop even after the stimulus is long gone.

I'm hoping his discharge will include a referral to the Northwest Asthma and Allergy Clinic and prescriptions for Marinol and Claritin. I was REALLY hoping they would help us determine the correct Marinol dose while we were here but it isn't worth staying another night.


## May 25

 If you emailed me in the last 24 hours, please resend the message. Due to some quirk of technology I know I lost messages from Cid, Vivian and Cynthia B. This is the first time there has been internet access in patient rooms. The signal is low and spotty but better than nothing. Ben has taught me all about IM-ing..

The ENT guy and senior resident were in this morning. The ENT confirmed that besides irrigating his sinuses AT LEAST twice a day, Ben needs to do it after he rides dirt bikes, is out in pollen...is around any small particles. We've been told that the Water-Pik irrigation is not better than what he is doing and that it is more aggressive. Hopefully someone can answer that question in Baltimore. One side of Ben's nose is back to yellow drainage. Ben is already on the first and second line antibiotics so hopefully it is just irritation from the pH probe.

Ben is wiped out, taking lots of naps. Assuming we'll be home, I'm trying to convince him to lay low for the weekend. He is trying to arrange a paintball party.

## Later May 25

 Looks like tomorrow is freedom day. They switched all meds to oral and pulled Ben's IV this morning. The Moxi was irritating his vein. His veins were swollen and purple looking. His skin had a big red patch. He should only have three more doses of the Moxi that will overlap with the 14 day course of Clinda. Marinol has been started at 2.5mg twice a day.

The pH probe is coming out soon with results available after discharge. We looked at the monitor occasionally and never saw any numbers that indicated a problem. Blood work results are pending but the lactate level is back in normal range. Neurology came one more time to talk about migraines. Hypnosis and acupuncture are being recommended (again).

## May 26


**Happy Birthday Uncle Ron!**

**Last night an Endocrinologist stopped in and we talked about stress doses of steroids (when and how much) and about increasing Ben's growth hormones. She thought 1.5" of growth since January was a good rate and maybe we don't need to increase at all (hopefully not because of the edema problem). There is a blood test she can do to check his response to the hormones and that will tell us if the dose should go up.**

**The IV team nurse pulled blood from his IV for the last draw saving a poke (usually they won't do that). Then thanks to Teri telling me about 'add ons,' we saved Ben a poke and added that test on to the blood that the lab already had. When Ben was diagnosed, he talked me into a pay-per-poke-program that nearly broke me!**

**The senior resident was just in talking about the Marinol dose and discharge plans later today. He has to tolerate his oral antibiotics (he threw up yesterday within 30 minutes). We need to get training for the steroid injection. They are happy that his vision is normal, his sinus drainage is much better and his IV site returned to normal.**

## May 27

 **We are home. Ben has his twice daily pill, his three time a day pills and his four time a day pills. Just figuring out the schedule is keeping me busy. There is another pistol shoot tomorrow that Ben plans to attend (actually I think he plans to win). We are blessed to have our friends and family rallying around us.**

## May 30

**Ben is doing ok. The nausea is down to a 'dull roar,' a 5 on a scale of 1-10. That means he isn't carrying his bucket around but he also isn't feeling well. Besides seeing the acupuncturist, we have no choice but to settle for this for now and keep our fingers crossed that it will improve as his sinuses heal. Now Ben is trying to squeeze two months of school work into the remaining three weeks of classes. He can take incompletes but he doesn't want to have to be working all summer. The pistol shoot went as planned. He won second place which paid for his entry fee.**

## June 2

**This is the second day that Ben is miserable. He woke up yesterday feeling an 8-9 on the retchy scale. Was miserable all day and threw up once in the afternoon. Unfortunately, throwing up doesn't make him feel better. Still an 8-9 today. Every possibility that the doctors can think of that could be causing this has been tested and ruled out. It is incredibly frustrating, scary, and depressing.**

## June 3

**We met with Dr. W yesterday mostly so he could look up Ben's nose and tell us what he saw but also to document a baseline in case this vomiting spell goes on and on. Ben gets dark circles under his eyes and his pulse was racing, 132 bpm during his standing orthostatics in the office. Racing plus is his trend when he is miserable but also indicates dehydration.**

**Dr. W said Ben's nose is healing well and looks great but there was still an elevated**

**blood level that indicated it would be worth trying an allergy medication.**

**I brought in an emesis sample. Dr. W said most stomachs don't contain that volume of water. We brainstormed and came up with a treatment plan based on something a friend told me. Ben will eat Triscuits and Shredded Wheat to try to absorb that fluid. We will let you know if the Triscuit therapy helps.**

## **June 6**

**The good news today is that Ben's growth hormone factor indicates that he does not need to increase his growth hormone dose. We were hopeful this was the case since he cannot tolerate the higher dose without significant edema. He has grown about 2" since starting treatment five months ago. It seemed to us that what he is doing is working but now we have scientific evidence.**

**We are considering packing up and heading to Dr. W's office for hydration. I broke down and ordered Netflix and Ben wants to wait until the mail lady brings his movies. We've done local hydration thing before but still wound up at Children's the next day. This time Dr. W is offering to heplock the IV so he could come back to him the next day for more fluids or go to Children's without an extra poke.**

**What a childhood.**

## **June 8**

**Ben continues to be a good sport about feeling miserable. He is vomiting about a liter and a half a day which is making it really hard to keep him hydrated.**

**Ben's acupuncturist suggested that he see a chiropractor. He went today and learned about his Vagus nerve. I was looking that up online and found information from the Mayo Clinic about autonomic neuropathy that is often associated with diabetes but can be caused by autoimmune diseases. Hmmm...**

**Read more at: <http://www.mayoclinic.com/health/autonomic-neuropathy/DS00544/DSECTION=1>**

**Ben's acupuncturist and chiropractor are the type of practitioners that make you feel better by just having a conversation with them. We are very lucky to have them in our home town.**

## **June 9**

**Despite throwing up, Ben was up all day even talking about skim boarding. I am keeping my fingers crossed and keeping the appointments with the acupuncturist and chiropractor.**

**Last year, Ben showed a 'normal' but unusual amount of stomach fluid in his gastric emptying study. He wasn't diagnosed with gastroparesis but maybe he just can't handle that level of normal. There are medications that can help the stomach empty sooner but he tried one already for the nausea (Reglan). Maybe not long enough? Dr. W is recommending a clinic appointment with the gastrointestinal folks.**

Ben's resting heart rate was great 67bpm this morning and he felt minimally better. He hates doing orthostatics because it takes so long (10 minutes). But it will be helpful to see if there is a correlation between the nausea and racing heart. That would support the autonomic neuropathy theory leading to more clinic visits with the neurologist. We crossed them off the list last spring after Ben was tapered off the seizure meds.

## June 13

Ben overdid it by paintballing and spent Monday in bed. Today his ankles and knees hurt. After having several really lousy days, he was a tiny bit better today, a 7 most of the day. He did throw up but managed to get to the Department of Licensing and get his permit.

## June 19

Thank you to all of you who helped us celebrate this weekend. Racheal was finally recognized for her FOUR YEARS of perfect attendance. Ben and his friend did double duty at Racheal's graduation serving as valets and baristas.

Ben doesn't feel better. I am certain the only reason he is able to be up and around is the Marinol. He is still vomiting at least once a day, nothing sounds good to eat and he is having a hard time drinking enough.

He finished his skim board and tried it out yesterday. He has a hard time running. The WG has damaged his ankle and knee joints. Today he is limping around because one of his hips hurts. He'll see his chiropractor this afternoon.

The weekend wore him out. Today he got up late and then took a nap before noon. He has just a few more assignments to finish up to get credit for his freshman year. Then he can think about our trip to Baltimore.

He saw his Renal/Rheum team last week. The same old thing...test results indicate the WG is in remission and they don't know what is causing or how to help the nausea/vomiting. He is continuing on 5mg of prednisone daily and considering the suggestion that he take a few weeks off of the growth hormone to see if he feels better. His acupuncturist prescribed some digestive enzymes.

## June 26

I'm doing my best to get ahead in my summer classes before we leave for Baltimore. Lucky Ben! He finished his last math class today. He is looking forward to Pre-calc this winter.

Ben just grilled up a beautiful panini but now can't eat it. He has been throwing up most nights...as much as 1500ccs. It is so frustrating!

He is still up and around, napping a couple times a week at most. He saw the acupuncturist and chiropractor today. We rescheduled his ENT appointment because it conflicted with a friend's birthday party. We've been spoiled by the combined clinic appointments. In September, we have to go see Rheumatology on one day and Nephrology on another. Plus we are working on getting Ben into the GI clinic. It means lots of trips to Seattle but it is worth it to keep him as healthy as possible.

**Dr. W prescribed Reglan again. It is drug that Ben tried before but it has helped in autonomic neuropathy cases so we are trying it again. It increases the contractions of the stomach. It helps prevent nausea after surgery and chemo. Ben will try it for 10 days and see what happens.**

**PS Happy Birthday, Hon!**

## **July 2**

**Ben hasn't been up and around as much the last few days. He has thrown up in the middle of the day and taken quite a few naps. Before that his pattern was being able to function despite feeling bad, then throwing up after dinner, most nights, usually a tremendous amount (1.5l).**

**It is nearing time to pack our bags for Baltimore. We are not expecting to get advice about the nausea/vomiting issue but are looking forward to getting emotional support and learning about WG from the experts (those with WG) and the specialists.**

## **July 13**

**We left on July 6 for Baltimore via Chicago and returned this morning after unexpectedly spending the night in 'town' due to a missed connection in Dallas. All in all, the travel was fine. It was 99 degrees in Dallas but comfortable in the airport. I sweated anyway when we were racing for our connection. Todd made it on the Skylink (monorail thingy). Ben tried to keep the door open with his foot (it doesn't reopen like an elevator). Ben and I were left behind as the shuttle whisked off with Todd (who didn't know where to get off). I am sure it was due to all of Todd's wilderness survival skills that we found him.**

**The main reason I wanted to attend this symposium was so that Ben had the opportunity to meet other kids facing a lifetime of vasculitis. And I wanted to connect with some parents who share similar hopes and fears because of a child's vasculitis diagnosis. We met several wonderful families and heard many stories to freshen our perspectives.**

**We learned from many of the more than 30 experts in this rare field who came to share their knowledge and give us hope. Todd and Ben's favorite class was on preserving kidney function. Ben also liked the talk on vasculitis of the eye. I think it was the gory pictures. A few pediatric families were able to discuss difficult situations face to face in a small, impromptu setting. I was given the name of an autonomic neuropathy specialist at the Mayo Clinic.**

**We had to cancel our tour of the Capitol Building because Ben didn't feel well. He had spells of vomiting and resting during our week long stay at the Inner Harbor. But he also managed to spend time with his new found friends swimming at the Hyatt, dining at the Hard Rock Cafe, playing at the ESPN Zone and eating at the Cheesecake Factory! He saw the dolphins at the Baltimore Aquarium, ate Blue Crab at Mo's, and had Chinese take-out delivered (just like Jerry Seinfeld).**

**Did you know there is such a thing as a long block and a short block? We learned the hard way trying to save taxi fare. After we finally got the 16 blocks to Penn Station, we rode the MARC train to Union Station and spent about 5 hours seeing what we could see**

in DC. It was so hot and muggy that my shins were sweating. The highlights for Ben in DC were the International Spy Museum, Korean War Veteran's Memorial and the pillow stained with Lincoln's blood at Ford's Theater.

We are so thankful have had this opportunity. The symposium was an incredible experience. Seeing Baltimore and Washington DC was an added bonus.

## July 20

Another week has passed without significant change. Ben has tapered off his Marinol for the most part. He still feels retchy, and if he winds up on the couch he will start up again. He threw up last night and was super pale and miserable the entire evening. We've been trying to sort out the mess where our credit card was being automatically charged for every prescription even if we paid the co-pay was already paid. His growth hormone prescription has been reapproved for another six months. He hasn't seen any growth recently.

Ben bought another truck. It is street legal but was bought for the diesel engine. It is supposed to get much better mileage than the one that was in the Scout. I think this makes the fourth donor vehicle.

## July 27

Things are going well right now, aside from the discovery that Ben has been slacking on his daily duties (weight, blood pressure, pills, viactiv, nasal spray, neti-pot, recording things). It IS harder to remember when he feels better. But he won't feel better for long if he doesn't do it.

Ben had a virus that had him down for about three days. His fever was 102 on those 95 degree days. The odd thing is he hasn't vomited since. He is still nauseated, but I'm keeping my fingers crossed that he is over the hump and improving so he can enjoy the rest of the summer.

He had blood drawn yesterday because his UA blood and protein levels are elevated indicating that his kidneys aren't happy. We try not to freak out without just cause. We will wait and see the results first.

Today is the last day of driver's ed. He hopes there is enough summer left to go dirt biking at least once, and he wants to go to the coast to skim board and fly kites.

## August 2

Ben has felt quite well this last week. His retichness is down to a 4 (on a scale of 0-10 with 0 being perfect). The blood in his urine cleared back to a trace but the protein is still a problem so he needs to do a 24 hour collection.

## August 5

Ben continues to see his acupuncturist and chiropractor. We believe they are the ones that have him feeling better. Ben's nephrologist said the virus he had could have caused the proteinuria increase, and that we can wait a couple weeks before considering the 24 hour collection and/or a change in meds.

**Ben saw his Otolaryngologist last week who scheduled him for a T & A job! Ben is on the OR schedule to have his tonsils removed December 1. They have always been gigantic but are now prize worthy. The doctor think these giant tonsils could be a contributor to the vomiting cycle. I was Ben's age when I had my tonsils out. I remember it wasn't a great vacation.**

## **August 13**

**Ben is feeling good! He is trying to cram all his summer activities into the last few weeks of summer.**

## **August 14**

**Ben started feeling sick last night after a few short weeks of feeling much better. He looks awful. He saw his chiropractor today and will see the acupuncturist tomorrow. He restarted his Zofran and Marinol. Because of a scheduling conflict, the hospital changed Ben's tonsillectomy to November 17.**

**Check out the latest hunting story at by going Ben's page:**

**<http://www2.whidbey.net/backhome/psb/b1.htm>**

**Then click on the interview link.**

## **August 23**

**Ben has been feeling good (not perfect), then not good for a few days, and then okay again. He and Todd have been working on the Scout. They swapped the engine from gas to diesel. I heard something about converting from 2-wheel to 4-wheel drive. I am sketchy on the details because I left for Montana on the last day of the fair to visit my sister. Right now I am in Butte taking pictures of the old buildings.**



## **August 27**

**The Scout runs! Ben was waiting in the Scout, down by our mailbox, to welcome me home from my jaunt to MT. Next week the focus is body work. Hopefully Ben will feel better than he did last week. He is complaining that his summer is nearly over. I almost hate to say it but I am looking forward to a little rain to green up the grass.**

## **September 6**

**Ben has four more days of summer vacation. He has been feeling better for the most part. It's a good thing because our fridge went out and ruined \$35,000 worth of medication! Most of it was growth hormones but some was his medical marijuana. It is a major nuisance to get approval for the Marinol. The growth hormones are working but slowly. He grew a half inch over the summer.**

**Todd and Ben worked day and night on the Scout for two weeks and got all the major stuff done. Once it gets plates on it, Todd will drive it back and forth to work for awhile to straighten out any problems.**

**Ben will be taking most of his classes at WIA with pre-calc at community college and independent woodworking credit if he can fit it in. In some ways it will be a relief when he starts driving. But in other ways...there is a reason boy's insurance is higher than girls!**

## **September 13**

**Ben say his nephrologist today. She said she hasn't seen him look this good...ever. Last time she saw him was in May during that spell of hospital stays. She decided that leaving him on the 5mg of Prednisone and Prevacid was a good thing...no need to rock the boat at this point.**

**She also said that Ben should have had stitches for the gash in his hand. She was the second doctor to say so, but Ben still disagrees. I thought stitches would be cool. Apparently it is much more cool to flex it open and gross people out.**

**We are in the process of fine tuning Ben's 504 Plan with the school, so he will actually get his homework when he is absent.**

**The Scout is fully licensed and on the road!**

## **September 15**

**Ben brought this packet of papers in to show me, "Did you see this? This is great!" It was his homework sheets from his teachers that were delivered through the home/hospital instruction provision of his 504 plan. I had seen it when I created the form. You probably "had to be here" but it was pretty funny.**

**Ben is happy with most of his classes. He is trying to wiggle out of one. My research class that was linked to geology was canceled at the last minute. I found one online to fill the gap but...my learning style and online classes aren't a great combination...it is five credits instead of three...maybe I'm trying to wiggle out of my class, too?**

## **September 21**

**Ben is has weekly chiropractor treatments to keep his vagus nerve operating at its highest potential plus acupuncturist visits as needed to keep things in balance. He has had a few days where he felt sick. His joints ached when the rain came. But overall he is feeling well.**

**I am thankful that Ben's disease is in remission and especially relieved that his stomach isn't bothering him. He is a regular teen age guy. However, being a realist has me doing my homework like a mad woman. History has repeatedly proven that I need to keep that hospital bag packed.**

**Special note to Tia: Have a speedy recovery! Love, Aunt Pam**

## **September 26**

**Ben on and off the couch with what appears to be a virus: fever, chills, and lack of energy. I knew he got the speakers hooked up in his Scout today when I heard Back in Black blaring full blast outside my office window.**

## **September 30**

## September 2006 Blogstream

**Ben saw his rheumatologist this week. She ordered a bunch of tests on his major organs to be done at his next visit in November. These sorts of tests should be done once a year. Plus she wants to check him out to make sure his disease is inactive before he heads to his tonsillectomy.**

**The gastroenterologist was wonderful (Dr. Suskind). He asked us to make a video so he can really see how Ben looks when his pulse is racing, orthostatic blood pressures are weird and his hands shake. This stuff usually coincides with the nausea/vomiting. Dr. Suskind said he wanted a couple uninterrupted hours to look over Ben's thick file. Then he wants to see Ben in two weeks. He also told us it would be the neurologists to make the autoimmune autonomic neuropathy diagnosis. Whether or not Ben's symptoms are diagnosed officially, everyone agrees some sort of nerve damage is the culprit.**

**Tonight Ben went to see a figure-8 school bus race! He plans to go to a hockey game next weekend.**

## October 7

Ben went to Children's two days ago for hydration. His veins are so spidery that his potential IV sites are limited. Children's has an IV team that can almost always get him in one poke. It was a "quick" ER trip; he just got one liter. That made him feel substantially better (a 6 on the retchy scale). He has not vomited since. It was nice because they gave him the liter and then asked what he thought. Did he want more? Did he want to stay? It was also the first time we had been in the ER during regular business hours so the Child Life Specialist came to see him and gave him a stress ball. Yesterday he started to get a cold. Hopefully he can make it through without activating the vomiting cycle.

We met with his 504 team yesterday and passed the management to the director of the school. We went over the potential changes and I believe they will be accepted and implemented. Ben has the BEST school and staff. They are so kind and accommodating.

## October 9

Maybe this is not a cold but the flu. Ben has that bronchial barking cough and sweats and chills. His dad is worried he won't be better in time for deer hunting. 🙄

## October 12

You may remember Ben had a pH probe test done in May. Today we found out, it showed SEVERE reflux. The GI doctor said he has only seen a couple cases this bad. In 24 hours a normal person will have less than 50 episodes of reflux. Ben had 526.

The GI doc is going to consult with his colleagues and Dr. Emery to come up with a recommendation. He said if the nausea/vomiting was a child's only issue, with these test results, he would not hesitate to schedule him for surgery. But Ben has never been a simple case. The doctor scheduled a meeting for us with the surgeon and recommended going ahead with the tonsillectomy.

On the way home I was thinking about what how miserable Ben was when he was a baby. Maybe he has been refluxing since he was born. Thank God he has been on Prevacid the last three years, or he would likely be on his way to esophageal cancer.

As you can imagine we aren't happy that four months have passed with this information sitting in his file. It is frustrating that Children's care is as good as it gets, and this sort of mistake still happens. If you want to read more about the surgery, Google "Nissen fundoplication."

## October 13

More details here:

[http://www.umm.edu/patiented/articles/what\\_surgical\\_treatments\\_gastroesophageal\\_reflux\\_000085\\_10.htm](http://www.umm.edu/patiented/articles/what_surgical_treatments_gastroesophageal_reflux_000085_10.htm)

## October 19

Ben's fundoplication surgery consult date is set for the day before he gets his tonsils out (Nov.17, overnight stay). We'll go ahead with the consult, even if we are doubtful about the surgery. The next combined clinic visit will be busy. Ben needs to have a bunch of tests every year (pulmonary function, echocardiogram, CT scan). They are all scheduled

for the same day.

Ever heard of Ayurveda? Older than Chinese medicine, it works to restore balance and harmony, resulting in self-healing. (Sounds better than fundoplication!) Doctors come from India to the island every four months or so. We just missed their last visit at Earth Sanctuary, so I ordered a truckload of library books on the topic. Hopefully the books come after midterms.

School is going fine for me. I hate being gone when Ben isn't well, but I hate online courses even more. Right now I have a combination which seems to be the best compromise. Ben FINALLY has a tutor, Kim, a wonderful lady who brings his assignments to our home, helps clarify any rough spots, and brightens the day.

## October 21

After having flu symptoms for 15 days, Ben developed a low grade fever. Dr. W wanted to "wait and see" three days thinking maybe it was another virus on top of the first one. We set an appointment for Friday morning, then Ben woke up without a fever. By 11am the fever was back. They are always good about getting Ben in to see Dr. W the same day. Dr. W gave Ben a prescription of antibiotics (at my insistence because it would be lot simpler to fill that if needed then to go to the ER). If Ben still has the fever Monday, Dr. W wants to see some blood.

During the appointment had a Big Talk about Ben's mental health. Ben always hates that and responds, "If I feel stressed, I just kill something." Luckily, it is deer season. Dr. W says Ben was handed a "death card" three years ago, and he wonders if this nausea is Ben's body's way of dealing with it.

I certainly can't say for sure, but it doesn't fit the pattern and symptoms to me. Ben felt excellent from May 2005 to March 2006, then a series of sinus problems set off the nausea. If Ben acted stressed, maybe it could explain his documented severe reflux and odd orthostatic pulses and pressures. When the nurse took his stats yesterday, Ben's sitting pulse was 100 and systolic pressure was in the emergency treatment range. Ben swears, and his actions show, that he is as well adjusted as can be given the circumstances.

If his heart was racing because of stress, it was because his dad took his sister deer hunting while he was stuck in the doctor's office. Sometime Dr. W went from considering autoimmune autonomic neuropathy to stress as the cause of Ben's collection of symptoms. It is frustrating.

I had spoke with Dr. Manning's (Children's ENT) nurse before seeing Dr. W. She called back after the appointment, and said Dr. Manning wanted Ben to start antibiotics. So we did. Dr. M was said flu symptoms should not last longer than 10 days. It's not like an essay question where I can BS my way through. It is more like walking through a mine field. What seems like a simple decision can have dire consequences.

## October 21

I used Ebsco, a library data base, to search for peer reviewed journals about chronic sinisitus treatment and came up with surprising results--studies that link gastric reflux

and chronic sinusitis! I wish I had access to more medical journals! Please pass on any information that you might know.

## October 25



We have put so much energy into educating our children. For 13 years my job of choice was schooling our children in conjunction with the local parent partnered program. Since our oldest went to the traditional high school and had a good experience, we thought that was the route we would chose for Ben. The district had other ideas. We have spent countless hours over three years to get the Home/Hospital Instruction program in place through the parent partnered program. Despite missing an average of 67% of the three previous years, Ben maintained a 3.8 GPA. Until this quarter he was 4 credits ahead, ready for college math three years early. In the past Ben's primary doc has called him "unmotivated." It was almost funny because it was so far from the truth. This week the doc indicated we weren't doing all we could to get Ben back in class, and that Ben wasn't getting a decent education by missing so much school. I lost my sense of humor.

This was on top of the "death card" speech. In attempt to quell the line of thinking that Ben is creating his own illness by stressing out, we have covered all the bases ever mentioned plus more (psychiatrist, pain management and adolescent medicine at Children's, self-hypnosis, acupuncture and chiropractic treatment). I strongly believe in the mind/body connection, and remain open to all kinds of healing. And there is no doubt that living with an anvil over your head (the next flare) changes the way a person (and his family) thinks. But given an option, the last thing Ben would do is waste his remission. People who KNOW Ben, KNOW he is upbeat, not one to lay around and dwell. He has plans; he has a sense of humor. He also has a deep connection to his local nurse, so he is reluctant to leave the primary doc even though dealing with him can be so draining for me.

Today Dr. Emery spoke with the GI doc and the primary doc. I asked her if the primary doc told her his theory. She yes, but that she is not willing to entertain that idea until every organic cause has been ruled out. She looked Ben in the eyes and said it must be frustrating as hell to be sick like this for so long. She gets it!!! She is especially concerned that Ben has been on the couch so much lately. Normally, even when he is miserable, he still tries to get out and get some fresh air. Dr. Suskind suggested another gastric emptying study because things may have changed since the last one, and the results could have implications on the Nissen surgery being considered. That will be the same day as all of those other tests.

Hopefully, plenty of time will pass before we need to see the local doc, so I can work on forgiveness. Ben has told me how much he appreciates my advocating for him. My close relationship with Ben gives me the strength to continue to face the fire.

## October 30

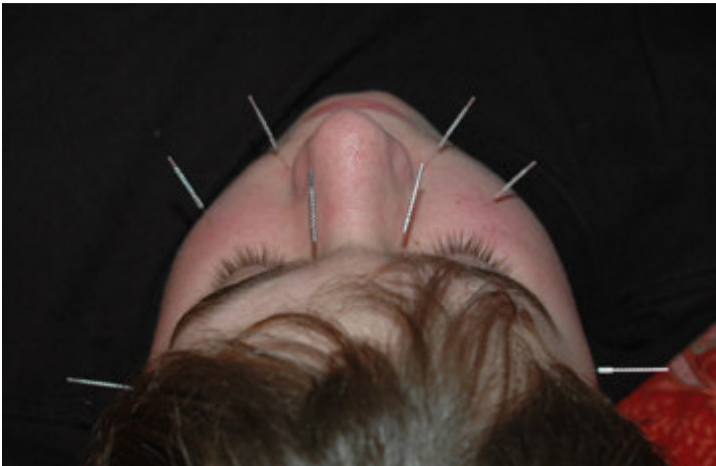


Todd and Ben have been hunting for elk in the Naches area. When I got home from class there was a message from Ben saying, "We got one." Just as I was saying "WHO got it?" out loud to myself, Todd's voice came on the line and said Ben got it. It is Ben's second elk. I am thrilled for Ben. But does this means they are coming home early???

## November 7

Ben is miserable. We doubt that the tonsillectomy (next week) will be the magic cure. We are leary about the fundoplication and will learn more next week. My biggest stress is Ben's local doctor believing that Ben is either faking it to get out of school or causing his own problems due to stress. The simple solution to switch doctors leaves Ben without his favorite nurse who can suck blood from a turnip and even posed with his elk head yesterday! I just can't take that one good thing away from Ben...yet. Besides that relationship, what gets us through is your prayers, visits, calls and emails, and even though they haven't been able to 'fix him,' the empathy from every specialist at Children's.

## November 9



## November 11

Because of clogging that showed on his sinus CT, Ben is on his fourth round of antibiotics. I believe it is connected to that low-grade fever (99.9) that came on a couple weeks after his flu the first of October. None of the other test results were immediately available. Dr. Emery said he was edemic and wants him to stop the growth hormone injection for a couple weeks. She wants to see him next month and again in January. The pediatric WG email group gave me a bunch of ideas to discuss with the doctor. We are pursuing an appointment at the Cleveland Clinic for Vasculitis.

He is expecting to lay low as he recovers from his tonsillectomy this coming Friday, so had some friends over to play cards tonight. He doesn't look or sound good but he was determined to have fun.

## November 12

I was told I did a Very Bad Thing and scheduled the upcoming surgery during our local late buck season! I worked around his two other out of town hunting trips. I hope to be forgiven soon.

## November 16

We met with Dr. Kim (surgeon) today about the possibility of Ben having the nissen fundoplication. He was great. This was just a research meeting because we not ready to make a decision, especially until we see if the tonsillectomy has any impact. At

**this point, the surgery is on hold indefinitely.**


**Ben was asked to be part of a GERD study. A doctor will come to the house twice to interview us. She seems to really care about kids and how GERD impacts their quality of life.**

**Ben's local doctor talked to Dr. Suskind (Children's GI doc) today about ordering a tilt table test to check out Ben's autonomic reactions to see if they are within normal bounds. Hopefully that can happen soon.**

**During our meeting, Dr. Kim mentioned uncoordinated motility as a possible cause for all Ben's nausea/vomiting trouble. And today Dr. Suskind told our local doc that he has some motility drugs he wants to try before considering surgery. We've never been fond of treating symptoms without knowing the underlying condition and are glad to have a few more ideas to try.**

**If all goes as planned, Ben will have his sinuses flushed also. He's never had that done before. Experience only seems to make the waiting worse for Todd and me. Imaginative people can create all kinds of worse case scenarios (of course, we don't verbalize these even to each other). Sometimes we can find a tiny private room and a cup of cocoa, but we can never relax until Ben's bleeding and breathing are under control.**

## November 17

 Ben is finished with surgery and snuggled into his favorite pillow and blanket. Dr. Manning was surprised that his tonsils were each the size of a golf ball and were very hard, evidence of past, severe tonsillitis. (He's rarely complained of a sore throat and never been treated for that!) The findings increase the doctor's hopefulness that Ben's nausea will be improved.

He is breathing very shallow and required some oxygen in recovery. He will continue to be monitored. He opened his eyes and said a few words but went right back to sleep.

## November 18

**Ben slept pretty good. The doctor's are letting Ben decide if he feels he can go home today or should stay another night. Supposedly it helps his throat feel better to keep it moist. But the wincing tells me swallowing really hurts even with a ton of pain meds. As we know, staying hydrated isn't Ben's strong point under the best circumstances, so I am not expecting to sleep in my own bed tonight.**

**He had declined my offer of a new X-Box game but has since rethought that and wants to get one on the way home. If anyone has Halo sitting around, I bet he would love to borrow it while he recovers.**

**The doctor said it will take at least a month to fully heal and not to expect to see any change in his nausea level prior to that.**

## November 18

**Ben decided we are staying at the hospital tonight. The 8oz he drank just isn't enough without an IV.**

## November 19

Thanks for all of the Halo offers; he's set now. Ben is in a lot of pain even with two Percocet every four hours. This surgery on a teen is MUCH harder on the body than on a child. Maybe like having wisdom teeth pulled compared to a loose tooth falling out on its own? He is clammy and I'm not sure if it is from the pain or ? We'll be watching his temperature tonight.

## November 20

Ben is pale, alternating between sweating and chills, still on full pain medication, reminding me 90 minutes prior to his next dose. If I would have been thinking, I would have asked Children's to hep-lock his IV so he could have gotten fluids locally. Today is supposed to be the worse day until the scabs fall off between day six and nine. I certainly don't remember that part!

## November 21

Turns out today was the worse day yet. If there isn't some improvement by morning, we'll made a decision about getting hydrated. His local doctor is concerned and mentioned steroids when I called about more pain pills. Besides the fact that Ben is at a bad age for this surgery, his tonsils were so huge that there was a LOT of cutting that needed to be done which means it hurts more and takes longer to heal. He can't wait to get his new tires on his Scout. In the meantime, he has a quarter of the living room converted to his personal space, and he has his self-appointed lap warmer (kitty).

## November 22

Happy pre-Thanksgiving from Children's. This morning Ben's blood pressure was 98/44 and he wanted to faint if he stood up. THEN he started vomiting. On the way to the hospital I was wondering if maybe I should have called the ambulance. It looked super painful, and I knew he didn't have ANY fluid to spare. His creatinine was at his baseline of 1.2; it is often 1.5 by the time he seeks hydration. But the vomit was bilious which isn't normal for him. After 2 liters of fluid in ER, we saw Dr. Emery. What a relief! Someone who knows the drill (that I'm not a munchausen mom and Ben isn't a hypochondriac). She wanted to get him good and hydrated and give him IV steroids. They also took an x-ray of his stomach to make sure nothing obvious is causing the bile. We hope to be home by noon tomorrow.

## November 23

Whether it was the IV steroids, the fluids or the combination, Ben is feeling better (pain scale of 1-10, 1 is best, throat = 4 with pain pill, stomach = 5). They are sending him home on a new drug suggested by the GI doc meant to help his nausea.

Yesterday in ER they used a new numbing thing on him that uses a tiny needle and pressure to numb the place where the IV needle will go. First the nurse dimmed the lights and used her flashlight to look all over his arms for good veins. After she choose one, she marked the path with a pen before using this "J" thing to numb the spot. I can't remember what it is called but it sounds like she shook a can of pop and opened it. She was not part of the IV team, but she was GREAT!

I might have already told you about the new thermometer that they run over his forehead and behind his ear? They are constantly improving things.

## November 26

 Ben's respite from pain and nausea didn't last long. His description is it feels like a chop stick stuck in his throat. He is spending a lot of time on the couch with his bucket but not vomiting frequently.

**"There is no prosthetic for an amputated soul."**

From Scent of a Woman

## November 30

Ben needs his own secretary for his medical stuff. Taking the most time at the moment are details regarding his visit to the Cleveland Center Clinic for Vasculitis. See clinic details at <http://www.clevelandclinic.org/arthritis/vasculitis/team.htm>

Today Ben's acupuncturist called and wanted him to see the naturopath. Ben last saw Dr. Jangaard for nausea in 2001. Dr. J got Ben right in, within minutes of me leaving a message at the office. Dr. J uses advanced German technology to pinpoint problems. He agrees that bombarding him with pills is not a good idea and prescribed homeopathics and acidophilus. Again, we have reason to hope.

## December 6

Ben saw Dr. Emery today. There was more discussion about autonomic neuropathy causing the nausea and vomiting. Dr. Emery's research could only find one case connected with WG. She will contact Cleveland and request that Ben see Dr. Langford or Dr. Hoffman (normally they don't see pediatric cases). We talked to the social worker about flight resources.

Ben had another bone growth x-ray of his hand to determine if it is still a good idea to continue with the growth hormones. If given at the wrong time, the hormones can actually backfire by forcing puberty and ending growth before genetic potential is reached. Ben's height was at the 25th percentile in January, and now he is at the 50th percentile. If his bone age and chronological age are close, he will not continue to take the hormones. It is hard to know what to wish for! It would be nice to be done with the shots and get rid of the bothersome edema. But Ben is not happy with the idea that he may be already at his adult height.

We need to be in Seattle 7 days this month (hard on people who don't like to leave their island). It is time and energy draining. I am thinking that this might be everyone's Christmas letter!

## December 13

 Ben went to school today! If would have been longer than one class, he wouldn't have been able to do it. But it was a boost to our spirits.

## December 19

Ben is improving, between a '6' and a '9' (10 is puking, 0 is perfect). We aren't sure if it is the naturopathic treatments, the amitriptoline, or if it is just time to feel better.

The amitriptoline's off label use has proved helpful for people with chronic pain, fibromyalgia, and peripheral neuropathy. It could be that it is decreasing the

**sensitivity of Ben's stomach nerves. Wouldn't it be wonderful if we had a solution after all of this time?**

**At a '6' he can go to his class and concentrate enough to do his work. He still feels awful at least half of every day, but he gets a little relief and that helps all of our mental health. For the most part, he is off the couch and outside...just in time for Christmas vacation!**

## **December 20**

**Ben saw Dr. Suskind in the GI clinic today. He is Very Nice. Dr. S liked Ben's AC/DC boxers and apologized for having us come in when he realized we had be back again tomorrow. This has been such a stubborn problem that I don't mind the back to back trips.**

**Dr. S ordered a tilt table test and bumped up the amitriptoline dose because he is thinking/hoping it has helped some and a little more might help more. If it is actually that med that is helping, that indicates autonomic neuropathy as would a positive tilt table test. Whatever it is, we are thrilled that Ben is able to resume much of his normal activity level.**

## **December 21**

**We had a productive first visit with the nurse practitioner from otolaryngology today. She was super. Ben passed his post-op exam with flying colors. She will schedule to see Ben quarterly in her sinus clinics and then can grab Dr. Manning for a consult as necessary. Dr. Manning gave her high recommendations so after meeting Ronna today we are comfortable with that plan. We had to do something different because last time we had an urgent need, the soonest Dr. Manning's schedulers could squeeze Ben into clinic was eleven weeks away. That just doesn't work for someone whose disease activity could kill them in that length of time.**

**Things are following a pattern. Ben feels fairly good from about 10am-3pm. He is worse in the morning, after he eats, and in the evenings. Remembering to take meds is always an indicator of feeling better along with dare devil stunts in/on motorized vehicles, and devising plans to make both sisters squeal.**

**The trips to Seattle aren't exactly relaxing for me as I am generally navigating without knowing my way around town and Ben suffers from road rage.**

## **December 30**

**Ben is holding his own...maybe doing a tiny bit better because he thinks he can do pre-calc at the community college. He is still very nauseated most mornings and evenings, but he has only vomited one time in the past month. He is still taking Marinol and Zofran plus the Amitriptyline in attempt to manage the nausea.**

**Ben is back to tying flies. He even got to go fishing at Lake Roosevelt over the winter break. I start sociology and ethics in a few days. It looks like a wild schedule for the next six weeks until Ben gets his license and can help with transportation.**