

# 2003 WG Journal

**Do not follow where the path may lead.  
Go instead where there is no path and leave a trail.**

Ralph Waldo Emerson

## August 17

We will be back at Children's for a two night stay starting August 27. Ben will receive his IV Cytoxan medication at that visit. Our first Nephrology / Rheumatology clinic visit will be Sept. 3.

## August 18

We will be going in on Wednesday morning to have Ben's permacath relocated. The place where he had stitches on his neck split allowing too much risk of infection for that line. We are hoping it will be an out-patient procedure so we can go fishing and camping as planned over the weekend.

## August 21

The replacement surgery was 4 hours late and then Ben had 'oozing' from his jugular which translated to an overnight stay last night. He finished dialysis at 1am and shared a room with 3 other kids and their parents so it was a short night.

## August 23

Ben's heart rate and blood pressure were high after dialysis yesterday but the nurse expected them to come back in line once his electrolytes and tissues adjusted. Eight hours later they remained high. The nephrologist 'held my hand' by phone and walked me through what to do next with the fast acting blood pressure medication. I wound up having Ben sleep in his bp cuff and setting my alarm so I could check him during the night. Things looked better around 1am.

## August 25

Same blood pressure problem today. The nephrology team is getting together to work out a new plan. The old permacath site is healing nicely.

## August 27

Ben had his second IV Cytoxan, Mesna, Zofran and 24 hour bladder flushing regimen. The actual drip only lasts about 30 minutes. Besides the discomfort of the catheter, the main thing Ben noticed this time was getting all hot and sweaty as the Cytoxan dripped in.

## August 28

NEWS! Ben's creatinine level has stayed relatively stable after three days without dialysis. Ben will have the weekend free of dialysis making seven days on his own. Blood will be drawn on Sept. 2 to check the levels. If the creatinine remains around 2.3, dialysis will be on hold and the permacath would be removed in a week or two. If he stabilizes at that level, he would expect dialysis in the future because the functioning portion of his kidney would be overworked.

## August 31

Ben is requiring more frequent blood pressure medicine. This could indicate that his kidneys are improving. This evening we discovered what looks like an infection on the exit site of Ben's catheter. We are taking him in to Children's have it cultured in the morning. His temperature is normal so it appears to be a surface infection. Ben gained more weight than we would have liked over the last 48 hours which is an indication that his kidneys cannot handle the volume of water he has been targeting. We hope tomorrow we will get a better picture of how all of these puzzle pieces fit together. Rather than 'one day at a time,' we are living one moment at a time.

## **Not all who wander are lost.**

J.R.R. Tolkien

### September 1

Ben's blood levels are allowing guarded optimism. The infection cultures are culturing. We are making our list of questions for the clinic visit on Sept. 3.

### September 3

It's official! Ben's function is improving so there will be NO MORE DIALYSIS (for the foreseeable future). The permacath is going to be removed as soon as surgery fits Ben into the schedule. Sounds like within the next two weeks. Being free from dialysis gives Ben three more days a week to do the important things: fish, target practice, plan hunting trips...go to algebra, English, computer classes and guitar lessons. Long acting blood pressure medication has been added to the regimen. Ben will keep with the renal diet but has more flexibility with fluid consumption. We are being told to expect six months of IV Cytoxan and then possibly oral Methotrexate for immune suppression. Steroid doses are still high but gradually tapering.

### September 7

Even though Ben is still edemic, his weight has stabilized. He feels well enough to be on the internet looking at dirt bikes. Sept. 9 I'll take him to have the heparin in his line flushed and his blood levels checked.

### September 8

That date for permacath removal is September 16. We can hardly wait to go swimming!

### September 9

Ben went in for a blood draw through the catheter today and found it was clotted off. They had to do three pokes in the arm because dialysis has made his veins tough. His potassium level is a concern, his creatinine was up, and his blood pressure medication was doubled. A frustrating day and not what we wanted to hear.

### Details of September 10

911 was called about 7:15am because Ben was having a seizure. While I was on the phone with 911 he totally stopped breathing and when he started back up, he aspirated some vomit. The EMT's beat Todd home. Todd works about 12 minutes away so it was good response time. They had an IV started before the ambulance left the house and got permission to airlift. They intubated Ben in the ambulance. There was a nerve wracking delay with the helicopter from Seattle so Airlift Northwest was called in from Arlington. Ben was airlifted from Nichols Brothers about 9:05am. We were told they planned to take him to Harborview and then ambulance him to Children's. The reason is...get this...the Sand Point neighbors get cranky when the helicopter lands in their neighborhood. As soon as the ambulance left, I headed to Children's praying that they would see the need to land there. Todd waited with Ben in the ambulance and transfer to the helicopter. At that point Ben was on his own. There isn't room for parents in the helicopter (we knew this from Racheal's ride nine years before). It turned out that they couldn't get Ben stable on the flight so they did land directly at Children's. I was told that one of his blood pressure readings was 190/143.

After arriving he was heavily sedated and intubated. I arrived at 9:30am. A doctor was on her way home but stopped to give me a run down on Ben's condition. Then Ben's nephrologist talked with me and took some information back to the team that was working on Ben. Todd arrived at 10:30am. We were finally allowed a quick glimpse of him about 10:45am. By that time he had been given a CT scan and a Foley catheter and an arterial blood pressure IV. As soon as we stepped out they went back to work trying to find the cause of the seizure with a spinal tap. They also re-intubated him and told me that he had his retainer in but they left it! They took him for an MRI, MRV, and MRA looking for clots and brain trauma. More teams than ever converged to look

for the source of the seizing: infectious disease, surgery, nephrology, neurology, imaging, rheumatology...I'm sure I'm missing some. It is so draining to tell the details over and over. Even harder because we are telling them to people we've come to know over the past six weeks. Some of the people we just saw yesterday afternoon when Ben was doing fine.

It was a LONG NIGHT. Sometime during that long night they reduced the sedatives and started trying to get him to breath over the ventilator. They reduced the ventilator to six breaths a minute. He would only breath if we asked him to. His pressures were too low and we would have to wake him up. All of that was very scary. Since he wouldn't breath on his own, they changed the plan and left him on the ventilator over night. Finally about 5am he was breathing on his own. Very shallow but it was progress.

Ben is in the Pediatric Intensive Care Unit on the 4th floor. If you want to call and leave a message at the desk, that would be okay, but we need to focus our energy on Ben and cannot handle calls at this time. We will do our best to keep you informed here on the web site.

### September 11

They are doing the shotgun approach of treatment (a method I am familiar with from raising sheep). The consentience is that the seizures were caused by a rise in blood pressure associated with his damaged kidneys...unless it was the seizing that caused the blood pressure to rise (the old chicken or egg problem). Based on MRI results the diagnosis is RPL caused by hyper tension. They will most likely send us home with blood pressure medication and seizure control medication. Ben had a chest x ray to check on his aspiration pneumonia, an EEG, and his Foley removed. The IV on his right hand was pulled and his Permacath is being used as IV access. He is awake but very, very groggy and extremely weak and unstable. They pushed a lot of fluid into him so he has so much fluid accumulated his eyes only open half way.

Ben woke up looking for the things he saw the last two days but they are gone. What a relief! He played cribbage with Todd. They moved us to 'the floor' at 7 pm. Ben's heart rate continues to race but it may be from being 'dry' after the diuretic given a few days ago so he is being encouraged to drink. More experimenting needs to happen to regulate his blood pressure. They are giving him fast acting IV meds until they find the right mix of longer acting meds. Ben has the most current Cycle Trader and has been shopping for his dirt bike. This is the first day we are able to relax enough to take a full breath.

### September 13

We are still in the Pediatric Intensive Care Unit. Ben's pneumonia is improving. The teams have grand rounds where they share information and brainstorm every morning and they invite us out to listen. They pulled up his morning chest x-ray on the computer for us to see. He received a PICC line today (peripherally inserted central catheter...more permanent IV access). He had his permacath removed. Finally! They are attempting to rule out every possibility of potential infection. This would all be good but Ben is hallucinating for the second day and his motor skills are lousy. They increased his Dilantin. We are beyond exhausted but it is more stressful to leave than it is to stay at the hospital. Only one parent is allowed to sleep at the bedside but even sleeping in the van feels too far away.

### September 12

Ben seemed stronger and more alert as the day passed but not yet ready for visitors. Progress is in tiny increments. Overnight Ben's oxygen saturation dropped below 88 so they started 1.5l oxygen. He has pneumonia from aspirating before he was intubated. Today he received a diuretic which helped get rid of some fluid that accumulated from the IV drips. They gave albumin along with it. His left hand developed cellulitis at an IV site. He has thrush from all of the antibiotics. Based on the change in mental status from yesterday they tried three times for another MRI. They gave MORE sedatives which I think are compounding the problem and delaying his recovery. I thought Wednesday was the longest day of my life but today was worse.

### September 14

I know it has been hard on everyone to be out of direct touch during our PICU stay. It is a gift to us when you allow us to give Ben our undivided attention. Things are so incredibly stressful this time around, more so than his original diagnosis. On top of that none of us want to relive that morning or the last few days.

### September 15

He had a CT scan of his sinuses and lungs. He went for a walk and pushed Todd in the wheelchair. He is in room A104. Ben had one dose of an IV antibiotic for the cellulitis in his hand. He is doing a 24 hour urine collection. Today he saw a magician and a therapy dog. His hand is terribly sore. Some calcium may have been put through the IV that irritated the tissue. It is one of many 'watch and see what happens.' His short term memory has not kicked in. Ben's heart rate and blood pressure are still high so he's pretty much confined to bed again. I got very frustrated with nurses that were taking and retaking his pressures ten times trying to get a lower reading rather than give him his IV med. It was meaning that his pressures were up longer than they needed to be and the chart reflected that his pressures were under control. Thanks to Todd, a nephrology fellow came to visit me and helped sort it out. Todd went home tonight planning to work in the morning.

### September 16

Ben's heart rate and blood pressure are still very high (day time: 157/105, night time: 125/75, heart rate 145). Todd only worked about 3 hours and came back to the hospital to help us deal with the latest news. The results came back from the CT scan. The sinus CT showed a deep infection. There are new spots on his lungs that could be scar tissue from his original Wegener's flare, a new Wegener's flare or a fungal infection from being immunosuppressed. It is impossible to guess and the treatments are vastly different. A lung biopsy is supposed to take place tomorrow. We are told it will be an open lung biopsy that will require several days back in PICU with a chest tube. Best case scenario would be a week before Ben would be back to this stage. The news was hard to take since it was so unexpected and just piled on to what we were already dealing with.

### September 17

Interactive radiology said they could do a guided needle biopsy instead of the other that would require a chest tube for sure. This way there is about a 15% chance of ending up in ICU because of a collapsed lung or air in the pleura (sp). His blood pressure is still not stable but they are starting to talk about a new med. It can impact his kidneys so they have been reluctant to use it. We are all so thankful that Ben sailed through the needle biopsy. He was gone a little over 3 hours. We got pretty antsy the last hour. Now we wait for the results. We don't even know what to hope for. Today nephrology social worker came to visit and the Child Life specialist brought a journal. Clowns came just as Ben was taking pills and they sang a song to help him swallow. It was cute. His roommate went home and gave him a beta fish. He was playing with Lego's today and laughing like crazy at the movie Anger Management last night.

### September 18

It was a quiet day today. His night time pressures were 90's/50's. No biopsy results came in. We were able to leave the room a few times with Ben in a wheelchair. He used his gift certificate at the gift shop. The ace-inhibitor seems to be helping his blood pressure. He made it through 24 hours without the Hydralazine IV. The nurse actually had it drawn up once but his pressures went down on their own after he had gotten all comfy in the bed, turned on John Wayne and got ready to be hooked up to the IV. They did another chest x-ray. We thought the chest tube danger was over and relaxed too early. But his x-ray was fine. Today was the first day Ben felt like making phone calls to grandparents. His new neighbor, age 3, has pneumonia so sleep is hard to come by.

### September 19

Medical team visits have slowed to a trickle and Ben's health has improved so Ben would love to receive phone calls and visitors now.

Rheumatology hasn't been in to see us yet but the Resident said the initial fungal stains came back negative. Nephrology wants Ben walking around today to see if he can maintain his pressures. Ben's hand is much better. This morning his breakfast tasted like plastic and they can't get the renal diet right. He is waiting for his specialty, homemade (low sodium) biscuits and gravy.

(late afternoon)

Ben had quite a few visitors today and had an uneventful day until evening. His pressures were high in the late afternoon and he was started on a fast acting oral drug in the evening. The IV Hydralazine had been working but isn't realistic at home. We weren't told they were experimenting with the dose. Things were tense for several hours while his pressures remained high. Once we skipped through the chain of command for the second time, and got everyone's attention, everything was explained to our satisfaction. A mild diuretic was added and that dose may be increased in attempt to find the magic combination.

The biopsy results indicate that there had been some inflammation while Ben was on the IV Cytoxan treatments. The Rheumatologist decided to be more aggressive (she calls it conservative) and started him on the oral daily Cytoxan which will suppress his immune system even more. My understanding is oral is harder on the kidneys and bladder plus makes him more susceptible to colds and flu and the dangerous secondary infections. The up side is he avoids the monthly overnights (which take two full days and multiple pokes) and, mainly, hopefully it suppresses the Wegener's better.

### September 20 or so

We came back to the room to find a precaution sign posted on the door for dealing with the neighbor. I complained that it was not appropriate to put a kid on immune suppression in the same with someone who has a 'use precautions' sign posted. We hung out in a waiting room for about 5 hours while they got everything sorted out and moved us across the hall.

### September 21

Ben's pressures are much lower and seem somewhat stable. He had one episode where he got dizzy and puked. There nurses were very funny, asking if he hit anyone. They said if you are going to do it, you might as well do it right. He got the fifth floor carpet, the elevator, and a nice line all across the first floor before he got to his garbage can. Todd said next time he would just have Ben sit down! We found out Ben has to have a few more things added to his med list. Mostly vitamins and minerals. One of them is Epogen to treat anemia and is to be given by sub-q injection so we will be learning that before we leave. The nurse informed us that Ben was going to practice on me before he gave himself the injection. Thinking he had so much sheep experience I let him bypass the orange and go for it on my arm. I think he even enjoyed himself a little. It wasn't nearly as much fun when it was his turn. Todd went home to vacuum out the heat ducts and try to get the house ready for Ben. The best way to protect his lungs is to act as if Ben has asthma. Rumor is that we can leave Monday.

### September 22

WE'RE HOME! A big thank you to everyone for every single thing. We truly could not be 'there' for Ben without all of you.

### September 28

We've been home SIX DAYS! This has been our longest stretch of time without going down to Children's since July 29. Ben is doing ok. His blood pressure has remained under control. We

have been reporting in to the Nephrologists by phone daily and by fax weekly. Weekly blood draws are being done locally with the results faxed to the Rheumatology clinic. This week Ben has had no energy, an upset stomach, and a weird bump on his arm. We will go back for a clinic visit on Oct. 8. We hope they will have brainstormed about hunting and risking fungal lung infections. In the meantime we are doing everything we can think of to keep our air clean: buying air purifiers, putting flooring down in Ben's bedroom, considering ripping the carpet out from upstairs, routinely drying the clothes in the DRYER for the first time in our marriage.

Sample day:

It is very important to keep the bladder empty to prevent damage from the oral, daily chemo drug. This means remembering to pee at least every two hours 'whether he needs to or not.' It also means drinking a certain amount of water so that he can pee but not TOO much water because of the damaged kidney status. Plus Ben needs to remember to wash his hands compulsively. It would be much simpler if we could lump everything together but we have to be mindful of drug and food interactions. When it is all written down like that it looks pretty concise. But I'll tell you, it is a full time job to watch the clock!

His 49 meds a day look like this:

5:00am antibiotic and seizure med

6:30am anti-nausea, four blood pressure meds, antibiotic (MWF only), Vit D

7:00am chemotherapy drug, bladder protection med

BREAKFAST Tums, antibiotic nasal spray

10:30am anti-nausea

11:00am bladder protection med

LUNCH Tums Ultra, nasal spray, antacid, steroids

1:00pm antibiotic, iron

5:00pm seizure med

DINNER Tums, nasal spray, five blood pressure meds

9:00pm antibiotic, Tums

Monday and Friday Epogen injection

**Keep your face to the sunshine and you cannot see the shadow.**

Helen Keller

October 1

A funny story I wanted to share...when Ben was awake enough to talk but still groggy I showed him the shirt he had been wearing the morning he went to Children's. It was his favorite camo shirt. The EMT's had to cut it up to get it off of him. I held it up and said 'look what happened when you went on the helicopter!' He said, 'They got me that close to it?!?!'

October 5

Ben is having a tough time with his oral daily Cytoxan. He takes it medicine at 7am. He can't take it at night because he has to pee frequently to avoid bladder damage. He feels 'retchy' and tired until about noon every day. He is trying some anti-nausea medication. Even though he has kept his breakfast down lately it hasn't been the magic cure. Today Ben's blood pressure was low which required three conversations with the nephrologist on call. It might be time to start 'thinning' that batch of medication. During the last hospital stay we were told it is more difficult to get the blood pressure under control than it is to keep it under control. We painted Ben's room but one whiff of fumes makes him retchy. He is on a cot in our room on the weekends so we can do his early morning medicines almost without opening our eyes. It reminds me of having a nursing baby. He generally feels good after about 1pm so that would be a good time for phone calls. He also LOVES getting mail.

### October 7

With the help of the rheumatology nurse and gut instinct we are attempting to fine tune the oral daily Cytoxan regimen so that Ben can remain on it for the next four months or so. The other choice is to go to weekly IV treatments which would really amount to two full days at Children's every week. Ben tolerated the IV treatment much better but doctors are reluctant to use it. From what I am reading the chances for remission are best with the oral daily dose.

This morning I redid his medication schedule so he wouldn't have to eat until lunch time or worry about throwing up important pills. We tried moving his blood pressure, iron, and steroids and different times than before. We added a second dose of anti-nausea medication. Today he did not actually throw up, he did not have heart burn, he did get out of bed about three hours before he had been getting up the past week, and he actually felt like eating a little something before 1pm. He was dizzy and slightly retchy but overall it was a big improvement. I only hope it wasn't a fluke.

### October 8

Our second Rheumatology/Nephrology clinic visit was a success. Ben was one of the first patients to try this combined clinic. It saves us a trip to Seattle and puts many brains in one room at the same time. We think it is a wonderful idea even though it can get lengthy (3 hours from the time we arrive until we leave).

Today they reduced his Prednisone by 10mg per day, took away the Procardia XL blood pressure medicine, and cut the Tums dose in half. Creatinine and BUN are steady. His potassium and phosphorus levels are under control. His albumin protein is rising so his edema is down. Explained simply albumin acts as a magnet to keep fluid in blood rather than seeping out to tissues. His white blood cell count is in the right range meaning the Cytoxan is doing its job. The last two days have been better but Ben has been dizzy and experiencing nausea morning and night. Hopefully the dizziness is from low-for-him blood pressure not the anti-nausea medication. The bottom line is good news: the kidneys appear to be healing still and the Wegener's symptoms are being suppressed with the meds.

### October 9

Back to the pharmacy twice today and to Dr. W once. It looks like Ben has re-pulled a muscle on his side. But we have to be watchful in case it is Wegener's lung involvement or a fungal infection. My adrenalin is gone and sleep is hard to come by. Nothing a nice hot, scented bath, a romance novel and a good night's rest won't fix.

### October 12

Ben's side is much better. Well enough that Todd, Ben and Amanda are out hunting again this morning. We are keeping him out of the woods. We are just thrilled that he is able to do this much hunting. Todd and Amanda position Ben in an open field and then go be 'dogs' in the woods. Yesterday Ben got a shot at a two-point. He came home empty handed. You know how those hunting stories go. The Zofran is doing its job so Ben is able to be up in the mornings now. He still sleeps more than usual and gets tired easy but this is a giant improvement over last week.

### October 15

Ben felt good over the weekend and on Monday. Yesterday he had a hard time eating. He has an especially hard time with meat and smells (paint fumes, smoked meat, trash) and doesn't even eat candy or snacks out of his special cupboard. He is losing weight and I know his doctors aren't going to like that. The good news of the day was that he gets to reduce his Prednisone down to 25mg next week and the latest blood levels that indicate kidney function slightly improved. His levels are about where they were prior to the seizure episode. YEA!

### October 17

Ben had his appointment with the neurology nurse practitioner today. She gave us a lot of good information and told us the plan for his anti-seizure medication. To keep Ben as stable as possible while attempting to avoid as many side effects including drug interactions, Ben is tapering off of Dilantin and onto Trileptal (oxcarbazepine). According to this lady, Patti, he will be on this medication for a year.

### October 21

I guess no news is good news. We moved Ben's meds around today but it was a flop. He wants to try again tomorrow because it would get him down to pills five times a day plus at meals. That would make life simpler. Of course, not if it makes him retchy. He managed to run after two squirrels this morning but after being up only two hours he was ready for a nap with a cozy blanket and a warm barley bag.

### October 24

4:40am ferry, the hunters are off. Todd and Ben drove over with a friend. John, Ron and my mom were meeting them at hunting camp where Dad and Amanda had reserved their spot the day before. They have three cow tags in camp which is an amazing stroke of luck. We all hope the luck holds out to allow Ben to come home with his tag filled. Ben called me and reported when and where he threw up on the way over, but he sounded very happy to be there.

### October 30

Ben came back late empty handed Tuesday night; Todd is still hunting bear. Ben had blood work done in the morning. His white blood cell count is in the normal range (meaning the Cytosan is doing its job) and his creatinine was back to 1.5 which was where it was before the September hospital stay. Todd called yesterday and said he needed Ben back!!! There was fresh snow and elk had walked right through Ben's hunting stand. So we met in Ellensburg last night to give Ben four extra days to hunt.

**The best thing about the future is it comes only one day at a time.**

Abraham Lincoln

### November 1

Todd and Ben came home with an elk. Hooray!

### November 2

I took Ben, his friend, and the girls swimming. It was our first outing of the sort since mid-July. Hip! Hip! Hooray!

WG took me through a long period of loss and grief:

- \* for the life I had been living;
- \* for the life ahead I had planned;
- \* for the loss of being the me I knew and not "Poor Sandra with an illness".

It is only now that I am learning that I am still here, I just need to adjust things slightly, and accept a modified version of what I used to do. I have also gained so much. I have found time to be me. To enjoy and appreciate things I once took for granted, or was too busy to stop and do or see - such as the beauty of a sunrise/sunset; the colour of autumn/fall trees; time with my parents, family and more. I also learned to paint and enjoy writing poems. I still have periods of deep depression, but know now that it does not last, no matter how far down it takes me - I will come back from it.

### Umbrella

Words can cause you heartache,  
words can cause you pain.  
Words can wound and harm you,  
and soak you through like rain.

I put up my umbrella,  
to keep me safe and dry.  
It keeps the words and pain outside,  
so I've no need to cry.

My umbrella keeps me protected,  
and keeps the world outside.  
The words just bounce right off it,  
allowing me to hide.

It also keeps out good words  
of Love, Comfort and Care.  
But alone in my umbrella,  
I do not hear them there.

I become a prisoner inside  
and no matter how hard you try.  
I cannot hear you calling,  
I only hear ME cry.

But my umbrella blew inside out,  
its arms they opened wide.  
And things have changed in my life,  
I welcome words inside.

The rain falls down upon me now,  
My shelter's gone... and yet:-  
When it's raining love and kindness,  
I don't mind getting WET!

--by Sandra, used with her permission--

### November 3

Ben made it to guitar and algebra classes today. We are still rearranging pills trying to find the least 'retchy' combinations. Ben, Todd and I have undergone a tremendous amount of grief since this all began. I wasn't able to articulate it but a woman with Wegener's summed it up for me...

### November 5

Today was the combined clinic (nephrology/rheumatology). We just love these clinics because it is such a good feeling to hear some of the conferencing that goes on. Besides when it is all good news we like to hear that, too! Originally Ben was taking five different blood pressure medications, most of them twice a day. He is down to four after the clinic visit: two in the morning plus all four at night.

The prednisone taper is continuing. He is down to 20mg once a day, working his way down to 15mg over the next month. Based on Ben's hematocrit count the epo injection has been cut to once a week. Of course, he is thrilled to only have one poke and one blood draw a week. We are both excited that his kidney is producing \*some\* epo on its own. And it is good for me because I have been telling him a joke each time, and I was having a hard time coming up with appropriate ones twice a week! With the Dilantin taper it means Ben will only have to take meds 7 times a day.

Dr. Emery and Dr. Eddy (two doctors for whom we have high respect) suggested going back to IV Cytoxan to get rid of the nausea and vomiting. After the lung findings in September, a different rheumatologist said the oral daily dose was better to keep his white blood cell levels consistent. I guess there is no WG study to prove this. We have a lot of thinking to do. Going from IV to oral does not prolong treatment (assuming no WG flares). The IV would simplify life as he wouldn't have to do Mesna and Zofran and pee on a schedule. He can switch back if we change our minds. In the end we'll leave the decision up to the Dr. E & E and Ben.

Ben's blood checks aren't coming back with critical marks on them anymore. There are highs and lows here and there and we are trying to learn what it all means. Based on Ben's recent blood work, his physical and some formula Dr. Eddy uses, she estimates his kidney function to be about 70%. It was less than 10% in July. We have many things to be thankful for this Thanksgiving.

#### November 6

At Dr. Emery's suggestion, Ben met with the doctor who runs the biofeedback clinic to work on self-hypnosis in dealing with the nausea. He will have two more appointments over the next six weeks. We all thought the doctor and his technique were wonderful. Ben walked me through it on the way from Seattle to Lynnwood. It sure was a fast trip on my \*cloud.\* After skipping one dose of Minoxidil Ben's pressures were in the danger zone. Good thing I have the emergency Minoxidil dose so I don't have to panic. I'll be calling the nurse this morning to see if he should go back up to twice a day.

#### November 8

The nephrology nurse said the bp med adjustment must have been based on his clinic pressure (117/68) rather than the two weeks of logs we turned in. Even with Minoxidil twice today Ben's blood pressure was 132/98 last night, higher than it has been since he was in the hospital. I gave him a third dose and practically packing my bags, envisioning all kinds of awful things. But this morning it was back down to normal and it held throughout the day. Today Ben felt well enough to have a friend spend the night for the first time. He taught his friend and sister the self-hypnosis technique he learned on Thursday.

#### November 11

An interesting night...last night Todd and Ben got up at 2am so that Ben could have a sleep deprived EEG today at 10am. He managed to fall asleep and do the twitches that he has been doing at night over the last few weeks. I hope the neurology dept. will figure out how to change his seizure meds around to get rid of the twitches without having a full blown seizure. FYI Grand mal is an old term; they are now called a clonic tonic seizure. I guess grand mal wasn't politically correct?!

#### November 17

We are at Children's again. It isn't especially stressful this time around so PHONE CALLS & VISITORS ARE WELCOMED! Ben woke up throwing up at 3:30am Sunday morning. He mostly gets sick after meds so the timing was unusual. I called the rheumatologist who said bring him in and bring a suitcase. More than likely bout of vomiting a virus or bacteria, but we've decided to go back to the IV Cytoxan to try to get a better quality of life on a day to day basis. If we don't have any surprises, I think we'll be here another night or two.

#### November 19

Ben was discharged yesterday morning and while we were on the way home the doctor called to say Ben has a bacterial infection in his gut. I guess it is a bacteria we all have. In his case it has become overgrown either because of being immunosuppressed or because he is on a prophylactic antibiotic to prevent PCP (the pneumonia that AIDS sufferers used to frequently die from). He will be on an antibiotic for 10 days; then we'll go from there. The plan is to go back to Children's tomorrow and then back for the overnight Cytoxan IV on Monday. (I'm reluctant to write that I have a 'plan' since not much goes as planned anymore.)

p.m. I guess that last sentence was a self fulfilling prophecy. Ben wound up throwing up off and on during the day. The specialist at Children's sent us to the local pediatrician to get some IV fluids and meds. Ben is still a hard poke. Probably partly because of the dialysis but being on the dry side doesn't help any. After two 'tries' Ben decided to give oral fluids another try. So far more is going in than is coming out...

#### November 21

Ben enjoyed his appointment with the self-hypnosis doctor yesterday even though he threw up before and after. Monday we should be in a room by early afternoon (2pm?) if you care to call or visit while we are at Children's.

As for Thanksgiving, 'we'll see.' I always hated when my parents said that! We have a few treats stashed away in case we spend the day at home.

#### November 25

The Cytoxan IV was uneventful, just as we hoped. Amanda is ill with a nasty flu (fever, vomiting, headache sore throat and muscles) so we are trying to keep her and Ben apart. Before our hospital stay Grandma Becky had Amanda. Now Ben is at Grandma and Grandpa Sires'. We might reschedule Thanksgiving for Friday when we hope to all be together (assuming Amanda's fever is gone).

Good news about Ben's recent hospital visit: he played 'Spoons' in the Teen Zone, he sang with the staff musician, and the doctor recommended a trial without iron and Epogen (two less pills per day and two less shots per week). His seizure med transition is complete today (two less pills per day). Switching back to IV Cytoxan means eliminating 3 more pills and two oral doses of nasty-garlic-tasting-Mesna IV liquid. Best of all Ben doesn't have to worry about protecting his bladder by peeing on a schedule except during the once a month treatment. Friday morning he will finish up his antibiotic and eliminate the 5am, 1pm and 9pm alarms. I think we will have meds whittled down to five times a day. That is half of what we were try to keep track of in September.

A great tip from the Rheumatologist...get your calcium from Viactiv. Find it at Costco in the vitamin section in a purple box. YUMMY CHOCOLATES each give 500mg calcium plus Vit. D. Less than 13 cents each, they are \*much\* better than Tums.

#### November 27

Ben's wacky sense of humor survived the oral daily Cytoxan torture. Not throwing up for two days is something to celebrate. We went to OH to pick up Ben. We retook Amanda's temperature with Ben's fancy thermometer while we were there. It was back up over 100 degrees. I guess he will come home Sunday evening now. It's a good thing the basement will be getting the vinyl soon (next week?) so we can have a separate sick bay. Ben has blood draws at 7, 10, 14, and 21 days. He has a Neph/Rheum clinic appointment on Wednesday, gets a week off, has a self-hypnosis appointment the next week, and the week of Christmas he has his next Cytoxan overnight. We are hoping, praying and keeping our fingers crossed that his health is heading in the right direction with the change back to IV Cytoxan.

#### November 30

We are happy to see the end of this month. Ben is feeling good. It feels like things are heading in the right direction. Hopefully I won't need to update this as often.

**Every little action of the common day makes or unmakes character.**

Oscar Wilde

### December 1

a.m. Ben is feeling so much better he has agreed to go to his English class after Christmas vacation. p.m. I spoke too soon yet again. Ben had hot flashes and chills making Todd think Ben was going through menopause. He also had a mild fever and medium-high retchiness.

### December 2

Ben's friend came over and they worked on algebra for FIVE HOURS!

### December 3

Today was the combined clinic (Rheum/Neph). We saw Dr. Emery and Dr. Eddy. Ben's WBC (white blood count) is on the low side and because of the horrible flu epidemic he is going to start a prophylactic antiviral medicine. He will also be getting a bone scan in January to see how delicate he is. In February they will reevaluate disease markers and possibly switch to a milder immunosuppressive drug.

Nephrology wants him off of some of the bp meds and are cutting some doses in half. It didn't work last month but Dr. Eddy said his steroids are lower now so 'maybe' it will work this time. Dr. Emery would like to see Ben off of the anti-seizure drug. I'm not sure I can sleep nights doing both tapers simultaneously. I want to get rid of any excess meds, too, but it makes me extremely nervous because Sept. 10 is too fresh in my mind. The medical team likes the daily log we keep, especially the 'retchiness scale.'

### December 4

Ben lasted until about 6pm last night and then got a headache and felt miserable. Then in the morning he threw up for the first time in a week. His headaches include pressure behind his right eye. Of course, yesterday at clinic we said things were going so well. So I left a message for the nurse and Dr. Emery called back with a plan. She said she hates to haul us in there again but is scheduling Ben for an eye exam and MRI then a neurologist will be called in if necessary. Ben is still having night twitches so I think the sooner the better on the MRI. (That is why he had that sleep deprived EEG last month. The twitches started in mid Oct. when Trileptal was added.)

### December 8

Nothing to report. Some days are better than others.

### December 12

I spent the better part of three days this week at the hospital. This time it was with my grama dealing with her broken hip. Ben is having 4-6 good hours a day where he does not feel retchy or have a headache.

### December 15

Ben's CBC blood levels are looking good just in time for next week's IV Cytoxan overnight. This was the first day in almost two weeks that Ben did not throw up. He got up late, took a nap and went to bed early, but not laying around with a barf bucket is an improvement. I would like to take credit for it since I woke him early and gave him crackers and anti-nausea medication. But we've done that before without it making a difference. In hopes that it helped we will rub the lucky rabbits foot, do a special Indian dance and try the routine again tomorrow.

Today Ben demonstrated how he makes his hair fall out. His Minoxidil (otherwise known as Rogaine) has been cut back so maybe that explains why it took so long to get to the hair-falling-out stage.

Because of a fever Amanda is sequestered to her bedroom or the trailer.

### December 20

Ben has discovered the art of magic and is working up a routine. He can turn a quarter into a dollar bill. Things have been going better on the retchiness front. Ben's throwing up has slowed to every other day. Two days in a row he didn't even take a nap. Emotionally things are harder these days. Treatment is a long haul. Feeling sick is hard, but feeling better and not being able to do outdoor, rough-and-tumble things is almost worse on a soon to be 13 year old boy. We are still praying for long lasting remission once this phase of immunosuppression is over.

### December 24

We went in early Monday for the IV Cytoxan treatment. Before treatment Ben was throwing up...in the car...in the waiting room...in the exam room...in admitting...in the family kitchen...in his room...we learned the technical term for 'barf bucket' is 'emesis basin.' Other than feeling miserable the treatment was routine. The dose was reduced by 10% because his white blood cell count dipped so low last month. Ben's hematocrit is stable, his creatinine level is staying at 1.3, and his potassium and phosphorus are within normal range. We are glad that part of treatment is over for another month and will be spending our holidays avoiding crowds (nothing new about that) and enjoying being home together. Ben started out the morning throwing up, felt good for a couple hours during the middle of the day, then threw up the little bit of dinner he managed to eat. The best diagnosis the team of doctors can come up with is cyclic vomiting related to migraines.

### December 31

Ben had a rough week feeling miserable up until the last three days. To top off his misery Ben's Lovebird, Leroy met a sudden death. We think he got into something toxic when he escaped from his cage. On Christmas Eve our friends delivered an aquarium to help Ben take his mind off of missing his sheep. The timing couldn't have been better. The day after Leroy died we were picking out fish. Now Ben is testing the water and trying to manage his aquarium by the book.

His blood pressure was low enough to cause dizziness (which can cause retchiness). A phone call the nephrology fellow on call gave us direction on that.

We had a pleasant surprise a few days ago when a representative from the Puget Sound Purebred Sheep Breeders' Association showed up with a revolving plaque and very fancy plaque to recognize Ben as recipient of the Outstanding Youth Achievement Award for 2003. Ben has been grieving about the sheep being gone so the award was extra special to him.

Not only am I still moving medical supplies from here to there, things that belong in the basement are stashed on, in and under things all over the house. There is a manufacturing problem with the vinyl that was installed in the basement so it looks like it will be awhile before we can move things back down there.

We are planning a quiet evening at home to bring in 2004 going with the theory that we will have our celebratory toast when it is midnight on the east coast. It was a wonderful surprise when our neighbor (and relative) brought us a basket of treats and a beautiful (and yummy) cake. We now have leis and glowing necklaces so it feels like we are really celebrating.

Thank you EVERYONE for all of the support you've lent us this year...has it really only been five months since this all started??? We appreciate all of your kind words, every single prayer, and each penny that has been raised. May 2004 be a year of health and happiness for us all.