# **My Story**

We will post information and messages on this site to keep everyone updated on how the treatment is going. Thank you for all the positive thoughts, love and support. We will make it through this!

This says "My Story" but I am writing this on behalf of my husband.

In 2005, Randy was diagnosed with testicular cancer. We thought we had caught the disease early enough to go through surgery and follow-up radiation. Everything had been fine with follow-up appointments, but the cancer has returned and has metastasized into a brain tumor.

Randy had a seizure on Friday, June 12 at 9:30pm. I am so grateful that I was home when it happened. Randy had the strength and forethought to run to me from the living room when he started feeling dizzy - he was unable to speak and shaking violently. I was in the computer room and turned around when he came in. He kneeled on the floor next to a chair and couldn't stop shaking or speak to me.

I called 911 and just held him. The shaking finally stopped but he still couldn't talk and the right side of his face was drooping. My first thought was a stroke. By the time the paramedics arrived, his face was back to normal and he could talk again. He was able to walk to the ambulance on his own and they took him to Good Samaritan in Puyallup.

After a CAT scan the ER doctor said there was definitely something there and that he was going to admit Randy to the hospital for more tests. Randy had a MRI the next morning and by Saturday evening, his oncologist from the testicular cancer stopped by and told us the news. What a shock. They scheduled a full-body scan the next day to see if there were any more tumors. They put him on anti-seizure and steroid medication to help the swelling and hopefully keep him from having another incident.

Randy was able to come home last night and will not be able to drive for the next two weeks nor be alone in case another seizure happens. I am staying home with him for the time being until we get a treatment plan in place. I will provide updates in the journal as much as I can (and maybe even get Randy to enter in a couple).

Robin

### Journal

### June 16, 2009

Today we met with the oncologist, Dr. Liao. The good news is that they did not find any more tumors. This means that we caught this early enough.

Dr. Liao thinks that the testicular cancer has come back in the form of a brain tumor. The tumor is about 2cm in diameter (a little less than 1 inch). It is in the top front of his brain on the left side which affects the speech center. This is why he has been having difficulty in speaking the last few weeks. We didn't think much of it until the last week or so. Randy was going to schedule a Dr. appt this week, but his body had other ideas.

The plan is to start chemotherapy next Monday. He will have a port put in on Friday morning (outpatient surgery). The schedule for the treatment is a 3-week cycle. The first week he will have chemo 5 days (Mon-Fri). 2nd and 3rd weeks are on Mondays. The Dr. wants him to go through 4 cycles of this at a minimum. It could take up to 18 weeks total depending on the progress.

The Dr. will schedule another MRI after the first cycle has completed. This will determine whether the medicine is working. If it is, then Randy will continue and get checked until the tumor is gone.

If the tumor does not shrink, they will need to do a biopsy to determine what kind of cancer it is. Apparently, the different types of cancer are not just identified by their location in the body - they are different diseases and have their own form of chemotherapy treatments.

This week we will be meeting with a Nurse Practioner to learn more about chemotherapy and what to expect. A pre-op appointment on Thursday and then surgery on Friday for the port. I will update this journal as often as I can, but please don't hesitate to send us an email or call.

### June 18, 2009

Yesterday we met with a nurse practioner to get the scoop on the chemotherapy treatments and came home with a stack of papers. Basically there are three different drugs he needs to be on in addition to some others that help with nausea and any allergic reactions. Pretty overwhelming. They will be monitoring his blood frequently to make sure his white and red blood cell counts are ok. There are plenty of contingency plans if something goes wrong.

We had a pre-op appointment today for the port surgery tomorrow. Due to the seizure he had they want to perform the operation at the hospital instead of the clinic - just a precaution. The procedure is scheduled for3pm and should take an hour. Recovery will be about 2 hours, then home for some rest for the weekend until Monday morning.

We are taking it one day at a time - Randy is feeling pretty good, just some well-deserved anxiety. Thanks again for all the well-wishes and support, it means a lot to us.

### June 19, 2009

Randy is home now after his surgery and doing well. The port installation was a breeze and we were out of the hospital within 2 hours (much to Randy's glee). Now comes a weekend of rest and a nice dinner out on Sunday before he starts chemo on Monday.

If you don't know much about chemotherapy treatments, here is a link: <a href="http://en.wikipedia.org/wiki/Port-a-Cath">http://en.wikipedia.org/wiki/Port-a-Cath</a>. It's completely under the skin - he just has a bump under his collar bone on the left side.

### June 23, 2009

First day of chemo was on Monday. They took some blood to get a base started and then it was off to the easy chair. He started at 9am and we were out of there by 3pm - long day. So far there hasn't been any immediate reactions. He seemed a little tired this morning, but we got up and went for a walk.

Hi speech is getting a little better as well, the steroids are working to shrink the swelling around the tumor so there isn't as much pressure. He is still on watch this week (by me). My new nickname is Nurse Ratched (from One Flew Over the Cuckoo's Nest movie).

The port installation looked good, he will have a nice scar. He is off to chemo again today at 9:30.

### June 25, 2009

Day 4 of chemo is done. Randy was feeling a little bit of nausea and was tired yesterday, but so far so good. One more day this week, then it's onto just Monday's for the next two.

What a weird day, Farrah Fawcett passing away and then Michael Jackson.

### June 29, 2009

Today was supposed to be a chemo treatment, but Randy's white blood cell count was pretty low (dropped 50% over the last week). They gave him some anti-nausea medicine and a shot called Leukine that is supposed to help build up his white blood cell count. Unfortunately, the side effects are bone pain and possibly fever. He has some achiness and general nausea, but overall is still doing ok. He gets tired really fast and so is taking it easy. He is scheduled for three more shots this week and chemo tomorrow so it could be a rough week.

### July 2, 2009

Tuesday was a pretty bad day for Randy. The effects of the Leukine shot made him tired so he didn't sleep well Monday night. He had a headache most of the day and a fever on Tuesday night of 101.

By Wednesday morning he was feeling better. He received another shot yesterday, and so far so good. He did have trouble sleeping last night so I gave him some Tylenol PM at 3 this morning and I can hear him cutting down a forest right now. Funny, I never thought I would be relieved to hear that snoring!

Today is a day off, tomorrow and Sunday are 2 more shots, then chemo on Tuesday. Hopefully he will feel well enough to light some fireworks on Saturday, but if not, well that's what sparklers are for :)

Thank you for posting to the guestbook - it means so much to both of us.

# July 5, 2009

Last day of the Leukine shot (this time around). Randy has chemo on Tuesday and we'll talk to the doctor about getting the MRI scheduled. His speech has improved and there haven't been any seizure scares so we are hopeful that the chemo program is working.

Randy is feeling pretty tired today. He is eating well, but has lost 19 pounds over the last 3 weeks. I am starting back to work tomorrow - it will be weird to be away from him after monitoring almost every waking hour since the 12th, but Taylor will be here to keep an eye on him.

# **July 7, 2009**

Randy had chemo today and Dr. Liao informed him that he can start driving - YEAH! - not that I minded chauffeuring him around - but, YEAH! As long as he feels up to it, he will be able to drive himself to his appointments.

Dr. Liao wants to wait on the MRI, he told Randy that since his speech has corrected and there haven't been any other seizures, he is confident the tumor is shrinking - especially since Randy has been off the steroid for over a week.

So all good news these days is tempered - he needs to have the Leukine shot every day for the rest of the week (Wed-Sun). His white blood cell count was down to 2 today (from 10.1 before starting chemo). Normal range is 4.5 to 10.9 so it's dropped pretty drastically. There aren't really any symptoms of this other than he is more susceptible to infections so we need to keep him healthy and away from anyone who is sick.

Today's chemo finishes up the first cycle. Depending on how well the Leukine shots are doing, he

will start the five day sprint of chemo next Monday.

# **July 13, 2009**

Good news on the white blood cell front - Randy's count has increased to 8 from 2 last Tuesday, looks like those Leukine shots worked well this time.

So far so good, although it looks like he is starting to lose his hair:(

We will be able to vacation in Bend, OR this year, just fewer days (Friday-Monday). Randy is excited to be able to go since we've been doing this for the last 7 years with my parents, sister and her family.

Everyone else is doing well, Chase has been doing a great job driving the van for the business and Taylor has been taking care of Randy and helping around the house (with less prompting). I am back to work full-time -Weyerhaeuser has been great in allowing me time off when I need to.



### July 23, 2009

We are back from Redmond, OR and really enjoyed the trip. It was short but sweet.

Last week was pretty rough on Randy with the 5 days of chemo, I didn't think a 6-hour road trip was going to cut it, but by the afternoon on Friday he was feeling a little better.

Only 1 treatment this last Tuesday and so far so good. The doctor says that Randy has 2 more cycles to finish after this one, so we are counting down the weeks (8 more to go). Next week we will ask about the MRI to see how things are progressing.

Randy's hair started falling out last week so he decided to shave it and be done with it. Thank goodness he has a nice-shaped head :)

Chase came home that night and surprised us by shaving his head too! I uploaded a photo of them I took today.

Still taking it one day at a time.

### **August 7, 2009**

I can hardly believe it's been two weeks since the last post - the summer is just flying by.

Randy is finishing up the first week in the 3rd cycle. Hopefully only 5 weeks to go. Dr. Liao says he will schedule the MRI after the last treatment to see how much progress has been made. Once that is done, we'll discuss what the rest of the treatment will look like (more chemo or possible surgery).

Not much else to report, the family is doing well and finally enjoying the cooler weather. Those 100+ days were bad!

Take care everyone-Robin

# **August 25, 2009**

Ok, I want to know where August went. If anyone has seen it, please let me know!!

2 more weeks until school starts for Taylor so the madness of back to school has begun. Chase will be starting at Green River Community College on the 21st.

Randy is doing as well as we can expect. He was suffering from severe anemia last week so went to the Dr. for a blood transfusion. He was so tired, he could hardly get out of bed. We weren't sure if the Dr. would keep him on his schedule due to the anemia, but his blood work came back within range so he is starting his last 5-day per week session. After this one only 2 more chemo treatments to go and he should be done.

The MRI will take place 2 weeks after the last chemo treatment.

The other little hiccup was getting 2 blood clots in his left calf. He started noticing soreness last Friday and by yesterday, it was swollen and red. They did an ultrasound and found 2 veins that were clogged. One of them was about 16 inches. They are going to start him on blood thinners today and he will need to continue taking that for about 6 months.

Randy's sister Renee is out this week visiting which has been a real boost to our morale.

I hope everyone else is doing well, I'll provide more updates after this last cycle of chemo. Thanks again for all the support and well wishes.

Robin

# **August 28, 2009**

Well crap. So about 2 hours after I posted the update on Tuesday, I get a call from Randy's sister, Renee, who was at home with Randy and his mom. Randy suffered another seizure.

They called 911 and the paramedics were there quickly. Randy's blood pressure was so low it wouldn't register so they whisked him to the emergency room. Taylor was also there and did a great job of staying calm although I know she was very scared for her dad.

The ER Dr. scheduled a chest and head CT scan. The chest scan came back and showed that Randy had 2 blood clots in his lungs (1 in each). This is called Pulmonary Embolism. The blood clot that he had in his calf had broken apart and traveled to his lungs.

The good news though is that the head scan showed that **the tumor is completely gone!** We were so worried that the seizure had been caused by the tumor.

The strange thing is that a Pulmonary Embolism doesn't cause seizures, people usually just pass out or have a hard time breathing. He didn't have any of the symptoms beforehand.

He was admitted to the hospital and they put him on a blood thinner (Heparin) and an anti-seizure medicine. They also transfused 2 more units of blood.

We saw the oncologist (Dr. Liao) and he still wants Randy to complete the last cycle of chemo, but they will wait until the 7th to give him some time to recover and get maintained on the blood thinner and anti-seizure medicine. He started on Coumadin last night.

He was released last night and is home resting. We are both pretty bummed about this latest development. The neurologist we saw doesn't have any clear answers as to why Randy had another seizure so that has us a little worried. There is also the fact that he will not be able to drive for 6 months (Washington State Law).

So we are back to dealing with the unknown, but will make it through this. I am so thankful that Renee and Irene were here, even though Taylor had to witness this, I am glad that she didn't have to experience this alone.

I'll keep this journal updated as best I can. The next few weeks will be filled with Dr. visits and blood work.

Thanks for all your support, please continue to leave messages for Randy, they really do wonders for his moral.

Robin

# **September 13, 2009**

It has been quite busy the last few weeks. I needed to take some vacation last week and this upcoming week as it was just too hard to try and juggle everything (imagine that!)

I tried to go to work on Friday, Sept 4th, but when I was 5 minutes away, I got a call from the kids saying that Randy woke up and couldn't talk. I called the neurologist and they had me double his anti-seizure medicine and after about 2 hours, his speech came back. It was a seizure, but not nearly the impact of the previous two.

Tuesday morning another seizure happened like the one on Friday. We had scheduled a MRI and the results came back positive. The tumor has shrunk significantly and there was no bleeding.

During this last week, Randy's Coumadin (blood thinner) level was getting close to normal so he is now scheduled back for his last cycle of chemo on Monday. We will go through the 5 days this week, then on Tuesday's for 2 more weeks. Hopefully this will take care of the rest of the tumor. 3 weeks after the chemo is done they will do another MRI and we'll discuss what the next steps are.

We met with the neurologist on Friday and he told us some interesting information. Generic drugs can be anywhere from 20mg less to 25mg over the amount of the medicine and still be approved for use! He wants Randy to take the brand-name (Keppra) instead of the generic for 1 month. He thinks this could have contributed to the 2 smaller seizures Randy had in the last week.

Randy felt well enough to go to the Husky Football game yesterday, it was nice to get out and do something "normal." Plus they won for the first time since November 2007!

Taylor is back in school and Chase will start community college on the 21st.

Take care everyone Robin

# **September 29, 2009**

Well today was the last of the original chemo schedule and we hope that this took care of any residual tumor that was left. Randy needs to wait 2-3 weeks before a MRI can be done to let his kidneys recover from the chemo.

A few days after the last post, Randy had another seizure and this one didn't go away as quickly as the previous ones. His speech took a couple of days to fully return. We saw the neurologist and he started Randy on a different anti-seizure medicine. So far so good, no seizures in the last 2 weeks. He will discontinue the previous medicine once the new one has built up in his system.

I would say that we are cautiously optimistic. I went back to work yesterday for the first time in 5 weeks and with Chase starting college we are all getting used to a different routine.

If the MRI shows that there is still some tumor left, the Dr. will want to do surgery. We'll cross that bridge if we have to go that way.

Take care everyone-Robin

### October 14, 2009



These photos were taken the first day Randy was scheduled to start chemo and yesterday (October 13). Doesn't even look the same! He still has a little bit of a moustache and eyebrows, but they are all gray. His hair is starting to grow back as well (gray). We'll need to nickname him Gandalf the White. He has lost a total of 42 lbs. which you can definitely see.

The MRI happened on Monday and we reviewed the results with Dr. Liao yesterday. The tumor is gone - yay! There is still some edema though and the Dr. is not sure if it's due to some residual abnormal cells or scar tissue. He is going to take Randy's results to the "Tumor Board" which is a consortium of specialists to get their opinion. They will either want to leave it alone and monitor him closely for any changes, or perform surgery to remove scar tissue or any abnormal cells. The surgery is a little riskier since the tumor was pressing on the speech center.

Randy is feeling better every day, and we did confirm with Dr. Liao that there won't be any more chemotherapy for this. All of his blood levels are starting to come back into a maintenance status which is great news.

We also met with the neurologist on Monday to discuss the seizures and are still working on long-term medication plan. The neurologist feels that Randy will need to be on anti-seizure medicine for the next 3-5 years to be safe.

So another 2 weeks before we get the results back from the Tumor Board. If Randy was to have surgery, they wouldn't schedule it for several weeks - they want him to continue to recover and get stronger from the chemo. He has started to go to work with Chase in the afternoon and went to a movie for the first time in 4 months last Friday. Getting out and seeing people has really boosted his spirits.

Until next time . . .

### November 2, 2009

I am looking forward to the day I can update this journal with only good news. It seems every time we experience a success, it comes with a price.

We met with the oncologist last week and he has confirmed that the tumor is completely gone. He considers Randy cancer-free which is wonderful news. Dr. Liao met with the tumor board and their recommendation was to consult a neurosurgeon to discuss the scar tissue that has formed since the seizures are still occurring. It is extremely unlikely they will attempt any surgery since the scar tissue is on the speech center. It would be too risky and could permanently impair or cause him to lose his speech entirely.

Randy has continued to struggle with the anti-seizure medicine over the last couple of weeks. The side effects of these drugs are pretty severe and he is experiencing quite a few of them. At this time he is unable to walk w/out assistance and cannot speak very well. I've been putting off updating this journal because it is so upsetting to even write about it and I know that everyone will be so concerned. It seems so unfair that he would make it through the chemo only to end up suffering with these symptoms.

We met with the neurologist today and they are doing some blood work to see what the medication levels are in his body. The Dr. reduced one of the anti-seizure medicines today to see how well Randy tolerates it. He is scheduled for an EEG on Wednesday so the Dr. can see if any seizure activity is occurring. At this point we are unable to tell if he is having a mild seizure since he is already experiencing the weakness on the right side of his body and slurred speech. Hopefully the bloodwork and EEG will provide us with a definitive answer.

The most frustrating thing is not knowing if we have hit the bottom. To make sure Randy can still get around without falling, I will be getting him a wheelchair - hopefully just temporarily -until we get the seizure issue settled down.

Please continue to send your positive thoughts and prayers, Randy and I appreciate the guestbook entries and it makes a huge difference to know how much everyone cares.

I will post more info in the next few weeks as soon as I can.

### **November 10, 2009**

I can hardly believe only a week has gone by. The EEG came back normal so our neurologist wanted to do a neck and another brain MRI to check for any bleeding or other issues that might be causing Randy's condition.

We found out last night that the cancer has returned. It's only been 4 weeks since the last MRI (October 12) and there are 4 more tumors. Both our neurologist and oncologist were shocked at how aggressive the cancer is and how quickly it came back.

There are three new tumors located in the center of the brain and the first tumor has started to grow back. The amount of swelling around these tumors is the reason why Randy has not been able to walk or talk.

On the one hand, we are relieved to have a reason for the mobility and speech issues and that it's not medication or effects from a stroke.

The oncologist referred us to radiology and we met with Dr. Bittner. He is recommending full-brain radiation over a three week period (15 visits). After the last radiation treatment another MRI will be done in 4-6 weeks to see if it was successful.

The oncologist also put Randy on steroids to help reduce the swelling, we are hoping that this medication along with the radiation will help Randy get back on his feet and improve his speech.

Long term effects of the radiation are not severe, there may be some short term memory loss and Randy may need to have some speech and physical therapy to regain all of his functions back.

We are cautiously optimistic since testicular cancer responds well to radiation. Randy is in good health otherwise and of course is still 55 years young - this helps his chances in beating this long-term. We can only hope and pray for the best.

Through all of this, his spirts are still positive, but then what else would you expect of Randy. He is such a trooper, I am just so proud of him and didn't think it was possible to love him anymore.

# **November 18, 2009**

Randy was admitted to Good Samaritan last Thursday night. His balance and mobility was so bad I didn't feel I could safely continue to take care of him at home. Being on the blood thinners, I was worried he would fall and injure himself.

His speech was also gone and with the brain tumor on his left side affecting the strength on his right side, he was having difficulty swallowing food and water.

He has been doing ok in the hospital. He is continuing radiation and is still taking a high dose of steroids to help reduce the swelling around the tumors. Yesterday he was doing better with both speech and strength so hopefully we are on the upside of recovery.

Since Randy is not critical, the hospital wants to discharge him tomorrow. He is still not ready to come home so I am looking for a rehab facility for the next few weeks to ease the transition and allow him to regain enough strength to safely be at home.

I've been spending as much time with him as possible at the hospital and have received great

support from family and friends. Thanks Cindy for bringing dinner on Wednesdays and taking Taylor to get her allergy shots; Mom & Dad for being here; and to my sister for staying with me last week and helping out.

I also want to give a big shout out to my manager, Christi Harris, and Weyerhaeuser. They have been so great in allowing me to spend the time I need to care for Randy.

I am truly humbled by all of the well wishes and prayers being sent our way.

### November 28, 2009

Once again, I am just blown away at how quickly a week goes by and all that can happen.

By last Friday, Randy was starting to recover a little so the hospital wanted to release him. We weren't quite ready to have him home so my mom and I toured a couple of nursing facilities. We found one in Federal Way that was decent and specialized in short-term transitions from hospital to home. Randy was released on Thursday afternoon.

The first night was a little rough, these places are not like any hospitals and with Randy's speech and mobility affected, he is really dependent on others for everything. We were both having second thoughts on Friday, but found out that the clinic wouldn't do a safe-discharge which could affect our insurance (argh). I spent the day with him and talked with the nursing coordinator and they wanted to wait until Tuesday. I was with him as much as possible during those 5 days to make sure everything was ok - I felt terrible leaving him at night.

Randy worked really hard on his physical and speech therapy and was able to come home on Tuesday. We were both so relieved. It was exhausting having him at the hospital and nursing home for both of us.

He is getting better each day. I can pretty much understand what he is saying now most of the time, but can tell when he is tired. His balance is improving and he is able to get himself from the wheelchair to the car, couch and bed. I learned some tips from the physical therapist at the nursing facility in how to best help him while not injuring myself.

The radiologist is pleased with his response to the radiation. We will meet with the oncologist and neurologist next Friday for a follow-up to see what the next steps are. He will continue radiation until December 8th (7 more sessions). They are only going to wait 3 weeks after the last appointment to do an MRI instead of the normal 4-6 weeks since the cancer was so aggressive.

We had a wonderful Thanksgiving holiday. Randy's sister Cindy put together an outstanding meal. It was great to be surrounded by family and friends that love and support us so much.

# **December 18, 2009**

Happy Holidays

Things are progressing quickly - in a positive way. Randy is able to walk on his own and his speech is getting better every day. He finished radiation on the 8th of December. He started chemo this week. Dr. Liao has proposed 4 cycles of treatment. Randy will get chemo for 5 days, have 2 weeks off for a 12-week period.

The chemo treatments are about 2 hours and he has to bring home a pump that he wears for the entire week. Chemo 24 hours a day for 5 days! The treatment is aggressive, but that is what the doctor thinks it will take to hopefully beat this for good.

Randy has an MRI scheduled for Monday. We will follow up with the radiologist on the 28th to discuss the results.

We also just found out today that Dr. Liao has arranged a consultation with Dr. Craig Nichols who is the physician that treated Lance Armstrong! Randy was so excited. Dr. Nichols practices in Portland, Oregon and we will see him on the 31st. Basically it's a 2nd opinion about the treatment and what could be next if the radiation and chemo have not cured Randy.

There haven't been any seizures which is a relief. The steroids he is on are causing some skin issues and making his face fat (his words, not mine). These are pretty common and will go away when he finishes the medicine.

His spirits are high and determination strong, but then what else would you expect. I am slowly starting to relax a little and feel like I could sleep for 24 hours straight.

We are heading up to my parent's house in Packwood for Christmas - looking forward to spending time with family.

I hope everyone has a Merry Christmas!

### **December 27, 2009**

First of all, I hope everyone had a wonderful, safe Christmas. It is a very special time of year to spend with family and enjoy each other.

I wish I could say we had a "normal" Christmas, but it was just not meant to be. I re-read my posting on Friday the 18th and we both just felt on top of the world about Randy's progress.

By Tuesday, Randy had developed a fever of 103.7 and needed to be rushed to the emergency room. The chemo treatment he received the prior week did quite a number on his white blood cells and he developed <u>neutropenic fever</u>. Basically his body is depleted of white blood cells and is not able to fight off anything.

His blood has bacteria and he has <u>cellulitis</u> on several areas of his body, the worst one being on his bottom left leg. It is very painful and he cannot put any weight on it.

He is in the special care unit at Good Samaritan and in isolation. He received 5 blood transfusions and had quite the array of fluids going in for 72 hours. To say he was wired for sound is an understatement:)

So that is where we spent Christmas, but we were together and that is all that matters. The kids were able to stop by on the 24th to see him and then went to my parents' house in Packwood. I expect them to come home today.

We are taking it just one day at a time now and not even thinking about what is next since it can change so quickly. Our first priority is to get the infection under control and get his white blood cell counts back up so he can come home. Once he is stable, we'll regroup and discuss what the next steps should be.

We've decided that we want off this roller coaster now. 4 times around in the hospital with plenty of twists and turns - the carousel is looking nice and boring.

Here is to a much better 2010. We both wish everyone a very happy new year.

### **January 4, 2010**

For those that subscribe to the updates, do you find yourself dreading the email? I know I dread updating it sometimes. I was so naive when I started this thinking that all I would be doing is telling everyone good news.

Randy is still in the hospital but getting better. They ended up removing the cath port from his chest due to the blood infection. His leg is recovering too but taking longer due to the diabetes.

They installed a <u>picc-line</u> in his upper right arm on Saturday to replace the chest port. He will need to

be on antibiotics for 2 weeks and this will allow him to use a pump at home. If he needs to start chemo again, they can

use it as well. White blood cell count, platelet counts are all going up which is good. We don't know what the next plans are for treating the cancer, right now the main goal is to get Randy home and stronger.

I appreciate everyone hanging in there with us; I know this has been quite the ride - 2 steps forward, 3 back. I am hoping and praying that the rest of my journal entries are all good news. Here is my list of things that do not suck right now: 1) He is alive 2) White blood cell count and platelet counts are good 3) Infections are healing 4) The nurses/doctors at Good Sam 5) Blood pressure and blood sugars are coming under control 6) I still have my job and health insurance

- 7) My kids are doing ok 8) I finished the last class of my IT degree program on the 28th of December. Just 3 more humanities classes starting in March and I will have my BS in Management of Information Systems by June. Yes, I was still going to school through all of this, I think they call that C-R-A-Z-Y.
- 9) Randy's business is still going well. Matt, David, Andrew and Chase have done a great job in keeping it running efficiently. 10) All of you providing love, support and prayers.

List of things that suck:

- 1) He is still in the hospital (that sucks for him, but I am kind of relieved because I had to start back to work today and I know he is being taken care of). 2) I had to shave off his moustache last night (this is only the 2nd time in 23 years I have seen him w/out it). 3) His speech is not back 100% although much better than it was.
- 4) We'll probably meet our yearly out-of-pocket maximum of \$7500 by the end of this week happy New Year!
- 5) Not being able to see into the future.

#### Here's a belated toast to a much better 2010! <clink>

Next time I will post a picture of Randy who now resembles a blend of <u>Yul Brynner</u> and <u>Mr. Clean</u> (minus the eyebrows).

# **January 13, 2010**

Today will mark 3 weeks in the hospital. It's hard to believe it's been that long.

Last Friday, Randy was moved down to the Rehabilitation Clinic to start recovery. It's been slow due to the infection on his leg, but he is making good progress. The rehab facility is amazing and Randy stays pretty busy with Occupational, Speech, Physical and Massage therapies. We are probably looking at another 7-10 days before Randy is strong enough to come home.

Dr. Liao will want to start Randy back on chemo again, but we will schedule a visit with Dr. Nichols in Portland first. Randy has to be strong enough to tolerate the therapy and precautions put in place in case this happens again. There was some talk of stem cell replacement, but that will be a decision made after the consultation.

Randy and I are cautiously optimistic. What a blessing it would have been to beat this at the start - we just had no idea the battle would be this difficult. Randy is keeping his spirits up as much as possible.

Until next time . . .

# **January 27, 2010**

I was feeling superstitious and didn't want to jinx anything so I apologize for not posting for 2 weeks. Randy came home from the hospital today after a total of 5 weeks.

He is getting stronger, but feels we are back to square one before radiation with his strength and mobility. His speech is so much better and considering where he was 5 weeks ago, his progress is amazing.

His leg is healing well and his blood counts are back to normal. We are keeping a close eye on his red blood count since he has been borderline anemic and gets very fatigued quickly. We will be starting an in-home physical therapy program in addition to having a nurse come out and do vitals/blood draws, etc. Friday is a follow-up appointment with the oncologist and then we'll be heading down to Portland in the next week or two to meet with Dr. Nichols. Randy had an MRI on Monday and it appears the cancer has not progressed any further since radiation, I didn't get specifics on the existing tumors, but will find out after Dr. Liao and the radiologist have reviewed the scans.

Everyone is holding up well considering all that has gone on. We are all adjusting to having Randy home - the dogs were so excited to see him, both of them just sat in the living room looking at him all afternoon.

Take care everyone, I will post some updated photos soon.

Robin

# **February 18, 2010**

Yes, it's been awhile, but I have been waiting to make sure we were through some appointments before posting. This will be a long one -- there is quite a bit to share.

First of all, Randy is doing much better since being home. He is recuperating and working very hard to get his strength back. We have physical and occupational therapy coming to the house several times a week to work with him.

We made the visit to Portland on February 4th for the consultation with Dr. Nichols. It was a little discouraging because he felt that Randy's cancer was not testicular. He has only seen 2-3 cases where the cancer has skipped the torso and formed in the brain. Needless to say we were pretty disappointed and concerned. The trip back was a long one. Thank goodness my best friend Cheryl went along to help out - it was nice to have her there for support both emotionally and physically. Dr. Nichols' recommendation was to perform a biopsy on the tumor in the front (I am going to start calling it Tumor A and the other ones X-Y-Z) to verify the type of cancer.

When we returned to visit Dr. Liao, he was very surprised at what Dr. Nichols had said. He did not agree and feels we are still dealing with testicular cancer. It never really occurred to Randy or me that it could be anything different. We were ready to move forward with a biopsy, but after consulting with a neurosurgeon, the risk of going into that area was too great. The neurosurgeon said that if any surgery was performed, Randy would lose his speech forever. That is not a risk either of us are willing to take right now.

So the next step was to look at <u>Gamma Knife Radiation</u>. It targets the tumors in the brain with concentrated radiation as opposed to full-brain (which Randy had in November).

We met with a gamma knife specialist on Tuesday. You would think that I couldn't be surprised by anything a Dr. says after all we've gone through, but sure enough I was. The radiologist does not recommend Randy undergo Gamma Knife radiation for 2 reasons:

- 1) Tumor A has significantly shrunk since the MRI done in November (Yay!)
- 2) He feels that Tumors X-Y-Z are not cancer at all (Ack!)

Neither of us were expecting this answer. Even if the tumors were not cancer, they are still cause for concern, but talk about being blown away. I was beginning to feel like we were stuck in the Twilight Zone.

After visiting with Dr. Liao today, he is sticking to his guns about it all being testicular cancer. The chances of it being a different kind of cancer or the development of non-malignant tumors x-y-z would be incredibly rare.

Where are we now? The wait and see game. Unless things change, we will schedule another MRI in

4 weeks to compare with the one done on January 25. If the tumors are smaller or have remained the same, we'll continue to watch them. If they show signs of growth or swelling, Dr. Liao will start Randy back on chemotherapy and possibly more radiation. Surgery on any of the tumors is not an option given their location.

Can you believe all of this? I sort of feel like we are starting all over again. We are so thankful that the tumors have decreased and are staying positive that they will continue to shrink.

Everyone has been so wonderful and supportive, I just can't adequately express how much it means to us. THANK YOU, THANK YOU, THANK YOU.

### March 23, 2010

I have good news to share. After the agonizing last couple of weeks waiting, we have confirmation that the tumors are gone!

Both of us are in a semi-state of disbelief due to all of the ups and downs of the last 5 months, but it sure feels good to be heading in the right direction.

We followed up today with the radiologist who administered the radiation treatments back in November. Randy still has nausea every day and his speech has deteriorated a little since leaving the hospital, but the doctor feels that is more than likely due to some residual edema where tumor "A" was.

He would like to follow-up with another MRI in 6 weeks to see how things progress. It is still very early in the recovery phase from radiation and chemo so he did not recommend putting Randy back on steroids until absolutely necessary.

From a physical recovery standpoint, he is continuing to improve on his strength. He is almost out of the wheelchair completely and can get around pretty well with a walker or cane. We still have Physical Therapy coming out to the house 2-3 times per week to work with him.

The wound on his leg is healing, we followed-up with the wound specialist last week and Randy still had some bacteria in his blood which has been delaying the healing process. She put him on antibiotics and we will follow up with her tomorrow.

I can hardly believe it's almost the end of March. We've been working through this for over 9 months now. We are still very optimistic about Randy's recovery and hope that the next few months will be very productive for him.

He also has his moustache and eyebrows back:)

Breathing a huge sigh of relief - until next time, please take care and keep sending support, it's working!

# **April 23, 2010**

This feels so strange - could I really have good news to share - again??

I am happy to report that so far so good. We moved the MRI up to last Friday (the waiting was just killing me), and the results showed no change from March 11th.

The last couple of weeks we have been working diligently to identify the cause of the nausea and I am encouraged that it's been 4 days since he's been feeling sick. We have eliminated almost all of the medication he was on in the hospital and I feel that really helped.

We are scheduled to see the radiologist and a neurologist in two weeks. There does appear to be some damage due to the tumors and radiation, but it's really too soon to tell if it's temporary or permanent. The good news is that the speech issues are mostly motor-related. Randy knows what he wants to say, it's just getting it to come out right that's the struggle. This can be worked on with speech therapy - we'll discuss that with the neurologist.

Randy celebrated his birthday yesterday. 56-years young! He actually felt good enough to have some birthday cake. The phone was ringing off the hook yesterday! It made Randy feel very special to have so many people call and wish him well. Plus it was the NFL draft and Survivor/CSI night - what a day!

Everyone else is hanging in there, we have good days and tough ones. I can hardly believe it's been 10 months since all of this started. Friends and family continue to offer support and although my type "A" personality gets in the way, it is very much appreciated.

I hope you all are doing well

Robin

# May 25, 2010

Just a quick note to let you know that Randy is continuing to improve. Although it is much slower than either of us expected, at least it's going in the right direction. He is off almost all of the medications they gave him during his hospital stay so the nausea is gone which has helped tremendously with his energy level.

We are starting to look at outpatient rehabilitation programs that will include occupational, physical and speech. We are also inquiring about a driving assessment to see if we can get him back to driving and more independent.

Next doctor appt is on the 16th of June. We'll determine when the next MRI should take place and are hoping for the best.

The rest of the family is doing ok and RJ2 Group is still running well thanks to Chase, Matt,

David and Andrew.

We are looking forward to a nice quiet summer, I hope everyone else is too!

# **July 19, 2010**

Wow, I can hardly believe it's been almost 2 months since the last update. Things are still continuing to progress for Randy. He went in for an MRI last Monday and the results came back ok - no new tumors. It had been 12 weeks since the last MRI so we were both anxious about it.

Randy also took a driving assessment and did pretty well, so he is now driving and feeling much more independent. The rehabilitation center told him to take it easy (no night driving or long distances just yet).

We also met with a new neurologist who we both liked. He has explained more to us about Randy's condition than anyone so far. It was nice to get a new perspective and to realize just how lucky Randy is to have come as far as he has through this. Dr. Trivedi called Randy's situation a 3-n-1 trauma. Brain Tumors, Chemotherapy, Radiation and Psychological. Besides a physical blow to the head, you really can't put the brain through more trauma than that.

He said Randy's recovery is still very early and it will take a long time to completely recover (2-3 years). This was very helpful for us in setting expectations. Randy is walking almost every day and can do 1.5 miles (on his own). The wound on his leg is almost healed, we expect another month or so and he won't need to have a bandage anymore. He is going to have one heck of a scar though. His speech is getting a little better and hopefully in August, he can start out-patient therapy at Good Samaritan. The in-home therapy "graduated" him about 2 weeks ago since he was doing so well physically.

He plans to start going to work with Chase and attempt to dispatch next week. This will be a good way for him to ease back into working.

I hope everyone is having a great summer. We finally got ours here in Washington just a week ago. It was in the 90's! Chase and Taylor are doing great and I am halfway through finishing up my classes for my Bachelor's degree. 6 more weeks!

Take care everyone-Robin

# **January 7, 2011**

Happy New Year! I wanted to wait until after the holidays to post an update - didn't want to jinx anything! It was a relief to not be in the hospital on Christmas or New Years.

Randy is 1-year cancer free. The doctors have moved him out to checkups every 6 months instead of

Rehabilitation continues to be the main focus, he is now in outpatient therapy 2 days per week working on balance, strength and speech. He is also able to ride to work with Chase 3 days a week. We have a follow-up with the rehab doctor on January 17 to view the progress and determine the next steps. The neurologist we met with had told us it could be another year or two before he is at the level of recovery possible. Randy looks like himself again (a little more white on top though).

The last several months have been crazy with holidays, a new job for me (back with the Web Team!). Plus a new addition to our family: Miles the Yorkie. Yes, we now have three dogs.

Chase moved out in October. He is renting our old house! He is doing great and enjoying it. He took the cat as well, so that makes me happy too.

Thank you for the Christmas cards this year and continued well wishes. I hope to keep in touch this year about more positive things!

### May 30, 2013

Hello everyone - I was hoping to not have to update this site until June of 2014, when it would have been 5 years that Randy was in remission.

Unfortunately, an annual MRI he had in April showed a small tumor in his brain. In addition, a lesion had started to show up on his face under his left eye that also turned out to be cancer.

The pathology from the tumor on his face has been diagnosed as Lymphoma.

Yesterday, Randy had surgery to remove the tumor in his brain. He is doing well and will be moving out of ICU today. He will be in the hospital for the next several days.

Next week, we have a follow-up with the oncologist to discuss the next phase of treatment that will include chemo and radiation. The positive news this time around is that we actually know what kind of cancer to treat. The last time it was a guess since surgery was not an option. It is possible that the cancer he had 4 years ago was also Lymphoma and not Testicular.

As always, we are hoping for the best. It was a shock after 4 years in remission that the cancer returned. We have made it through plenty of trials over the last several years, we will make it through this one too.

I will post again after the appointment next Wednesday.

Take care-Robin

# **Post Surgery - Next Steps**

June 10, 2013 The surgery went very well. The surgeon and pathology reports confirmed it is B-Cell Lymphoma.

We met with Dr. Liao (Oncologist) last Wednesday and Randy will start chemotherapy next Monday, June 17th. He will have one day a week (8 hours in the chair), for 9 weeks for the tumor on his face. Dr. Liao is working up the plan to treat the brain, which will be more chemo.

Randy is doing well - considering everything. I posted some post surgery pictures, he will have a gnarly scar, but his hair should hide it once it grows back after chemo.

Randy will also have his bone marrow and spinal fluid tested to verify the cancer has not spread any further.

Thanks so much for all the well wishes, it means the world to all of us.

# **Update - Finally!**

July 31, 2013 First of all, I am sorry it's taken so long to update the journal. It has been a crazy ride the last 6 weeks. I am finding that this time around it is actually harder for me to talk or write about what's going on without getting completely overwhelmed. Even though the cancer is back and we've been through it before, it's a new experience.

Randy is doing well. He has started chemotherapy treatment. There have been complications with a blood clot in his arm and his kidneys having difficulty with one of the stronger chemotherapy drugs (he is taking 3 of them). It was so bad that Randy cannot take any more of the Methotrexate. Unfortunately that drug is the best one to tackle the cancer in the brain.

One of the options is to put Randy on dialysis while getting the drug administered in the hospital so it won't go through his kidneys. This requires a 2-4 day hospital stay every other week.

We also saw a radiologist and since Randy received whole brain radiation last time, he cannot have more without serious side effects.

We will be making an appointment with the Cancer Care Alliance group in Seattle in the next week or so. Given the history and Randy's current state we'd like a second opinion on what the options are.

Chase, Taylor and I are hanging in there and managing the best we can. Taylor has been great in helping Randy during the day so I can go to work. I have been at Coinstar/Redbox for 4 months now and they are very supportive - I just can't take the same amount of time off like before w/out financial repercussions.

Thank you for the emails and the posts to the Guestbook - they really do help and I hope you understand if I don't get back to everyone individually. At times it feels like I am not handling this as well as last time, but I am trying to remember to take it one day at a time and support my family as much as possible.

Thanks for listening (reading).

Robin

# Still Fighting:)

October 13, 2013

Randy has settled into a new treatment plan now. Back in July he had difficulties with one of the chemo drugs (Methotrexate). After consulting with the doctors at UW Medical, they have recommended an alternate drug called Ara-C. It is given in the hospital intravenously and requires a 4-5 day stay to monitor kidneys and blood counts. Randy had his first treatment on Sept 30.

One of the side effects is a low white blood cell count and that is happening now. Randy is getting shots every day to help bring them back up to an acceptable level. This makes him pretty tired most of the time and we are keeping a close eye on him to make sure he isn't exposed to anyone with a cold or flu (he did get his shot in the hospital.).

I guess the most sobering news is that he will need to continue this therapy for another 5-6 months. Taylor and I are making sure he gets plenty of rest and is staying hydrated. I am not sure when the next MRI will be scheduled, I am sure they will want a few months of the full-cycle of chemo drugs.

The rest of the family is doing well - as always, taking it one day at a time.

Take care-Robin

# Has it really been six months?

April 7, 2014

I was just reading my last entry and I can hardly believe it's been six months. So much has gone on, it's really quite incredible. The most important thing is that Randy is doing ok right now.

This is going to be a long post so bear with me.

Right before Thanksgiving Randy had a MRI and the tumor they removed in May of last year had grown back and was 50% bigger than the original one. This was pretty sobering news. Back in 2009, he had enough radiation to last his lifetime. This includes both whole brain and gamma-knife radiation (pinpointed). They also cannot operate on him due to the risks of blood clots and brain damage.

The only other option we had was to start the methotrexate chemo again (the one that caused him so many problems last July with his kidneys). Since it was so close to the holidays we made the decision to wait until after Christmas to start the treatment. From there it's been a bit of a roller coaster.

He had his first treatment January 6th. The chemo has to be administered in the hospital and requires a full week stay. The schedule is to have the chemo administered every other week. They spend the first day pumping him full of fluids to get ready for the methotrexate and then the last couple of days getting it flushed through his system. This time, they gave him medicine to help protect his kidneys and it worked! That was great news.

The 2nd week of January, Randy developed a fever and ended up back in the hospital with a blood infection. They did a CT scan and the pictures showed that the tumor had grown about 30% since November and was causing an alarming amount of swelling in the brain. They put him on steroids and antibiotics right away. He was in critical care for about 5 days.

Since then he's been in the hospital more than he has been out. He ended up in the emergency room a few times with dehydration and ANOTHER blood infection. They had to take out his chest port and install a PICC line in his arm. This latest crisis and aggressive chemo schedule took a toll on his poor body. He is back in a wheelchair now because he just doesn't have the strength to support himself. The good news is that the latest MRI showed a decrease in the tumor of 60%. He has had 2 more treatments since then so we are encouraged that the next MRI will be good news.

Given the new demands of the disability, I have hired home health services to come in and take care of him while I am at work. Taylor has been really great with all she's done in the past year, but I cannot ask her to take care of her dad to this extent. It's difficult for me to maintain - and we all know that I am wonder woman;)

So, we have good news that the chemo is working on the tumor, but sobering news in Randy's overall strength. He is working with Physical Therapy on a regular basis and given all we know about my Superman, he's not giving up.

I know that many of you have offered and asked what you can do for us. The truthful answer is that the day stuff is pretty well taken care of. Our family has defined a new "normal" and is adjusting. For Randy, visits while he is in the hospital really make him happy. As you can imagine a full week stay is pretty boring and lonely for him. I will post when he will be at Good Samaritan in Puyallup on this site and if your schedule allows, he would be thrilled to have some company.

Thanks to all of you for your prayers and support. If you post a message to Randy on this site, I will be sure he gets to see it.

#### **Comments**

Thank you so much Robin for the update... you must have been getting my vibes. Please let us know the weeks when Randy would appreciate a hospital visit and we'll just come on down. Bless your little hearts for being so brave through all of this. You and the kids are amazing. Love Amy & Thyce

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-Amy Colyn, April 9, 2014
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Dearest Randy, Robin, Taylor, and Chase: There are not words to say how grateful I am for prayer and for modern medicine. I love all of you so very much and my heart aches for all of you. I will put your names on the prayer roll at our temple. I believe in miracles and have seen many come to pass in our lives.

Please don't hesitate to give me a call if there is anything I can do for you. Cancer is such a horrible thing to have to go through. I hope Randy gets some relief very soon.

We will be cheering for you. Love you always, "Grandma Ruth" You will always be a part of the family of my heart.

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-Ruth Ann, April 9, 2014
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Robin, Thank so much for the update - great news that the tumor is shrinking and Randy feels well enough to get bored in the hospital! You have been fighting the battle with all your might - Warriors! Please give Randy and the kids big hugs from us - You are in our prayers!

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—Lisa & Fred Gallagher, April 8, 2014
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Praying for all of you. Keep up the fight, Randy! I am thinking positive and that Robin's next post will be that the tumor is gone. Stay strong!

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—Stephanie Goff, April 8, 2014
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Robin, thanks for the update. I've been thinking of you a lot lately and wondering how Randy's doing. Glad to hear that there's good news with his treatment progress. You all have been through so much, it's hard to imagine. Such a strong family. Keeping you in my prayers. Miss you.

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-Gayle Rembaugh, April 8, 2014
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Hi you guys. Just thought I would let you know I'm coming out on the 4th of May. I checked with Mom and she says Randy should be home that week, barring any unforeseen complications. Can't wait to see you all. Love you Renee

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—Renee Smith, April 8, 2014
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# **April Update - Randy**

April 28, 2014

It's been a year since Randy was diagnosed with B-Cell Lymphoma. You've all been on this roller coaster ride with us for the last 5 years and all of the love and support has been humbling. Randy is the bravest man I know and I am so lucky to be his wife.

Since the last post (I know, only a few weeks ago), things have changed again. Randy's MRI results on April 8 showed that the tumor is not responding to the chemotherapy and has grown. It is now about twice the size as the one they found a year ago. There is also quite a bit of swelling that we are treating with steroids. Since the methotrexate is no longer working, Randy does not need to be in the hospital every other week (which makes him very happy).

Given all of the regimens Randy has already received, the last resort is experimental therapies. The first therapy is a drug that is used to treat lung cancer (Alimta). There is a clinical study going on right now to research the impact on brain lymphoma. This treatment has been tried on just 13 other people in the country. There is not much information on it since the trial is still in process. The risk is that Randy is getting about 15 times the normal dose, and we won't know how he will respond or the extent of the side effects. He had his first dose last Thursday. The schedule is to administer the chemo every 3 weeks. After the 2nd treatment the Dr. will have an MRI done to see if the cancer responds.

The other drug is called Bendamustine and is primarily used to treat leukemia. It has shown some success in treating Lymphoma, but the side effects are much more severe. If the Alimta does not work, we will try this therapy.

I don't want to sound like we've given up or have lost hope, but I do need to be honest and let everyone know that the prognosis for Randy is not good. Left untreated the brain tumor will continue to grow and Randy will most likely slip into a coma and die. There is no timeframe for this and could happen at any time.

I so desperately want to be proven wrong and hope that I am. I want to encourage anyone who wants to visit with Randy to do so soon. It truly is better to be safe than sorry.

If you would like to arrange for a visit, please email me at rjsquared@comcast.net. I don't want to overwhelm him with many visitors at the same time so will need to manage the visits.

I have recently needed to hire home care services during the day so I can maintain a somewhat normal schedule. My company has been extremely supportive during this and I will know when I need to be with Randy more.

My dearest family and friends, I am truly sorry to convey this news. It feels very surreal and there is a part of me that wants to believe I am over-reacting. I would rather be proven wrong and know that I did everything within my power to ensure you have an opportunity to visit before it's too late.

Love Robin

#### **Comments**

I love u brother and hope to see u this Saturday if it's a good time for u guys. I'm praying always and thinking of

u. Love ur lil sis, vicki johnson-krumm

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-vicki johnson-krumm, May 7, 2014
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Robin, I feel compelled tonight to send you and Randy and Chase and Taylor hugs and much love. Sending so many loving thoughts and prayers toward you all. May you be surrounded by pure love and find hope and comfort in each other.

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-Cousin Lisa, May 5, 2014
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Robin,Randy and family, Our prayers are for all of you. What a remarkable family you are! Your strength, your heart, and your wisdom are so great, we admire you and love you!! May your guardian angels keep you safe on this path.

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—love you all =Mary, May 3, 2014
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Robin - thank you for making this post, I know it's difficult to do. You're strength and dedication has inspired me throughout this ordeal. Randy's optimism is also an amazing this, he's still strong as an ox, if anyone can beat this damn thing it's Randy, with you by his side.

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—Love you - Cheryl, April 29, 2014
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Robin, my thoughts and prayers are with you and your family. Hang in there and stay strong.

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—Darryl, April 29, 2014
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Robin and Randy, it's so impossible to imagine what you are going through - as a couple, as a family, and as individual human beings. I just know that you are the strongest people I know and you will remain so in this life and beyond. Sending love and prayers for Randy's brain to respond well to this experimental treatment and for your continued strength.

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—Love, Gayle, April 28, 2014
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Oh, Robin and Randy, I am so sorry. Life is not fair sometimes, but at least we have the next life to look forward to. Without, life really would be hopeless. I will put Randy's name on our temple prayer roll. I would love to come see all of you. You can give me a call and we can figure out the logistics and time. I love and miss your family.

—Love you, Gma Ruth, April 28, 2014

Robin- please know that even though we don't know you very well, our thoughts and prayers are with you and Randy at this difficult time. May you be able to have the best and longest time possible together.

-Vicki Martinez, April 28, 2014

# July Update on Randy

July 13, 2014

Randy had his second MRI last Monday and unfortunately, the experimental chemo has stopped working. The tumor has grown back again and is the same size as before he started. Apparently, this is a common occurrence with this type of brain lymphoma. Initially the treatment has a positive impact, but the cancer is so aggressive, it loses its effectiveness with the way the brain is designed to protect itself.

We met with his oncologist on Friday and there is one more drug to try called Bendamustine. This treatment is for Lymphoma, but has never been used to treat it in the brain. Given the complexity of trying to get the medicine to the brain, there is 20% chance that this will be effective. Dr. Liao has been working with neurology oncology department at UW Medical.

The treatment starts tomorrow and is given every 3 weeks. After the 2nd treatment on August 4th, he needs to wait 2 weeks before getting another MRI (week of August 18th). If it works, Randy will continue a 5 week cycle to keep the cancer from growing, extending his life for as long as possible.

If the treatment doesn't work, we are out of options. We asked for the prognosis and Dr. Liao said Randy will have less than 3 months.

This is really hard news to share, the kids and I are trying to enjoy the time we have.

We are all truly grateful for the well wishes and prayers you have sent our way.

#### Comments

If there is anything I can do, please don't hesitate to let me know. For the past year I have weekly

added Randy's name to our healing prayers at church. Please know so many people have him in their thoughts and prayers and only wish the best for Randy and your entire family.

—Linda Melhoff, August 7, 2014

Sending more love and heartfelt prayers to you all. I hope the treatment is doing its job and you are sharing some precious family time. I pray for you for closeness to each other and the Lord, for healing and strength and joy and peace and seeing the aching beauty in your lives, even now. My love to you all, Lisa

—Cousin Lisa, August 6, 2014

Ok, pesky me, back again! I have been stalking Jake's wedding on face book and I just can't believe that he is getting married - so very happy for them. I think of you guys all the time and pray daily for your health and happiness and that the treatment will work. And for your strength because being sick is crappy. I hope you don't mind, but I want to write every now and then so that you know so much love and well-wishing and praying is coming your way. You are my family and my heart hangs on every word we hear about how you all are doing. Anyway, just a Sunday check-in - love to each of you! Lisa

-Cousin Lisa, July 27, 2014

Hey Randy, I have been praying for you and keeping you and Robin in my thoughts every day, many times a day! I pray for healing and strength - I know what a great warrior you are. I am hoping you are able to enjoy looking outside at the beautiful sunshine and the mountain that sits in your backyard. I always thinks God must love us a lot to give us so much beauty in our surroundings. I am at my computer listening to the birds outside just enjoying their songs, and I hope that even through this chemo and treatment you are able to see the beauty and hear the music too. As we all know, the little things turn out to be the best things sometimes. Every day, our hearts are with you, may God bless you today all day long. Love you all so much, Lisa

—Cousin Lisa, July 21, 2014

Randy you hang in there and know that only God makes the decision when he wants his angel back. I am praying. Robin please reach out to me if you need anything. Love you guys! Love Dee

—Dee (creamypeanutbutter), July 16, 2014

Robin and Randy, words cannot express my care and concern for you all but please know you are in my prayers :-)

—Cindy Moores, July 14, 2014

Randy: We wish you the best with the above treatment. I can only imagine the trials you have endured. If there is anything we may do let us know. Phil & Nancy

—Philip Johnson, July 14, 2014

We love you and we are praying that this will be the right treatment.

—love you all =Mary, July 13, 2014

# **September Update on Randy**

September 6, 2014

Dear Family and Friends -

A lot has happened in the last few months with Randy's treatment. After several rounds of different kinds of chemotherapy, we are at the end of this journey for a recovery from the lymphoma. We've had numerous discussions with specialists and with each other and have decided as a family to try and cherish what time Randy has left.

One of Randy's wishes was to stay at home so Hospice has been called and now we are trying to make Randy as comfortable as we can. He has declined quickly over the last 10 days and is confined to bed. The blessing is that he is not in a lot of pain and is sleeping most of the time.

Now I ask for your prayers to help Randy pass peacefully and to give me strength to help Chase and Taylor through this difficult time.

I still have a home health nurse coming in Monday through Friday (8-3) and Randy's sister Cindy as well as my sister and parents are standing by to help with whatever is needed.

Love to everyone -Robin

#### **Comments**

Robin - Please let Randy know I cherish the memories we made together! Tooling around in the Suzuki Samurai and the Celica terrorizing the Seattle area! Ramming the boat into the dock coming back from Alaska because you were standing there waiting and he found out you were pregnant! So many good times spinning through my head right now. Thank you both for some of the best memories of my life! Cheers!

—Jayme Thompson Crew Member of Suzie Q and Friend!, September 15, 2014

Robin - I'm thinking of you and your family, praying for a pain-free passing. Cherish this time with him; I know you have the strength to get yourself, Taylor & Chase through this tough time. I'm so

sorry you have to go through this.

-Margaret Larkey, September 8, 2014

I hardly know what to say except you are all in my prayers. Randy has a wonderful family and he will be missed by so many people. Cherish the time you have left with Randy on this side of heaven. Hugs to you all. May God hold you all close in his arms and give you strength, comfort, and love.

—stephanie goff, September 8, 2014

Our hearts are full as we think of the many cherished moments with all of you. You will always be a part of our family. Please give Randy a hug and kiss from us. Stay in touch.

We are so sorry that he is losing this battle, but in the end, he will triumph and be free of the suffering that he has so valiantly endured. Chase and Taylor will be fine, they are strong and wonderful young adults. After the initial pain has subsided, they will have so many wonderful moments to reflect and find comfort and joy from. It is never easy to let go of someone you love so very much, but it is made easier to not have to see them suffering any more. I lost my dad when I was 22 and my mom when I was 27, just weeks before Britney was born. It was so difficult. But, that passed and I still have many sweet memories and a heart filled with gratitude for their presence and influence in my life. Now both of my brothers have passed and I am the lone survivor. Feels a little surreal at times, like when I type it. Thank you for being such a wonderful part of my life and filling my heart to overflowing with love. We will keep you all in our prayers. Love you, Gma Ruthie

-Ruth Ann Evenson, September 8, 2014

I have been praying for a gentle transition and strength for your family. I wish I had words that better convey how I feel, but please know I am thinking of you all every day.

—Linda Melhoff, September 7, 2014

Robin my prayers are with you and the Family. God will give you strength and keep you strong. I will you and the family in my prayers and please reach out if you need anything.

-Love Dee Ford, September 6, 2014

Robin - I am so saddened to hear this. My prayers are with you and your children and all family members. I do pray peace, comfort and strength over you. Our God is great and mighty. May His peace that surpasses ALL understanding rest upon you.. I worked for Dr. Nieman for a number of years and I always enjoyed you and your family.

—Patti Goff, September 6, 2014

#### **Our Final Post**

September 19, 2014

Dear Family and Friends:

Randy passed away last night around 9pm. Taylor, Chase, my sister and I were there to comfort him and say our goodbyes. He did not appear to be in any pain and I can say that he looked very much at peace.

The last 5 years has been such a journey and struggle and I cannot begin to even convey in words how much your love, prayers and support has meant to all of us. Randy knew how much everyone was pulling for him.

Since Randy loved Hawaii so much, we put a new Hawaiian shirt on him that his sister Cindy had given to him on his 60th birthday in April. He had on his favorite swim shorts too and looked so handsome.

I will be in touch with everyone soon regarding a memorial. Randy's wishes were to be cremated and spread in the Ocean for his love of fishing, and Crystal Mountain for his love of skiing. Randy also did not want a typical funeral. He wants us to have a crazy Hawaiian Shirt party to celebrate his amazing love of life and I cannot think of a better way to pay tribute to him. My email address is rjsquared@comcast.net. and if you want to provide me your email address, please do.

Forever grateful, Robin

#### **Comments**

Robin, Chase and Taylor my heart is with you! I love your dad and have so many find memories of him. My love to you all during this time.

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—Stephanie Jones (Evenson), September 21, 2014
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Robin, Chase and Taylor, there are no words that can express the sorrow I feel for you on loosing such a wonderful man..may the love of your family and friends wrap you in warmth and prayers. Please let me know when his memorial is, hugs to all.

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—love you all =Mary, September 20, 2014
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Oh, Robin. I'm usually not at a loss for words, but I just can't convey how sorry I am for you and your family. He may not be there physically, but he will be there spiritually loving and guiding you all from the other side.

Please do let us know when his memorial is: melhoffl@gmail.com. Big hug.

—Linda Melhoff, September 19, 2014

It doesn't matter a whit Robin. The Dude still abides so long as he is in Your, Taylor's and Chase's hearts. I can only imagine that that's what he'd want. No more. No less.

Be as well as you can be, but be comforted in the great life and times that you shared.

-Ken McIntyre, September 19, 2014

Oh My,

Kim and I are so saddened by this news. Randy was my kind of guy. Our deepest sympathy and condolences pour out to you and your family. I sincerely hope you are getting some sense of relief from his long, long illness; and if not now soon.

We will certainly be attending his shirt party. Tommy Bahama will arrive in the inimitable style of The Dude with the Dudette. Please let us know when this shindig is, and you can reach me if you don't have my email address.

Robin - may the Lord bless you, keep you and make His face shine on you just as he is Randy right now...

-Glenn Melton, September 19, 2014

Oh My, Robin - I am so sorry for you and your family. This has been going on for so long now. I hope you too are at peace. Kim and I will definitely join you for Randy's Crazy celebration. see you then. Until then please know we are praying for you for your peace of mind and a sense of relief.

Our deepest sympathy and condolences,

—Glenn Melton, September 19, 2014