

On the morning of September 20th, 2003, Deb and I went to Novato Community hospital after Deb suffered through a night of paralysing headaches and vomiting. After a CT scan we were told that Deb had a brain tumor. The description of what we felt at that time can't be put in writing. Three hours later we were on our way to UCSF in an ambulance. Deb had surgery on Sept 22nd after two long days of tests, disbelief and numbness. Deb was clearly the strongest throughout this period of time.

The tumor is located near the thalamus and very close to the area of the brain that controls motor skills and speech. Because of its location the tumor was deemed inoperable and only a biopsy was taken. The pathology report classified the tumor as an [Anaplastic Astrocytoma](#). Brain tumors are given a 'grading' on a scale of 1 to 4. Grade four would be considered the most aggressive tumor type. Deb's tumor is a grade three.

Deb remained in the hospital for five days after surgery. She was out of bed and walking within three days. The doctors intention was to attack this growth aggressively and four weeks later she began attending radiation and chemotherapy at Marin General. She attended radiation daily for six weeks with the weekends off and took chemotherapy in the form of a pill ([TEMODAR](#)) on a daily basis.

Once again, throughout this time, Deb was amazingly strong and handled the mixture of radiation and chemo very well. All of the doctors we met with were surprised by how little hair she had lost and at the high energy levels she had during this time.

At the end of the six weeks we had our first set of MRI's done and we were all anxious for the results. In hindsight, probably too anxious. The first post-radiation scans showed no change in the tumor size. We have come to realize now that 'no change' is a good thing. At the time of the

scan results I think most of us were disappointed the tumor had not shrunk. Deb had been feeling so good at the time that I really thought we would see a reduction in the tumor. It was another tough day in that we now had to head back to UCSF to talk about the next step.

One of the things we have found out about the treatment of such a disease is that there are no true answers as to what to do. There are no guarantees and the medical consultants, as great as they are, have no definitive answers 95% of the time with regard to treatment.

I think we all came to realize this upon our visit to UCSF. They confirmed what we found out at Marin General and offered three options. Again, they couldn't tell us the best way to go. Option one was to continue on the Temodar (Chemo Pill) and monitor the Tumor with scans every two months. The most common side effects associated with TEMODAR therapy are nausea, vomiting, headache, fatigue, and constipation.

Option two was to utilize Temodar but do so in conjunction with another drug known as Thalidomide. It's been noted that thalidomide can prevent the formation of new blood vessels in tumors. In order for a rapidly growing tumor to maintain its growth, a tumor "signals" already existing blood vessels to sprout new branches to feed it. Without a supply of oxygen and other nutrients, tumor growth would be impaired. Thalidomide (tha-lid-o-mide) was first marketed in Europe in the late 1950's. It was used as a sleeping pill and to treat morning sickness during pregnancy. At that time no one knew thalidomide caused birth defects. Other side effects include drowsiness and constipation (most common) as well as rash and neuropathy (nerve damage) in the arms and legs.

Option three was to sign up for a clinical trial that UCSF was currently running. Deb just happened to fit the qualifications. The trial was for an experimental drug clinically referred to as OSI-774. The

generic name being [Tarceva](#). Tarceva is one of a new class of cancer drugs, known as EGFR inhibitors, which seek to stop the spread of cancer cells by blocking a protein associated their growth. The side effects include the following: Rash, Acne, Diarrhea, Nausea, Vomiting, Headache and Fatigue.

So these were our options from which we would have to 'guess' the best one. The Neurologists at UCSF presented options two and three as the most aggressive and made us feel that 'aggressive' was they way to go. Naturally, we wanted to be as aggressive as possible so option one was ruled out.

We left UCSF and began researching our options. We read all we could on these drugs and spoke with numerous other doctors about option two and three. Again, there were no definitive answers.

After a week of picking apart our options Debbie decided on the clinical trial. I think all of us favored the drugs intention and its low toxicity level. By far the side effects were not as severe as in option two. Deb wasn't to fired up on the rash (acne) that was pretty much guaranteed to appear but if the drug worked as hoped it then bring it on! With the decision made we scheduled an overnight stay at UCSF to get things started.

Deb started on the OSI on a daily basis. As she was coming in on the tail end of the phase I trial the acceptable dosage had already been determined by other study participants. Deb was on the maximum amount of OSI.

The first couple of weeks went by without incident. Deb took the OSI everyday and within a week or so a rash began to appear. It never got as bad as it was described. For her, it was contained to the chin and looked like acne. It was pretty minimal. Eventually, the time came to start on the Temodar again. It's taken in a 28 day cycle with five days of taking the pills and 23 days off. There

were no problems at first but starting around the day twelve of the Temodar cycle she started to feel pressure in her head. It would come and go throughout the day and sometimes Ibuprofen seemed to do the trick. Unfortunately, as the days progressed so did the pressure until eventually Deb was in a state much similar to the evening before we went to Novato Community and received the initial diagnosis.

It was very difficult to watch. These headaches were beyond anything most of us have ever experienced and I can only imagine the pain she felt. There seemed to be no position that relieved the pain. Sleep seemed to be out of the question. Ibuprofen no longer worked and when we tried Norco (Extra strength Vicodin) she just threw it up. Once again we went to Novato Community and in all honesty I thought we were heading back to UCSF for surgery. They did a CT scan and found no change in the tumor. After an IV of saline and a huge dose of Decadron (controls the brain swelling) we were sent home. After a few days the headaches subsided and Deb started to feel better. Never during this time did Deb complain. She had every right to....she just doesn't. She is very strong.

As the next Temodar cycle began we went through the same thing. The pressure and headaches seemed to come on around the 10th day of the Temodar chemo cycle. For the past six weeks Deb had taken Temodar without issue. Only when she began mixing in the OSI did these pressure patterns start to appear.

What to do? The headaches certainly seemed related to the introduction of OSI but do we stop the trial? What if the drug is working? More decisions had to be made. As it turned out the decision was made for us. The last set of scans (2nd set) showed an increase of 'blood product' around the tumor. It had appeared in the first scans but now seemed to be a bit larger. The doctors refer to it as 'blood

product'. We know it as hemorrhaging.

We were told that a drug similar to OSI-774 had been shown to produce hemorrhaging in rare occurrences. Because of this UCSF has opted not to take any chances and removed Deb from the clinical trial. The decision was made for us and I think we all feel good about it. Deb stopped the OSI on February 27th and started her next round of Temodar on March 1st. As I write this today, March 7th, she has not felt pressure and has regained her appetite. Next week will be the big test. Traditionally, it would be about 10 days (March 11th) after starting back on the Temodar that the pressure and headaches would return.

Deb is on a real roll ever since she stopped the clinical trial and the OSI-774 She has been feeling good for the past eight or nine days. So good in fact, that she went running today. I'm close to concluding that the OSI was doing more harm than good. Life seems pretty normal.

We heard back regarding our second opinion from Cedar Sinai today and they have made the recommendation of [Stereotactic Radiotherapy](#). It's been showing some positive results. If Deb qualifies we could go for the treatments over in the East Bay at John Muir Medical Center. I'll be on the phones tomorrow making arrangements to get over there.

2/20/04

Deb had her second set of MRI's today.

2/23/04

We met with Dr. Prados today at UCSF. No growth in the Tumor! Deb has been on the clinical trial drug OSI-774. OSI is an experimental form of Chemo and Deb takes it in conjunction with her other chemo drug Temodar. Prados noted today that the tumor

may even look smaller in some areas. An area of concern was a small amount of hemorrhaging that had shown up on the original scans and seems to have grown as indicated by the latest scans. Dr. Prados will be bringing Deb's case in front of the UCSF Tumor Board this upcoming Thursday. Until then he has asked Deb to stop the clinical trial until further notice. We should hear back from UCSF by the end of the week.

2/27/04

Dr. Prados called today and felt it was in Deb's best interest to stop the clinical trial.

There is concern over the area on the scans referred to as "Blood Product". My understanding is that there is a drug similar to OSI-774 that has in rare cases shown to be a cause of hemorrhaging. Perhaps it's best....one less poison going into Deb's body.

3/9/04

We heard back from one of our outside scan reviews (second opinion). This one was from Cedar Sinai in Los Angeles. It was sent down for review by Dr. Keith Black. He is "the man" when it comes to cutting edge treatment of brain tumors. Deb spoke with one of his neurosurgeons who said they recommended fractionated radiotherapy. I have not had a chance to speak with them yet but we have a new option to consider at this time. I'm all over the phones today trying to find out more about this treatment . Will keep you posted after speaking with Cedar Sinai and learning more about their recommendation.

3/9/04

Spoke with Dr. John Yu of Cedar Sinai. He highly recommends the radiotherapy and says they have seen "amazing" results with its use. We are very fortunate that this treatment is offered over in the East Bay at John Muir Medical Center. We will now work through UCSF and the insurance companies to get Deb over to John Muir.

Deb is
on a real roll ever since she stopped the clinical trial and the OSI-774. She has
been
feeling good for the past eight or nine days. So good in fact, that she went running
today.

3/12/04

First off, Deb is feeling great and has continued with her running. I'm working from
home today and plan on taking Deb on a mountain bike ride. SWEET! This will be
her
first ride and our first together since the week before she was diagnosed. It looks
like
the next MRI will be on the 26th with a meeting at UCSF on the 29th. Until then we
are
going to hold off on the Radiotherapy. I've spoken to UCSF about it and they have
some reservations. It also seems that the more research we do the more we find
out
about some risks involved. These can be pretty substantial. We certainly want to
be
proactive as opposed to reactive but at the same time we don't want to try and fix
something that isn't broken. Deb is doing very well at the moment so we have
decided
to get the MRI on the 26th and make decisions based on what we see. Once again,
we
live MRI to MRI. These are beautiful days with great weather and lot's of energy
around the house. Deb is herself and I'm loving every minute of it. We continue to
kick
this tumor in the butt!

3/15/04

Deb continues to feel well. A bit tired over the past few days but she continues
with her
running. Deb took a big step yesterday when she drove her jeep to the store by
herself for the first time since she was diagnosed. Her recovery is evident as she
has
expressed interest in shopping for new clothes.....something that she had no
desire to
do while she was feeling poorly. Actually, I remember distinctly asking the surgeon
at
UCSF to remove the 'shopping' part of her motor strip during surgery...looks like
he

missed it!

3/26/04

Marin Magnetic Imaging called today and told us we had to reschedule the MRI due to glitches in the scanner. That means we also have to reschedule the appointment we have at UCSF on Monday, March 29th. A big disappointment. Deb has continued to feel great so we are all anxious for the next scan. As I've mentioned before it's best to stay cautiously optimistic. Deb is now completely off of the anti-seizure medication; Dilantin. She has also dramatically reduced the amount of Decadron (anti-brain swelling) medication that she takes on a daily basis. Both have numerous negative side effects so it goes without saying that Deb is very happy with the reduction of drugs she takes everyday. She continues with the Eastern herbs and supplements to build up her immune system.

3/30/04

Deb and I didn't sleep well last night knowing we were going in for the results of yesterday's MRI. It's always a bit stressful anticipating the news. GREAT REPORT though.

As you may remember, this MRI was scheduled a month early because the last one done on February 23rd showed signs of hemorrhaging. Yesterday's scans showed the same 'blood product' but it had not grown and the doctors now feel it's just a matter of time before Deb's brain absorbs the blood. The absorption of blood and dead cells is a natural process although it takes time. The tumor has not grown and at the moment is classified as 'stabilized' We both looked at each other in relief when we heard the news. The doctor was very happy with the results and feels Deb is doing very well.

Let me give you an idea of how these visits go. We get there on time and an hour later we are seen. Deb goes through a series of strength and reflex tests of which she has

always done well even when the tumor was in full force. The doctor makes her push
and pull on his hands with her hands. She pushes and pulls with her legs. He wiggles
his fingers off to the sides of her head checking her vision. He watches her stand still
with her eyes closed and she gets to walk the straight line as if she has been pulled
over and is being tested for drunk driving. Her favorite is when he pulls out the drum
stick and hits her in the knees and elbows to test her reflexes. We are thinking about
buying our own stick so we can have fun at home during our down time. Only after the
series of test are done do we find out the results of the MRI. Did I mention they are
posted on the wall all lit up and ready to go during the whole physical? I just sit there
trying to figure out if the tumor has shrunk or grown. It's a long five minutes. The last
test they do is looking in her eyes at the optical nerve. They can determine the extent
of pressure by looking through the pupils. Today the optical nerve looked better than it
had since this all began.

We were kind of at a loss for words today at the end of the meeting. As far as UCSF is
concerned Deb continues on the chemotherapy cycles (next one starts tomorrow) and
we go back for another MRI in two months. Until then.....we just live. It's a strange
feeling hearing them say that because it's not a lot to do considering how serious the
situation is.

Anyway, that's their plan. I've said it before and I'll say it again. You have to take
control of your own recovery if you expect to beat a tumor like this. Don't get me
wrong. UCSF has been great and done a lot for us. As a matter of fact, they saved
Deb's life. It's just that there is no way we are going to relax until the next MRI and
hope things turn out well. There are no suggestions from UCSF as to what else we
should be doing to beat this. Unless it's been scientifically proven over time then it
holds no merit. They don't tell you NOT to do things other than their treatment but they
don't encourage it either.

That's where we take control. Deb will continue on with her Eastern herbs and supplements. She will continue her visualizations of the tumor dying and leaving her

body. She will continue massage therapy and periodic visits with healers. She continues to exercise and eat healthy. Most of all she continues to receive and appreciate the positive thoughts and prayers that all of you send on a daily basis. Cruising along until the next MRI and hoping for good results without putting any energy besides chemo into your recovery is asking for trouble. What do I know?

Am I a

doctor? I'm not a doctor but feel like one these days and I simply know that we are not

going to sit and wait for monthly results without being extremely proactive in between. If

I thought frog legs would help Deb she would be eating them daily! This is how you

beat a brain tumor! Probably more than you asked for but it makes me feel better writing it down.

I almost forgot. We asked about the use of Radiotherapy as suggested by Cedar Sinai.

UCSF feels it would be a last resort option as it can have serious side effects including

paralysis. As Deb is doing so well it just doesn't make sense to do something so extreme at this time.

Until next time.....

4/13/04

Deb continued on her roll since the last update on 3/30. Feeling good, exercising and

eating well. She started her next chemo cycle on Wednesday, March 30th. Two days

later on Friday we noticed a rash appearing on her chest and back so we called UCSF.

We were aware that a rash is something to watch for. UCSF recommended that we stop the chemo cycle two days into it and wait through the weekend to see if the rash

cleared up. A rash can indicate an allergic reaction to the Temodar (chemo). It's something that doesn't always appear in the first couple of cycles as it takes time to

build up in your system. Unfortunately, if it persists it can turn into a real itchy

mess
and in most cases one would be taken off the Temodar indefinitely. This made us a bit nervous as Temodar is one of the most effective chemotherapy's currently available for a brain tumor.

The weekend came and went and the rash disappeared so Deb proceeded with the rest of her chemo dose starting on Monday, April 5th. She got through the remaining treatments without the rash returning. After our visit with UCSF on March 30th Deb was given the green light to slowly start reducing the Decadron (anti-swelling). By the time she started this last round of Chemo she was down to 1 mg a day of Decadron. She had been at 8 Mg's a day only a couple of months before.

It would seem that the reduction in Decadron combined with the latest round of Chemo are what brought back the pressure and headaches over this past weekend (4/10/04). Saturday was a tough day for her. Similar to the days when she was on the clinical trial. As of today she is feeling better with a touch of a headache but nothing like the weekend. She has brought up her level of Decadron to 2 Mg's a day and it seems to be working. Tanner is spending the evening tonight with Grandma Roth and it gives us both a bit of a much needed rest.

4/20/04

After eight days of headaches Deb is once again feeling well. We are hoping that she has turned the corner and her body has adjusted to the lower dose of Decadron. The past three days have been headache free. We have an appointment with UCSF on Friday the 23rd for a check up.

4/27/04

Tanner's 10 month birthday! Deb's birthday is Monday, May 3rd. The last visit to

UCSF

was fairly uneventful. Deb ran through the routine of push and pull, stick out your tongue and 'let us tap your knee to test the reflexes'. Naturally, DebShred passed with

flying colors. She was also up a pound and now weighs 1%@. Did you think I would really tell? The main reason for our visit was the weight check. They use her weight to

determine the dosage for the next round of chemotherapy. Deb starts back on the chemo tomorrow (4/28). This time she is going without the Eastern supplements as we

try and rule out all variables that may be contributing to her cyclical headaches. As of

today, Deb feels great and she is as beautiful as ever. A tad bit sassy but that's one of

the reasons I married her!

5/4/04

Deb has finished the latest round of chemo with no signs of a rash. No headaches at

this time either. Great news! The next MRI is scheduled for May 11th with a follow up

for the results on May 14th at UCSF.

5/18/04

Ooops! I had my dates wrong. Deb had her MRI today (5/18). We will be at UCSF on

Friday the 21st for the results. She has been feeling great and continues to shine. We

are very optimistic for the upcoming visit.

5/21/04

Great visit today at UCSF. Our neurologist greeted us with a big smile and the news

that Deb's latest MRI scans "looked great". The report: the tumor mass has decreased

in size. There was a noticeable change in the size of the mass when comparing the latest scans to the ones taken two months ago. With the decrease in the tumor size

comes a reduction in the blockage of the left ventricle. This means the fluid being produced in the brain is now able to exit into the spinal cord as it should. The

result

being less fluid pressure in the head. Needless to say, we are all very happy with today's visit and feel optimistic that the reports will continue to get better with every two month visit.

6/12/04

Sorry it's been so long since the last report. Between work, Tanner becoming much more active (almost walking) and Deb feeling so well it's been easy to overlook the web site and focus on other areas of our lives. I realize though how important it is to keep everybody posted on how well Deb is doing. Another round of chemo ended on June 1st and again Deb is progressing through the cycle without pressure or headaches. As of the 9th she has started the process of decreasing the dose of Decadron she takes daily.

You may remember that the Decadron is used to control the brain swelling. Deb has tried to lower the dose in the past but the head pressure returned and she was forced to increase the dose. We have gone through the process of decreasing the dose a few times only to raise it again when the pressure headaches returned. Deb will reduce the dose by .5mg every two weeks to give her body a chance to start naturally producing what the drug provides. We are always optimistic but this time we are bit more so taking into account that the tumor has shrunk and we are decreasing the dose at a very slow rate. The goal is to eliminate the drug all together over the next 45 days. In turn, Deb can rid herself of the side effects such as a difficulty in sleeping. At the moment, she takes another prescription drug to help her sleep and it can be addicting.....soooooooooo....it's time to reduce all these drugs and eliminate them from her daily routine.

Deb continues with the Chinese herbs designed to build up her immune system

and
she has recently done acupuncture as well. She is also out on the trails running quite
a bit. I think she has run four times this past week. She is fast and she runs far.....can
you say DebShred?

As always, we thank you for taking the time to check out the web site and send you
loving messages. I'll try and keep you posted on a weekly basis from here on.

6/22/04

Hi everyone. A quick update for you. Deb had her bi-monthly appointment with the optometrist last week. She has been visiting on a regular basis since ending radiation.

In short, the purpose is to check for pressure on the optic nerve that may result from

the tumor. The outcome of the latest visit? Dr. Shin says Deb "should be a clinical study as to how far she has come and how well she is doing". He couldn't say enough

about her progress since the first visit some nine months ago. Today, we have yet another appointment with the neurologist as Deb prepares for the next round of Chemotherapy. Once we leave the Neurologist we are off to Novato Community for blood tests. If all checks out then Deb will start her chemo tomorrow (6/23). Deb has

dropped another .5mg's of Decadron as of yesterday (6/21). The latest reduction so

close to a new round of chemo will keep us 'watchful' as the cycle progresses.

Overall,

Deb is doing very well. She's been on me all morning to join her for a run this afternoon. She's getting a bit cocky so I may just go only to keep her in line....

(Update

1 hour later). I went running with Deb and all I saw the entire run was her backside and

the cut of her calf muscles...I'm going to need a little secret practice if I plan on keeping
up!

6/28/04

Deb has completed the five days of taking her chemo drugs. She has exercised daily

while taking the Temodar to get her blood circulating and the Temodar up to the tumor. She is feeling fine...perhaps a bit more tired now that Tanner is walking.

7/17/04

Deb continues to feel great. Her next MRI is on July 21st and we will be at UCSF on the 23rd to hear the results. Both of us are very excited to hear more good news like that of the last MRI. Deb is now down to .5 mg's of Decadron a day and will finish with that drug all together the week of the MRI's. At that time, the only drug she will be taking is the Temodar (chemotherapy). There is no doubt she will beat this tumor. Her strength and determination are unbelievable.

7/29/04

The results from the meeting on the 23rd at UCSF were once again very positive. The word for the day was "stable". Deb and I were perhaps a bit disappointed that the scans didn't once again show that the mass was smaller but the reality is that it takes a great deal of time for the brain to absorb dead tissue. We left UCSF with the feeling that a good portion of the mass was indeed dead tissue. Time will tell. Regardless of the scans Deb is doing beautifully and feels great. She is now completely off the Decadron and is trying to wean herself from the sleeping pills that were necessary while she was on the steroids. One big piece of news was that Deb may stop Chemo as soon as October. It's good news but a bit scary at the same time. UCSF tries to get you off the chemo after 12 months if your condition is stable. Like antibiotics to cold germs, they don't want the tumor cells to continue on the chemo drug to the point that they adapt and make the drug useless. If Deb does come off the chemo (which is likely) then we will cruise along with MRI's every two months and simply monitor the tumor. If the tumor wakes up she will have to go back on the Temodar. From a selfish

point of view I hate to stop the chemo and give the tumor a chance whatsoever.
We will
have to make the decision when the time comes.

8/17/04

Deb is just back from a run as I write this. She is looking and feeling great.
This week we will meet with one of our Neurologists as Deb gets ready for the next round of chemo. She did blood work this morning and assuming the blood counts are where they should be she will start the next round of chemo on the 23rd of this month.
Not to much more to report other than that. Life is good!

9/17/04

Great report! September 20th will mark one year since our lives changed a bit.
Deb
and I went to UCSF today for the results of the recent MRI. For the first time since we have been meeting on a bi-monthly schedule we were able to notice a significant improvement in the size of the mass. It was evident when comparing the latest films to the film taken two months ago that the tumor has decreased in size significantly.
The swelling around the area of the tumor is gone and the ventricles are clear and open.
This is made more significant by the fact that Deb is no longer on the Decadron.
You may remember that the Decadron was being used to control the swelling. In fact, Deb is off all medications outside of the chemotherapy. This includes the sleeping aids as well. Because of her great results it's projected that she will stay on chemotherapy for two more cycles and then stop that as well. What more is there to say? We are ecstatic!

I think I mentioned in the past that I knew Deb was getting better when she regained her urge to shop. Naturally, after such great news we did just that to celebrate.
That was followed up with some sushi and than a swim at "The Club".

"The Club" refers to the Rolling Hills Health Club of which we have just joined. The inside joke around the house is that we will be going to "The Club" because it sound so snobbish. In actuality, it's a great place and it offers Deb new activities such as swimming, spin-cycling, a fitness center and a ton of classes that she can use to keep her strong and healthy. We really feel that Deb's ability to exercise has contributed greatly to her ability to kick this tumor in the rear.

It needs to be noted that the factors contributing to her recent success are vast. The main factor being the love and support she has received from all of you reading this update. I'm not sure it's possible for a person to give up fighting when they are constantly reminded about how much they are loved and just how many people are pulling for you. The messages Deb receives through the web site are powerful and motivating and I would personally like to thank all of you for taking the time to send Deb your encouragement. I'm not sure if you actually realize what a difference it makes.

There are other factors such as a complete overhaul of her diet, the compassionate care she receives at UCSF, the addition of Eastern herbs and supplements to help build her immune system, massage and visualization. Naturally, we can't forget our son Tanner. He is not mentioned last because of a lack of importance. Deb lives for Tanner. He's an amazing little guy whom we truly believe knows what his mom is going through. In knowing that, he does everything he can to make us laugh when we need to. He alone is a huge reason for Deb to win and she will. Things feel really good right now and we truly believe we have the upper hand at this point. Thanks again for your support. It's made a difference.

10/10/04

This last round of chemo was a little tougher on Deb than the previous cycles had been. From what I can remember this was the first time since she started chemotherapy that she truly felt nauseas and uncomfortable. We had discussed

with
UCSF the possibility of stopping the chemo all together in the near future. UCSF prefers to stop the chemo if one is considered 'stable' after a years time. Taking into consideration the fact that Deb had handled the treatments without issue over the past 11 months perhaps her body is in agreement with UCSF and is simply signaling that it is time to stop with the chemo treatments. As of today, Deb is fine and feeling great once again. Chance are she will endure one more cycle of chemo and call it quits after that. She continues to exercise regularly by swimming, running and attending yoga classes.

11/15/04

The past month has flown by and Deb continues to do very well. She is busier than ever with Tanner. As one might imagine, at 16 months old he is everywhere and raring to go in all directions at once. Deb is indeed "Supermom" and keeps up with his every move.

We had a bit of an adventure since the last update of 10/10. Deb was supposed to start the latest round of chemo on October 15th. She went through the standard procedure of getting her blood tested before starting the round as she normally does. This time the results of the test came back indicating that both her red and white blood cell count were dramatically low. I was in Las Vegas at the time for a trade show when I received a call from Deb letting me know that their were issues with her blood count and that our Neuro-Oncologist wanted Debbie to immediately start with self injections of a drug called Neupogen. Naturally, I was caught off guard and could not believe that Deb would have give herself shots.

This is a rather lengthy story so I'm going to provide the condensed version. Under doctors orders, Deb deferred her chemo cycle for two weeks while she gave herself

shots and continued with frequent blood tests hoping to see an elevated count of red and white blood cells. At about the two week period I could tell Deb was getting a bit stressed out about not being on chemo. Understandably so, as the results have been so good that any prolonged interruption was a bit of a concern. At that time, I decided to get on the phone to the doctors office and learn a bit more about what we were trying to achieve with these shots, how long they would go on for and what we would do if they cell count did not return to a satisfactory level? I was told that Deb's Absolute Neutrophil Count (ANC) was at 200 and needed to be over 1000 before she could once again start chemotherapy.

At this time I asked Deb to fax me the current blood test results (I was at work). Once I received them I went online and educated myself on how to read and understand the blood test results. I also educated myself on how to calculate the Absolute Neutrophil Count, which I did. The blood test I calculated showed an ANC of 1539. Being confused and concerned I placed a call to the doctors office once again. I was met by quite a bit of push back from the doctors nurse who felt I had no place questioning her diagnosis as "It takes years of training to calculate a patients ANC." I told this nurse that it was my wife's health we were talking about and that I would continue to call as long as there were questions about the current condition and the difference in the results we seem to be getting regarding the ANC. I told her I wanted a call from the doctor to explain what was going on. Here is where I cut out a lot of the story. Later that Day Debbie received a call from the doctor who apologized. It seems she had been calculating the tests incorrectly and Deb's ANC was indeed 1539 and not 200. She pointed out that it was only the last test in that an error had been made. As of today, I have reviewed all the tests and not one produced an ANC lower than 1100. It would seem the doctor was wrong from the start. I'll have my calculations

reviewed
upon our next visit to UCSF and then decide how to proceed at that time. There
you
have it.

Deb is now doing well and we are all happy to have that fiasco behind us.

11/24/04

Deb and I were at UCSF yesterday (11/23) for the results of the MRI she had done
the
previous day. The results were not what we expected. The latest MRI showed a
small
area of growth in an area where there had been nothing two months ago. The
results
over the past six months have been very positive so Deb and I were both a bit
taken
back by the recent findings.

Yesterday was a tough day but now it's time to move on. Next week (12/2/04) Deb
will
be back at UCSF for a PET scan. During the PET scan Deb will be injected with a
radioactive glucose (sugar) prior to the exam. Many cancer cells are highly
metabolic
and therefore synthesize the radioactive glucose (sugar) that is injected. The
areas of
high glucose uptake are displayed in the scan imagery, as opposed to the
anatomical
imagery of CT or MRI, which cannot detect active, viable tumors. This test should
give
us a clear picture of which cells within the entire tumor mass are alive or
regenerating
and which ones are simply dead. Why didn't we do this six months ago?

This latest 'blip' on the radar could be cell regeneration but it can also be dead
cells
that have breached the blood barrier around the brain. A couple of different folks
at
UCSF told us that some odd things can start showing up on the scans eight to ten
months after the initial radiation.

OK, so it's not the news we wanted the day before Thanksgiving. It is what is and
now

we just deal with it as we have done with everything in the past. Deb continues to feel great. She did her first spin cycle class this week and now she has a new sassy hair dew to compliment her 'kick butt' attitude. She is strong and simply awesome. I'll update the web site as soon as we get back from UCSF on December 2nd.

12/4/04

Deb's PET scan went smoothly and the results indicated nothing "new or suspicious" in the area of the tumor. The new mass that showed up on the November 23rd scans are thought to be dead cells that have migrated.

Deb has now started on what I believe will be her last cycle of chemotherapy. She will be back at UCSF in a month for a spectroscopy. As far as we are concerned the more tests the better if it gives us a clearer picture of what's going on within the tumor and perhaps the option to be proactive instead of reactive.

Deb is still on track and beating this tumor. Thanks to all for the messages of support.

01/04/05

It's been exactly one month since the last update and I apologize to those of you who check frequently for the updates. Frankly, it was nice (especially during the Holidays) to walk away from the web site and everything it represents if even for a short time.

Briefly, the Holidays were a great time for the Roth and Parsons families. Deb was feeling good and Tanner was very excited for his second Christmas. He was tuned in this year and couldn't get enough of "Anta" or as you and I know him "Santa". It was the first time in a year that we simply relaxed and placed our worries behind us.

Well, the holidays are over and it's time to get back to business. Sorry for the

abrupt
reality check...read on - The past few days have presented Deb with some pressure in her head and this morning was one of her worst headaches in months. UCSF has been kept aware of these issues and has not felt the need to bring Deb in based on what we are reporting. It just so happens that tomorrow (01/05/05) will be at UCSF for a Spectroscopy with a follow up visit scheduled for this Friday (01/07/05). These are timely visits indeed. As of this writing (4:30 p.m.) Deb is up and about with no pressure headaches.

Days such as today are difficult. We have seen so much progress over the past few months that it has been easy to lull ourselves into a false sense of complete victory. I'm not saying that we aren't winning this battle but until the report comes that the tumor has disappeared it's always important to keep your guard in place. As our surgeon told us at the beginning this is a "medical triathlon" that Deb is now running and there will be ups and downs along the race. To forget that there will be "downs" only makes them tougher to handle when they come. Make sense? The last few days have brought our focus back to the race and we are now getting ready for the next couple of miles which we will run this week. Corny analogy? Sorry!

I know those of you reading this care very much for Deb. Therefore, I want to convey that my primary goal for constructing this web site was to keep you up to date on Deb's current state. I think it's only fair considering that you are like family to us. Over time a second goal has emerged and I want to make sure you are aware of it. The second goal is to provide those who may be at the beginning of this "process" (especially caregivers) somewhat of a journal and a resource to use in getting started. Personally, upon our return from the hospital after the initial surgery I was all over the Internet looking for resources and stories of others who had faced what Debbie was about to.

Finding these resources were a great help. I think it's important to for those reading this as a resource to get a real feel for what we are going through and perhaps what they can expect.

Why am I telling you this? I'm telling you this because I want you to know that I'm going to write about the reality of our experience in order to make this site one in which others dealing with a brain tumor may be able to identify with and gain insight and strength from. Knowing how close you are to Deb I don't want you to get down if my entry isn't the greatest news we could hear. This is a long process and there will be many hurdles and tough days. As always we deal with them as they come. We live a day at a time and we ALWAYS remain positive that a setback is simply another hurdle on the way to completing the triathlon. I hope you don't find this off the wall. The fact is that I have had a couple of people just starting the "battle" discover Deb's site and it's made a difference to them. Knowing that, I want to make sure it remains "real" as I know they will be reading my entries.

I'll be back next Saturday to bring you the latest news.

01/06/05

Where to start...it's been along day and it's now late but I wanted to post this so all would know what's happening with Deb. As you know we were scheduled to go to UCSF tomorrow for the results of the Spectroscopy that was done yesterday. I was at the office today and called home to check messages - there was a call from UCSF. I'll tell you now that when a doctor calls you the day after a test it's not because they want to thank you for being their patient. I knew that before I returned the call.

The MRI portion of the Spectroscopy revealed a cyst growing somewhere within the original tumor area. This cyst is encroaching the left ventricle and cutting off the ability

for the fluid produced in the brain to drain into the spinal cord. This is the exact complication we experienced before the initial surgery and unfortunately it will require surgery once again. This would explain the pressure that Deb has been feeling lately. I spoke with our surgeon today and he was pretty adamant about getting Deb into UCSF quickly.

The process of getting Deb into UCSF started today and it looks as if she will be admitted tomorrow. My limited understanding at this time is that we will be admitted, more MRI's will be performed, we will meet with the surgeon to discuss the game plan and the surgery will be performed. My guess will be either Sunday or Monday. The details and the exact location of this cyst are still a bit blurry as I only found out a small amount of information during our phone conversation. I probably couldn't have taken in any more information anyways. I think I shut down after I heard that surgery was required. We will know the whole story tomorrow.

Perhaps at some point I might try and describe the ramifications of such a surgery; Deb's first days after the surgery - that's a story in itself with ICU being no fun, the immediate effects and stress on the families, the true recovery time for not just Deb but all those closely involved with her care, Deb's medications and the eventual period of reducing the doses to get off them; the side effects. Working (trying to focus on work) to pay the bills and now the issue of how we deal with Tanner who is much more aware of situations than the last time we all went through this. I swear he knows what's going on as tonight was the first time Deb and I had seen him so fussy at bed time. We had to go in and comfort him and he insisted on seeing both "mama" and "dada". This description really only begins to scratch the surface and it's coming back to me as I write this. It really is heavy stuff.

Here is the bottom line. We have reached a hurdle. Deb will undergo the surgery and

she will come out of it fine. We have talked a lot this evening and we are convinced that's the case. Let me tell you that this family will be incredibly strong after the entire experience has passed and Deb is cancer free. I'll be completely gray but that's another story. We are blessed by an extraordinary amount of support and let me add we realize that and don't take it for granted. Deb will be fine.

I'm guessing we will be at UCSF for around seven days. I didn't make it home the last time we did this and I'm not sure if I will this time so I won't be adding any updates. Fortunately we have Sue and I'll ask her to keep you all current via her email updates.

I look forward to being back home with Deb and Tanner and updating the site once again.

01/14/05

Well here we are....back home. Let me start this entry by first restating the fact that Deb is an absolute SuperWoman. I don't mean that she is simply a super woman - which of course she is. I mean that Deb has the strength and power of that gal who used to fly around in the invisible plane and ricochet bullets off her wrists as if she was swatting flies. Does anybody know who I'm referring to? No matter if you don't - just take my word that Debbie is one strong woman.

We checked into UCSF on Friday and her surgery was Monday. Originally, the surgery was scheduled for Monday evening between 5 - 8 p.m. Let me tell you, when you are having surgery of this magnitude it stinks to have it scheduled for the evening because you sit around all day anticipating the time that the gurney will come and take you away. Alas, the luck of the Roth's prevailed once again. Bright and early Monday morning our nurse bust into our room and announced the surgery was on - turns out the patient scheduled for the first surgery of the day ate something after the cut-off time and had to be rescheduled! Oh how happy that made us as there is nothing

like a
freshly rested surgical team when you are having brain surgery. From that point on
it
all happened very fast and the next thing we new it was 1:00 p.m and we were
speaking with our surgeon who announced that all went well.

Ironically, this cyst may have been a blessing in disguise. The pressure Deb had
been
feeling leading up to this surgery was caused by the cyst pinching off the left
ventricle.

A pinched ventricle results in a fluid build up within the brain and hence the
pressure.

It's a long story but the result of this pressure was the manipulation of the brain in
such

a way that more of the tumor was exposed during this surgery than during the
original

surgery. End result - not only was the cyst successfully removed but more of the
tumor

as well. There were also traces of dead tumor cells that were removed. Ultimately,
there will always be parts of the tumor that cannot be removed surgically. For that
we

will have to rely on a medical approach...either more chemo or some sort of clinical
trial. We will know more about that after our next meeting on the 26th. At that time
we

will have the results of the pathology reports and have a further understanding of
what

we are dealing with. Until that time, we won't focus on the remaining tumor. All we
are

concerned about at this time is Deb's recovery from surgery.

Her recovery has been amazing, astounding and unbelievable. Late the first night
after

her surgery I received a call on my cell phone from Deb asking for her soft pillows.
I'm

not sure I can describe my surprise at hearing her voice at that time. The day after
surgery (Tuesday) she was very much herself albeit very tired. Wednesday the
drain

was removed from her head and she was walking by the evening. Thursday she
was

feeling very strong and we were sent home - we walked around the block upon
getting
home.

Today has been simply unreal. Deb has been as active as I will let her* and has not needed even a Tylenol for the pain. Four days after major surgery with 29 staples in her head and she is home, active and blowing all those away who see her. Her recovery has been unreal. (* I won't go into detail but "stubbornness" is a trait that runs in a portion of her family. I literally had to lay the law down just to keep Deb from doing too much today. This morning she announced she would be walking down the street to drop some stuff off at the neighbors...she thought she would go for a stroll by herself... I let that idea last for about 10 seconds.) We ended up with two good walks today and she would have gone further if it was up to her.

That's about it. Surgery went well. Deb is doing incredibly well and it would seem we are further along in terms of progress since this adventure began 15 months ago. Once again, we have had an outpouring of support and offers to help in any way possible by an unbelievable amount of people. We truly can't thank you enough.

Schedule:

Thursday the 20th - Deb is back at UCSF to get the staples removed.

Wednesday the 26th - We go back for the pathology results and "the next step".

At this time - great days once again.

01/27/05

Yesterday was our post surgery follow up visit with Dr. Chang over at UCSF. It's clear that Deb's second surgery was a success. It was quite obvious when comparing the post operative scans to the pre-operative scans that a significant portion of the tumor has been removed. This was tumor that had been inaccessible in the original surgery. Adding to that was the fact that Deb looks and feels great just two weeks after her craniotomy. Dr. Chang was very pleased with Deb's current condition.

There is still some running to be done. There will always be a portion of tumor in an area that simply can't be accessed surgically. The area in which it lies is much too 'sensitive' and performing surgery in this part of the brain would bring a very high risk of creating conditions that would negatively alter Deb's quality of life. It also seems that at this time any form of additional radiation is not part of the solution. The solution will be to treat the remaining tumor cells medically and that's what we will be doing starting this weekend when Deb begins another cycle of chemotherapy. This time around Deb won't be using Temodar. Because there had been some growth of the tumor while on Temodar we have been advised that another chemo drug called CCNU or Lomustine will be used in place of the Temodar. Lomustine can also be taken in a pill format and is taken one pill every six weeks. Strong stuff!

Naturally, it would be nice to have more options in our arsenal but we don't for the moment. There are still more chemo drugs to try if this latest one doesn't perform as expected plus a number of clinical trials that are in the works and should be available to Deb. Without question we remain very optimistic and positive in all facets of her recovery. Why shouldn't we? We are further along than we were 14 months ago. Deb is her old self and doing unbelievably well very soon after a major surgery. Her resiliency is like no others as this tumor will soon find out.

I'll be back in a few days to let you know how she is tolerating the latest chemo drugs.

2/06/05

Just a brief update to let you all know that Deb is feeling well these days. She has had some struggles trying to sleep at night - a side effect of the Decadron she had been taking to control brain swelling. She has now stopped that medication and the last couple of evenings she has been able to make it through most of the night. The

added rest has made a big difference in her days. Let's not forget that she still has Tanner to contend with and he is on the go like never before.

There are no reports of pressure and no headaches. The incision has healed nicely and once again we are seemingly back on track to kill the tumor. The new chemo seemed to hit Deb a little harder than the Temodar did in the early stages of taking it

but at this time(a week after starting the new chemo) she seems to be past the nausea.

The picture on the front page of Deb riding a bicycle was taken a week ago.

Lately,

we have been placing Tanner in the child seat and going for family rides to the park.

Deb is VERY happy to be back on a bicycle. Other than that, she has been back in the

gym working mostly on the cardio side. Slowly but surely she will work her way back to

the heavy weights and her once proud record of bench pressing 500 lbs. Really!

2/21/05

Sorry for the delay in updating the web site. I know from looking at the site statistics

that you've been coming by to learn the latest on Deb. The past week has been surreal. Honestly, I'm not even sure I can remember how the recent events unfolded.

Here is where we are at this time.....

A little over a week ago Deb started feeling pressure yet once again. It would come and go and at first we thought it may be related to simply picking up heavy objects. I

was on the phone immediately to keep UCSF posted. We both agreed to see how things progressed and limited Deb to picking up very little assuming that might be the

cause. The headaches persisted over the next couple of days and I was starting to notice symptoms we had experienced in the past. I wasn't sure but my gut told me things were not right. I once again called UCSF.

Based on my feedback to UCSF they thought it best to get Debbie back in that day.

We were instructed to go to the emergency room. At this point we were thinking that

perhaps the left ventricle was a bit blocked and a shunt may be needed. We were told after the surgery last month that this may be the case.

Once checked into the emergency room Deb was sent out for a CT scan. After the results of the scan were reviewed it was confirmed that a shunt would be needed. Furthermore, we were told that it was a very basic procedure. Having to be back at UCSF was a bummer but we were relieved to hear there was a solution to the pressure Deb was feeling and that it didn't seem to have anything to do with the tumor growing.

Unfortunately, that wasn't the case at all. Our surgeon finally saw the CT scan and didn't like what he saw so he ordered an MRI. Deb was kept over night with us still believing that a shunt was the solution. The next day our surgeon came in and dropped a bombshell on us. The tumor had come back very strong in the matter of one month and the situation is now very bad.

For my own sanity, I'm not going to go in to all the details on the web site. We have a few options to choose from - one of them being another surgery. The surgery decision has to be made by tomorrow (2/22). Ultimately, the solution to this tumor will have to come in the form of a medical treatment. Neither surgery or radiation are the solution. We know that as a fact.

It's now Monday evening and we still don't know the best course to take. The entire family is very stressed at the moment. We have gone through some periods where it simply felt like we were losing this battle. UCSF left us feeling as if we were simply trying to buy time. Deb and I have had to talk about that possibility and it's been extremely difficult. The past few days we have spent together as a little family. Thankfully we have Tanner. He has been making us laugh and further realize how much we love each other.

We are now over thinking about what might happen. We simply can't accept the worst outcome. We will make the right decisions on how to proceed and as I've told Deb I'm sure we will look back and say to ourselves "Man, that was a tough period."

Donnie and I have been busting our butts trying to research everything we can and all possibilities that may hold the answer. As always, there is never a definitive answer. Deb and I will have to decide this week what is the best step to take. I'm sure we will pick the right one.

2/26/05

In case you haven't heard Deb was fortunate to avoid another surgery. Originally, we had planned on a surgery this past week but a last minute MRI showed that the tumor had not progressed since the week before. Our surgeon didn't feel the risk of the surgery outweighed the benefits especially since Deb is doing well from a physical standpoint.

This good news came at a time when it was needed. It's given us a chance to take a breath and regroup. At the moment we are in a holding pattern waiting for a clinical trial that Deb will participate in to open. That should happen in about three weeks. At this time she is back on the Decadron and seems to be doing well or so she assures me when I ask her how she is feeling constantly throughout the day.

It's feels great to be home where we belong and even more so knowing we were hours away from another surgery when it was called off. Thanks to all who have been sending Deb the positive messages. She reads each and every one of them and gets a lot of strength from your supportive words.

3/23/05

I've used the term "marathon" in the past to describe what it is we are experiencing during Deb's battle with this brain tumor. I want to revise that description to "Roller Coaster". We are on a long emotional roller coaster and at the moment we are riding

high. Our first bit of good news came almost a month ago when Deb was able to avoid another surgery. Last Friday, March 18th, we were at UCSF to review the results of an MRI taken the day before and we were greeted with what I can only think of as a miracle.

The latest MRI showed a dramatic decrease in the size of the tumor mass. It hadn't just stopped growing - it had shrunk in size. Not a little bit but a lot. I don't have many specifics to share as this last meeting was more of a celebration than a hardcore meeting where we are faced with making tough decisions in a hurried amount of time.

Deb and I simply had to laugh along with our Oncologist who had to check the scans twice to be sure she was actually looking at the correct ones. We left UCSF that day in a delighted haze and only when we got home did we realize that we had not really absorbed the specifics of what just occurred. Even today we are just 'going with it' and once again feeling that assurance that Deb is going to beat this.

Perhaps in the scheme of things this past month has been an empowering blessing. Just about one month ago we were not sure how long we would have Deb with us. That's the truth. It's not that we gave up but the answer to the question "What are we going to do now" wasn't presenting itself. Here we are a month later and the tumor has reversed course. Oddly, the 'blessing' is that we are in a completely different frame of mind now than in the past. This last experience has strengthened us in a way that potential future challenges will not have such a devastating effect as this last one did.

At this time, Deb is preparing to start another round of chemotherapy with all talks of the clinical trial out the window. Outside of the tumor vanishing this is the truly the best we could hope for and we are very grateful for where we are at. As always, we have to thank you for your support.

4/03/05

Naturally, we are still enjoying the recent decline in the size of Deb's tumor but things have been a bit rough for Deb in that her sleep patterns are all out of whack. For the past month she has probably averaged about 3 - 4 hours of sleep each night. She is now off the Decadron completely and trying to get back to her old sleeping patterns. I figured it would be just a matter of time before her body hit the wall and told her it was time to sleep - I think it happened yesterday.

Deb was playing with Tanner yesterday morning when all of a sudden she seemed to crumple over. All she could tell me was that she was extremely tired. I got her into bed and could tell she was completely wiped out.

I figured something like this may happen since she hasn't been sleeping well but it was still somewhat of a scare. Just two days before Deb had gone to the gym and had a big workout - treadmill, weights and swimming. In addition, she had just started her latest chemo cycle the night before so perhaps both of these events combined with a lack of sleep were contributing factors to the episode. As I'm writing this Deb is still in bed and seems a bit brighter. Fortunately, there are no headaches to report.

5/03/05

Today is Deb's Birthday! Once again I have been delinquent in my duties when it comes to keeping the site current. Deb's recent party at Servino's was a complete success. There are numerous folks to thank for that success but three in particular need to be mentioned here - Mark Wakelin; who's idea it was to have a party for Deb and despite twins being born he poured his energy into the event to make it the success it was. There is also sweet Sue Parsons who coordinated the auction amongst

other tasks and also made this event one to remember. Lastly, there is Ray Wilson. Perhaps you noticed the balloon decorations? That's all Ray. Give Ray a couple of balloons and he can make a prison cell look good! Call Ray at Balloon Delights for all

your party needs! 461-8119. (Just a little plug there for you Ray ;>) Overall, approximately \$15,000 was raised for Deb's Health fund. Thanks to all. It was an amazing evening.

If you attended the party you may have noticed that Deb was having a bit of a tough

night. The fact is she had a very tough evening and in true 'shreddah' form she sucked it up and made the best of the evening. The following Sunday we were back at UCSF emergency.

Deb woke up Sunday morning around 5 a.m. with extreme pressure and pain in her head. After some time trying to get her comfortable we made the decision to drive in to

San Francisco and get her to the emergency room at UCSF. CT scans were taken and

the results showed swelling and potential tumor growth. We went home that evening

with an MRI scheduled for the next day. The results of the MRI were very similar to the

ones taken in February. The scans showed extensive swelling with a dramatic increase

in the size of the 'mass'.

Certainly, we had hoped we wouldn't see scans such as this again. Once in February

was enough. Although the scans are ominous looking we have a different outlook than

we did in February. There seems to be an extreme correlation between the Decadron

and the increase in swelling and mass size. This may seem obvious since the role of

Decadron is to decrease the swelling in the brain but in Deb's case though it seems to

have an extreme effect. The following time line may help illustrate my point:

- February 15th Deb goes to UCSF Emergency with major headaches. Scans reveal major

'growth' and she is placed on 16 Mg's of Decadron a day.

- One week later pre-surgery scans are taken and 'growth' seems to have stabilized and in

some areas it appears smaller. The surgery scheduled for the next day is cancelled. Deb

remains on a dose of 16 Mg's of Decadron a day.

- Four weeks goes by and an MRI shows a major reduction in mass size. UCSF is amazed.

We start to taper off the Decadron.

- The Decadron is driving Deb crazy. She can't sleep and she feels 'wired' all the time.
- The house is tremendously clean and the gourmet in her is emerging but the lack of
- sleep is getting to her and we are constantly on the phone to UCSF asking them to
- reduce the dose and get her off the Decadron. Why not right? The mass has gone down
- dramatically.

- Deb is off the Decadron by Easter.

- A few weeks go by and Deb is feeling pretty good but she is aware of some 'sensations'.
- As the days go past these 'sensations' turn into pressure and eventually the headache
- she experienced on April 24th. Once again Deb is placed on Decadron - currently on 12
- Mg's daily.

So it seems that the Decadron has had a major effect on controlling the swelling and

what 'appears' to be a tumor mass. Although, all indications are that Decadron won't

decrease the size of a tumor. Again, we ask the question of what is actually tumor out

of all that 'mass'? We have the next MRI scheduled for May 11th and the optimistic outlook is that we may once again see the dramatic effects of the Decadron with the

swelling and mass dramatically smaller. If that's the case our Doctor has promised she

will write a paper on Deb's case as the effect of the Decadron on the mass is unheard of.

If the mass truly is smaller after the next scan Deb will stay on a 'manageable' dose of Decadron and continue on with the CCNU chemotherapy. We should also have a clearer picture of what is actually tumor as opposed to swelling. Tune in after May 11th for the next update and results of the MRI.

5/13/05

Surprise, another surgery for Deb. We went to UCSF on Wednesday of this week to have Deb's latest MRI and then have a follow up visit immediately afterwards to review the results. As we suspected, the swelling had gone down some and it was definitely contributed to the Decadron that Deb has been taking. Although quite a bit of the swelling had subsided there was an obvious issue with the size of her left ventricle. It was rather large and expanded like a balloon.

Let me take a step back. It's become very obvious that there are issues to discuss within these 'review' meetings when the first action taken is a physical for Deb and a series of questions about her recent health and strength. When the meeting starts off like that we know there are issues. I've just learned that over the last couple of years - sure enough that's how this last meeting started.

The good news was that there was no apparent tumor growth and that the recent swelling seems to be the result of other actions outside of the tumor. In this case, it seems that scar tissue was blocking the ventricles ability to drain and this was creating pressure and the squeezing of the brain against Deb's skull. We only have so much room in our skull for added pressure and once you exceed that limit you are going to feel it as Deb has over the past couple of weeks. I was just about to write that it 'was strongly recommended that we consider the placement of a shunt" but that's not

the
way these meetings unfold at all. Once our Neuro-Oncologist saw the scans she
was
on the phone to our surgeon who commented that "he had never seen such a
large
ventricle". The next thing we knew they were working to get Deb admitted to the
hospital with surgery scheduled the next day. We never know what's going to
happen
at these meetings and that's what makes them so nerve racking.

Take a look at the following web page for a clearer understanding of the 'shunt'
and
it's placement. [Click here](#)

The kicker for me during this whole procedure is that I have had the flu and have
been
unable to be with Deb during the surgery. That part of it REALLY sucks! I'm at
home,
she is at the hospital with her Mom and Tanner is staying with my mom. Thank
God for
Mom's!

I spoke with Deb this morning and she is doing very well. Once again in good
spirits
after a tough time. She is absolutely amazing and just goes with the flow. No way I
would be so calm. I'm telling you now - we could all learn a lesson from Deb. She
simply takes on each challenge without a fuss. It's this strength that will beat this
tumor.
Our doctor made the comment that she looks at Deb's scans sometimes and
expects
Deb to come dragging in the door based on what the scans told her but there
comes
Deb walking in with no problem; she passes the physical and looks great. This
tumor
has no idea who it's dealing with.

Deb will be back home tomorrow (5/14). That's providing that I'm well and the
house is
disinfected. If that's not the case then I'll probably pack up a bag and go stay
somewhere until I'm healthy. Thanks for checking up on Deb. Now would be a
great
time to send her a message - she loves reading your notes.

5/15/05

Deb is doing great. She left the hospital yesterday and went to stay with a family friend until I get over the flu. I'm feeling much better today and Deb is planning on coming home on Monday. I'm looking forward to the middle of next week when we should all be back together as a family.

As in the past, Deb is showing signs of a speedy recovery. First off, she looks great. Her stomach is sore from the incision but her overall pain level has been low with only one Tylenol taken yesterday. She simply amazing.

Thanks again for the nice messages to Deb. I know she enjoys reading them as she recovers in bed.

6/6/05

Thanks for checking in on Deb. Last week we went to UCSF to follow up on the placement of the shunt. Deb had a CT scan in the morning, stitches out at Noon and then a meeting with Dr. Chang shortly thereafter. The scans looked good with evidence that the shunt is working properly. Deb's ventricles have returned to a 'normal' size and the dramatic indications of swelling that we had seen in the previous scans now appear to be subsiding.

Before the shunt was placed Deb had been experiencing some difficulty with her left side. Her coordination was a bit off and the range of her peripheral vision was reduced. Since the placement of the shunt she has seen a recovery in both areas.

Deb started her latest round of Chemo on May 31st and all seems to be going well. Even though she is a bit fatigued and needs a rest break in the afternoons she continues to stay motivated and continues with her daily walks.

We are feeling pretty good with everything that is happening at the moment. The shunt is working and once again Deb is steadily reducing the daily dose of Decadron. At

this
time we feel like we are back on track fighting the tumor. We are very optimistic
that as
the next month goes by Deb will continue to see a rebound in her coordination and
strength. We are looking forward to a 'doctor' free summer!

7/16/05

Once again I have slacked off on keeping the site up to date AND IT'S BEEN
GREAT!

For the past six weeks we have been cruising along with little mention of tumors or
cancer. It's been a 'doctor free' period of time and very refreshing as the first six
months of 2005 seemed to be mired in discussions of treatment and 'next step'
decisions. As much as I want to give you the periodic updates it's been pretty easy
not
to while things are going well. Updating the web site means I have to think of
cancer
and if I can avoid it then I will.

Here is the latest. Deb and I were at UCSF a couple of times this past week for
MRI's,
results and the next round of chemotherapy. Deb started her latest round of
chemo on
Friday, July 15th. At this time she seems to be handling it well. She has a bit of
fatigue
(who wouldn't) but no nausea.

The best word to describe the MRI results would have to be 'stable'. The swelling
has
continued to decrease and the ventricles appear normal with the mid-line of the
brain
in place where it should be.

There is still a 'mass' present but as always it's undetermined as to what this mass
is
made of. Is it dead cells? Live Cells? There seems to be no way to truly know
without
doing a biopsy. This has to be the most frustrating portions of our visits. We see
that
there is Something there but we never know what we are truly looking at. All we
can
surmise is that if it's not getting bigger that it may simply be dead cells.....it's a
guessing game.

Deb has been having a bit of a tough time with her left side lately. She experiences some odd feelings in her arms, hands and feet. There is no real answer for it but it's thought that with more time and the reduction of swelling that these issues should go away. Her motor skills are strong with Deb passing all the tests with flying colors.

She does have a gap in her visual field and lately that has thrown her coordination off a bit. Whereas you and I walk down the street without even thinking about the act of walking Deb has to pay more attention and use her eyes more to give her brain the added information about what the next step to take. Obviously, it's no fun for Deb having to deal with odd feelings or a lack of coordination but these are minor hurdles in the big picture. We are on track and at a good place at the moment. Another six weeks and we are back for an MRI and whatever steps will be necessary at that time. Until then, we will look forward to more doctor free weeks.

9/10/05

September 20th signifies two years as a 'survivor' for Deb. Along the way we have had many coincidences and 'timely events' that keep reminding us that someone is watching over Deb.

My mom couldn't make it over that day so our friend April offered to come over and help with Tanner. Deb had gone running the day before and was looking forward to another run. She was able to do so with April taking care of Tanner. By chance my sister called that day and happened to stop by to visit with Tanner. Deb was back from her run and taking a shower when she started to feel her leg tremble. As I understand it, she was calling for help but softly enough that both April and my sister at first couldn't hear her. Finally, my sister heard something and went to check on Deb. By that time, Deb had recovered from the tremors and my sister placed her in bed to rest. Not long after that Deb had a stronger seizure and my sister called 911.

My sister had called me at the office shortly after the first tremor and I was racing my way home when she called again to say that Deb was having a full on seizure and that she was calling for help. I arrived home as the paramedics were rushing to get Deb out of the house and over to Novato Community Hospital; Novato Community being the hospital in which we received the original diagnosis.

As I looked at Deb lying on the stretcher I could see that she was pretty out of it. That sight, combined with the rushing of the paramedics, created a pretty hectic scene. Fortunately, at the first sign of these seizures, April had taken Tanner for a walk while my sister stayed with Deb. My sister doesn't just normally drop in and once again we view the fact that she did as a sign that someone was looking out for Deb. Had my sister not been there it would have been a struggle for April and very traumatic for Tanner.

By coincidence, the exact same attending doctor and nurse who originally diagnosed Deb were working Thursday as well. Actually, to add to that coincidence the Doctor wasn't scheduled to be there Thursday but had been called in, as the originally scheduled doctor was ill. The crew in the emergency room at Novato Community are awesome and it's clear they have a soft spot for Deb. We can't thank them enough for their help and compassion.

Deb's fourth seizure occurred in the hospital and I happened to be speaking with her as it came on. I had never seen a seizure before. It's pretty tough to watch. I'm not going to go into detail but I guess the best description I could give would be to relate it to someone who is being electrocuted and their entire body contracts uncontrollably. Deb told me later that she was conscious of having the seizure while it was occurring but could do nothing against it. After a few hours of monitoring Deb was released and

brought home. She is now on Dilantin, which hopefully will eliminate any further seizures.

We all wondered about the cause of the seizures and will never know for sure what brought it on. At this time, I'm convinced that the past two days of running and dehydration triggered the events. I have now hidden Deb's running shoes.

10/21/05

Thank goodness for Sue's email reports considering my lack of attention to the web site. I have some time this morning and thought I would try an elaborate on the news you have been receiving over the past couple of weeks.

This latest 'chapter' began around late September when Deb suffered four seizures after a morning run. At that time I think we all wanted to believe that the seizures were brought on by the exercise and dehydration and not directly related to tumor growth. We will probably never know for sure what caused the tumors but in hindsight it was probably related to changes and activity in the tumor.

The day after the seizures (Friday) Deb and I went to UCSF for an MRI that had been scheduled weeks before. Once again the results didn't show a dramatic change in the size of the mass although there was a 'wispy' area that seemed to slightly concern Dr. Chang. We left there that day feeling pretty good about what we saw as it wasn't much different than what we had seen over the course of the past few months.

From there things took off. Dr. Chang had gotten together with Deb's surgeon, Dr. Parsa, to review the scans. Dr. Parsa's office called us that day and said a meeting had been set up for the following Monday to discuss the MRI results. Well, after two years and four surgeries, I know enough that when the surgeon wants to meet with you it usually means one thing. In this case I was correct. Again, we were faced with making

a tough decision.

Dr. Parsa was obviously concerned. He felt that at this point in time it was now worth the risk to go in for another attempt to rid Deb of this tumor. He based it on a few factors. The first being that Deb had just recently had seizures, something she had never had in the past. Also, her left side seemed to be progressively getting worse. For example, she would be walking down the street in flip-flop's and not even realize that her flip-flop had come off her left foot. His greatest fear was that the tumor was growing and may reach the motor strip. There had been an obvious deficit on Deb's sensory skills but now it seemed like the motor skills were being affected.

The other reason given for surgery was the opportunity to clean out some more tumor thereby creating space in the cavity with the hope of getting Deb off the Decadron. She has been trying to get off that stuff for months and every time we get to a reasonably small dose there seem to be problems. By removing some more tumor they theorized that the added space would give her brain a chance to relax enabling us to eliminate the Decadron completely. Lastly, surgery would provide us the answer to a question we had long asked, "What exactly are we dealing with?" The only way to know was by getting a sample.

On the other hand was Dr. Chang who felt comfortable enough with what she saw on Deb's scans to suggest the possibility of continuing with Chemo for another six weeks and then doing another MRI to see if the wispy area had changed.

So now we had to decide which path to take. These are terrible moments in time when we have to guess and second-guess what we should do. There is no help in making this decision from the medical community although Dr. Parsa did mention that if

Deb

were his sister he would recommend the surgery. We respect and appreciate Dr. Parsa immensely and that comment drove home the severity of the situation. I truly feel he has a concern for Deb that exceeds his medical duties.

The ultimate decision was very difficult although I never felt comfortable about going another six weeks and simply waiting to see what happened. I was already feeling as if we were stuck in a rut and not being as proactive as we should. Deb has been desperate to get off Decadron, there were certainly signs that something was going on and we really wanted to know what we were dealing with...a mass of dead cells perhaps? We decided to go forward with the surgery.

Based on what Deb has gone through over the past few weeks I've questioned our decision on a number of occasions. It's not fair to continually ponder the direction we chose because it's still early in the recovery process and as I write this we are seeing great progress in her recovery.

This surgery was unlike all the others. In the past, Deb bounced back in a few days and was usually home on day five without any pain medication. Naturally, we hoped this pattern would continue. It didn't. Deb looked pretty good immediately after the surgery in ICU. She was able to wiggle toes and fingers on the left side so we were pretty relieved that she made it through without paralysis. The second day after surgery she took a dramatic turn for the worse caused by massive brain swelling. Her left side was pretty immobile and she was fairly incoherent. Naturally, we were all surprised, shocked and once again devastated at the possibilities. It's then that we had a hard talk with Dr. Parsa about what was going on and the potential of a situation like this. Basically, we were told that Deb had two roads that she may travel down. Thankfully, she has displayed her warrior attitude and went down the correct path.

As of Wednesday Deb has been at Kentfield Rehabilitation Hospital and we are pleased that she is there rather than UCSF. They are paying attention to her and

working her hard to recover the mobility lost on her left side. She has a lot of work to do and it will be tough but Deb can do it. We see her getting better from one day to the next. Visitors are welcome and encouraged. That's it for now. If you haven't signed up for the email reports then do so as I only have limited pockets of time to sit down and update the site. The email alerts are the way to go if you want the latest updates in a timely fashion.

02/03/06

Well, well. The period of time between updates has grown over the passing year. I think it has something to do with my overloaded brain and my current lack of ability to articulate exactly what is happening in our world.

Frankly, I'm not so sure any of us know what is truly happening within our lives at the moment, as it's a period of time filled with mixed messages and perceptions derived from our daily observations.

What does all that mean? Let me explain. There are days where Deb is very lucid and the Debshred of old. On these days she is as sharp as a whip tossing out cheeky comments that are usually directed towards me. I love these days. She is bright, awake and she projects an aura that things are going to be all right. It's on days like these where I find it easy to believe that Deb is pulling off another one of her miracles and is actually on the mend. It's just too damn hard to accept that a person so bright could be in a situation so dire.

There are also days where Deb is simply tired. Her speech seems to require a bit of effort and this is reflected in the tone of her voice. Her desire to stay in bed on these days is strong and her wishes are respected even though there are times I (we) would

rather she joined us in the living room or outside. Days like these make us look harder at the reality of the situation.

This is how it's been for the past couple of months. Honestly, I think she is better off than she was a month ago. There are signs of 'decline' we have been told to watch for; one of them being a lack of appetite. Let me tell you, if a lack of appetite is an indicator of decline then we have no issues here. Deb's appetite is awesome...I have never been happier to see someone eat

Each day is different and yet the same. I keep a routine to maintain my sanity and keep the house in one piece but what issues Deb may have on any given day is an unknown.

We have had many 'health phases' since Deb has been home. For example, there was a period of a few weeks where I could not get Deb to keep any food down. She would eat and within 20 – 30 minutes it would come back up. We did a lot of cleaning during that time! All the 'phases' have been a challenge and the types of things we probably never thought we would have to deal with. Somehow we have.

I could write for hours to come and perhaps one day I will in the form of a book. For now, I want you to know that Deb is happy and comfortable. She is constantly surrounded by her friends and family and only receives the best of everything. I won't have it any other way. On her bad days, she is comforted and loved. On her good days, you will more than likely find her up at the end of our street, happily sitting in her wheelchair, enjoying the fresh air and the sun on her face. We were at the end of the street not too long ago and Deb commented more than once about how good she felt and how much she was enjoying the afternoon. These are the words I hope to hear everyday.

More to come but I'll need more Kleenex on hand before I write the next entry.

These
are tough entries to write. Our love to all of you. We could never thank you all
enough
for your love and support. I know there are times that folks write or email offering
help.
Please accept my apologies if I don't reply. Honestly, there are days where I just
hide
from all and get through the day.

4/11/06

Deb is pretty tired these days with today not really being an exception. I guess it's
not
a surprise considering that everything she takes claims to make you tired. We did
cut
her pain medication in half and have seen a difference in her alertness since the
reduction.

Deb is still very much with us. She knows a good joke when she hears one and it's
evident by the smile on her face. Unfortunately, it looks as if her vision is failing. I
think
at this point she can see light but she's not able to tell me how many fingers I'm
holding
up even when my hand is directly in front of her face.

She is comfortable, warm and clean. She will always be that way.

She looks great.

She has Tanner whom gives her plenty of kisses. Tanner knows Mom isn't well and
he
does his best to show his love and concern. He would take care of her every need
if
we let him. Lately, we had to start picking and choosing the tasks he performs
once we
realized Deb didn't appreciate oatmeal up her nose.

She is still enjoying life and we try and live these days as 'normal' as we can.

She is very peaceful. She isn't scared of the situation. She is unbelievably strong.



Sometime in 2007

I haven't been very motivated to update the web site since Deb's passing but something hit me yesterday and it felt like it was time to do something with it.

Deb passed on the morning of May 6th, 2006 at 11:00 a.m. Three days after her 39th birthday. She was just as beautiful on that day as she was in the previous days, months or years. In fact, she looked so beautiful that day that her passing caught me off guard.

I had convinced myself that there would be a period where Deb wouldn't eat and that would signify that the end was near. On this day we had breakfast together as we normally had over the previous four months. We took our morning medication and spoke about getting outside that day. She wanted to.

At this point in time Deb was speaking very little if at all. Most conversations were based on asking 'yes' or 'no' questions and she would reply with a nod or a shake of the head. As for going outside, I think we went a period of a month or so where Deb was confined to her bed. Her seizure activity had picked up and it seemed movement was the key to setting it off. Giving her a bear hug and placing her in and out of her wheelchair was no longer an option. The period of time that Deb spent in bed was really gnawing at me. She was an outdoors girl and aware enough to know she was stuck in bed. We decided that perhaps a gurney such as those used in ambulances might be the solution to getting Deb mobile once again. It was.

We had been given a new freedom in the form of a gurney by the incredible folks at the Sonoma Fire Department. Deb's Mom made an inquiry and within a day she had the gurney. I can't tell you what a difference that gurney made to us. All of a sudden we were able to get Deb outside in the sun. Just like that we had the answer at our home and Deb was immediately taken outside. That was a great day. We could see the difference in Deb's face. She knew where she was and she was all smiles. All of us felt a great weight lifted.

Many things were happening on the day of Deb's passing. One was the Bay Area Angel Adventure walk in sponsorship of the National Brain Tumor Foundation. Our friend Mary was there with a large group helping to raise money for the Foundation in the name of her late daughter and Deb's good friend, Summer

Skye. Mary was also walking in honor of Deb that day.

That day was also a big visit day for Deb as a large group consisting of Aunt's, Uncles and Cousins had come to see her. Her friend Brooke was also in Maui that day and I'll come back to the significance of that later.

I guess at this point it's just time to say she passed that morning. I was able to hold her and love her as she went. The memory of that day is strong and admittedly some days it seems to haunt me.

A memorial service was held not long after at Stafford Lake in Novato. I don't think the day could have been any more perfect. Ironically, it rained. It had rained during every stay we had at UCSF over the course of 2.5 years. This 'coincidence' of rain is only one in a series of events that have convinced me that Deb is here with us. Her spirit is here and giving signs to announce her presence. STOP! Right about now you are probably thinking that Ole Tony has gone off his rocker! To much stress, etc. Perhaps. Read on and you decide.....

Deb and I spoke frequently of "Maui in May." We had been trying for sometime to get there for her Birthday. We were close last year with reservations all lined up but that came to a halt when UCSF suggested that the pressure in the aircraft during the flight could be a real issue. Naturally, we were not going to take any chances so we canceled. Obviously, we were disappointed but almost more so because for years we had been trying to use our United Miles and could never get the dates to work. This past time everything had worked out and we were able to book the trip using our miles.

Deb's memorial was held in mid-May and it struck me that there was still time to possibly get Deb to "Maui in May." A long story short, I called up and using Miles found a flight that would get me into Maui on the morning of May 31st. It was almost too easy.

OK, let's bring Deb's friend Brooke back into the story. The day Deb passed Brooke was in Maui. That same day in Sonoma a friend of Deb's Mom was preparing to do some work with silk. She's an artist who works in a number of mediums but had been thinking of dying some silk. This is the same gal who once before had made Deb a silk "power" scarf. Deb loved it and brought it to all her appointments at USCF. So, at this point we have two different people at two different places in the world. One in Maui and the other in Sonoma. Brooke had heard of Deb's passing and that evening she took a picture of the Maui sunset not long after releasing a Lei into the ocean near Kapalua. As I understand the story Brooke threw the Lei in the ocean only to have it come back ashore. From somewhere appeared a boy on a surfboard who paddled the Lei out into deep

water.

The day before I left for Maui I went to Sonoma to pick up some of Deb's ashes. On their piano was the picture Brooke had taken. Beside that was a note and a letter. The letter was from the artist. She wrote that she had intended to dye some silk but started to think otherwise as it can be a lengthy project. She also wasn't sure about the design. She stated that she decided to go to the shop anyways and when she got there she was struck with a vision of what to do with the silk. She stated that it came to her and she simply put down her keys and whatever she was carrying and went right to work. I mentioned there was a note and a letter. The note was from Joyce asking that I first read the letter, look at the scarf and then compare the scarf to Brooke's photo of the sunset in Maui the day Deb passed. I did and could not believe what I saw. The colors and the layering of the colors on the scarf were identical to the picture of the sunset.

At the airport I decided to try for an exit row at the last minute and got it. It turned out later that the gentlemen I sat next to on the flight had also switched seats at the last minute. I was pretty much a mess flying out there and I shared with this guy what had happened. We spoke almost the entire flight and I felt a lot better by the time we landed. Was it fate that we both switched seats at the last minute? I don't know but it couldn't have worked out better.

Every morning I tried to play some music for Deb as I fed her breakfast. I played two albums in particular. The first being Jack Johnson's "On and On" and the other being a Hawaiian album named "Facing Future" by Israel Kamakawiwo' ole. I played these two albums for months on end. Deb loved Jack Johnson and we both associated many good times in Maui with the album by Israel.

I arrived in Maui the morning of May 31st and by the afternoon I was at the pool of the hotel. I swear to all that read this that within five minutes of sitting at the pool Jack Johnson came on. They played the entire "On and On" album. Coincidence? Could be but then there is the fact that immediately after Jack Johnson ended on came Israel and THEY PLAYED THE ENTIRE "FACING FUTURE" ALBUM. I couldn't believe it. Someone had to be choosing the music for the poolside. Right? What are the odds that they would pick those two albums? At that point all I could do was laugh. I remember saying "hi" to Deb out loud. She was there...Maui in May.

Another event had to do with a marble. For the record, I don't own marbles. I never even played with marbles when I was a kid. Deb's mom did though. As a matter of fact, she was once a marble Champion in Sonoma. To this day she has thousands of marbles. The second day in Maui I walked down to the beach and opened my backpack to get out a towel, etc. What I found at the bottom of my

backpack was a marble. I was in a daze packing for Maui but I'm pretty sure I didn't pack a marble. Deb?

The Maui trip was bittersweet. Frankly, I almost came home after the first day because it didn't feel good without Deb. I went by myself for a few days and then Donnie flew out and joined me. That helped a lot. Don and I fell into the normal routine of things that we all used to do when we travelled as a group (Don, Sue, Deb and myself). It was a trip of mixed emotions. Deb's memorial service was held in Kapalua at a little spot that we all used to go snorkeling at. It's a bit off the beaten path and a beautiful spot for sunset. Donnie and I were joined by Deb's friends Kenny and Dave. Deb knew both of them from her days living in Maui. They were good friends to her and she was always sure to call them when she was in Maui. I'm happy to say they have now become good friends of mine. We scattered Deb's ashes at sunset and threw three lei's into the ocean. One in particular was given to me on my first day in Maui. I kept it wrapped around Deb the entire time I was there and used it along with two fresh lei's the night of the memorial. Naturally, after eight days it was a little wilted and off color.

That next morning, after the memorial, Donnie and I went for an early morning swim in Napili Bay. Napili Bay is just south of where we scattered Deb's ashes. Keep in mind there was a southern swell that day. We were both in the water throwing a Frisbee back and forth when he called me over to wear he was standing. Floating in the water was a flower from a lei. It was an identical match in color and aging to the lei I had tossed in the ocean the night before. It happened to be right in the middle of our Frisbee game. I know. It could have come from anywhere but Donnie and I took as a "Good Morning" from Deb. It was almost like a sign from Deb that she was with us and happy to be back in Maui.

Part way through my trip I received a message on my cell phone from a friend I had known in High School some 20 years ago. I may have seen her once or twice in passing since then. Her message indicated that she had heard about Deb but only after making some phone calls to some mutual friends because of a dream she had. She asked that I call her. I didn't for a good number of days. I was curious but a bit worried about what I might hear. Eventually, I did call her and what I heard my friends is what I consider the clincher. There is no doubt that Deb

is still with us in one way or another.

My friend, Kate, was kind enough to put her dream in writing. I'll post it for you to read but not before some more background. The big question is why did she have that dream? Why her of all people. We kind of explored that as we spoke about the dream. The more Kate and I speak the more connections we discover:

- It turns out that Kate was a Hospice nurse here in Marin before leaving for Chicago last October. Hospice played a big part in helping us take care of Deb.
- Kate's father whom also passed on from Cancer loved the song "Somewhere over the Rainbow". It turns out he enjoyed the version sung by Israel. As a matter of fact, Kate's family played Israel's version of the song for him as he was passing.
- It was around that time that Kate's brother introduced her to Jack Johnson. Later that year Kate bought everyone in her family Jack Johnson Cd's.
- Both Kate's father and niece are buried in the Mt. Tamalpais cemetery. That happens to be the place that Summer Skye's ashes are. Deb and I attended the memorial for Summer.
- Kate was baptized in Trinity County - just up the road from where the Parson family cabin is. Deb has been going to Trinity County for family vacations since early childhood.
- Brooke coincidentally attends the same church in Marin as Kate did when she lived here.
- Kate had 'dreams' before the passing of both her Father and her Niece.
- Her nephew was found to have a Sarcoma (tumor) on his brain. He is since doing very well.

Here is the Kate's description of the dream she had on 6/4/06. Keep in mind it had been over 10 Or 15 years since I had spoken with her:

The Dream...

It was one of those kinds of dreams where your conscience mind slips through

and is narrating...

In the dream, Tony was hugging me extremely tightly. I realized that we were involved and we were very much in love...It as if it was me, but it wasn't me. I remember thinking to myself in the dream, "Oh no...what am I doing?...I'm cheating on my boyfriend, I'm supposed to be in love with George!" ... But then it popped back to the dream as if I was watching a movie and playing the character at the same time...Tony was hugging and kissing me and I felt incredibly safe and comforted by him. His love was so nurturing. In the dream, he had taken my face in his hands and lifted my head up to look into his eyes and I saw the deep love in his eyes for me. But then it seemed as if he was very sad and his eyes were filled with tears. Even though I hadn't actually said anything to him in the dream, somehow it seemed I had communicated that I was leaving and he didn't want me to go... I felt so sad and I wanted to comfort him in the way he had been comforting me...I was trying to let him know that it was going to be okay, that he was going to be okay, but he couldn't hear me...He didn't seem to realize I was there.

It then flashed to an older woman who seemed to care very much for Tony and appeared to be quite concerned about him..."Is this his mother?" I thought... This woman looked at me skeptically in the dream..."Who are you?", she asked....I then told her that I was Kate and I have been living in Chicago...I told her that Tony was going to be okay and that the dream I had was real...She then looked at me very intently as if what she wanted so much to believe what I was saying was true.

Then I woke up.

Deb might not be here in person but she is always here in spirit. We love you Deb.

May 2007

It's now been a year since Deb's passing. I have truly wanted to update this web site many times over the course of the last year. There were a number of times I sat down to start writing and simply couldn't bring myself to do so. To a degree, I have been hiding from all of this.

For a couple of months after Deb's passing I stuck around the house and lived in a state of disbelief, sadness and perhaps depression. Those were very difficult days for all of us.

Deb and I always liked to acknowledge certain milestones in our relationship such

as the day of our first date. In keeping with that I decided to scatter Deb's ashes on days that were important to both of us.

You may recall that I took Deb's first set of ashes to Maui in late May not long after she passed. She and I had a running joke about "Maui in May" so we could be there for her Birthday. A number of times over the course of Deb's illness we were very close to going to Maui in May but her health issues at the time prevented us from traveling. This is why it was so important to me that I get her to Maui before the month ended.

We were engaged on July 3rd, 2000 and so it was on that day in 2006 that I took the next set of her ashes to the top of Little Mountain which is directly behind our house. Little Mountain stands 806 feet tall with beautiful 360 degree views of the surrounding hills, the East Bay, Stafford Lake and our backyard. It was a place Deb wanted to be so she could watch over Tanner and I. Her ashes were scattered around the base of a lone oak tree that sits on the top of the mountain. The following pictures will give you an idea of the area.

Towards the end of July I went back to work. The period of time between August, 2006 and February, 2007 were the toughest days of work I had ever experienced. Physically I was in the office but mentally I was simply checked out. It was a very frustrating period of time for me and there were many days that I could not see how I could ever 'produce' in a work scenario again. With that mentality came the worries of how I could possibly continue to support Tanner, myself and our house. I was my own worst enemy and would often get myself so worked up and stressed out that I would have to leave the office. I left the office a lot hiding my tears as I did so. It was a very uncomfortable place to be on those anxious days and I didn't want to subject my co-workers to my grief.

Deb and I were married on Mt. Tam on August 10, 2001. Fittingly, it was on August 10, 2006 that I brought yet another set of ashes back to the spot at which we wed. As it was on the day of our wedding the weather was beautiful on Tam and Deb enjoys many incredible sunsets I'm sure. The views from that location are spectacular. These are a few photos from that day:

Sometime around October of 2006 I was informed that our company had been acquired and would be moving to New Jersey at the end of April 2007. We, the employees of ASO.com, would not be invited to stay on and would be unemployed by May 2007. At first this hit me pretty hard. The timing of the sale was too close to Deb's passing and I was still very concerned about making ends meet, etc. The thought of having to find a new job while feeling the way I did scared me. On top

of that were the Holidays. The Holidays were a period of time in my life where I actually became a bit worried about myself. It was an extremely emotional time and one where I think I really fell into a state of depression.

I am adjusting to being unemployed (Ha Ha) and these days I look at the sale of the company as another of life's changes. Finding a new job pales in comparison to my experiences over the past few years. Frankly, I'm grateful for the time off to stop, think and regroup. I'm planning on taking the summer off and spending time with Tanner.

The sale of ASO did bring about another positive. As Director of Sales, I was tasked with creating a sales training manual and a sales training program to follow along with the manual. I struggled with this for a long time and there were many days back in January when I honestly did not think that I could produce what was being asked of me. Adding to the stress was the fact that a severance package had been offered but was dependent upon me completing the manual and having three new sales people trained and ready to work by May. I can't put into words how helpless I felt towards the beginning of this year. I wasn't able to concentrate, I couldn't focus and all I did was think about Deb. At that time in my grieving I was still haunted by bad memories of the past three years so my thoughts of Deb were not of the good days but rather the bad. Today, the majority of my thoughts focus on the good times we shared and not the bad. I have my days but I also realize they will come and go and therefore I'm dealing with them better. In the end, being able to hunker down, focus and complete the job was an important step forward for me personally.

Deb's Birthday was May 3rd and I spent the day on Tam hanging out at our spot and enjoying a chat with Deb. Donnie was up there as well.

On May 5th I joined many good folks for the Angel Walk in support of brain tumor research and support. I was there in honor of both Deb and her good friend Summer Skye who we also was lost to a brain tumor. I was in a bad way leading up to the event and did not have the energy to organize a group to walk this year. I hope you all will join me next year in honor of Deb and Summer and the thousands of others dealing with this nightmare everyday.

Just yesterday, the one year anniversary of Deb's passing, I got together with the 'Chico Crew' and we hiked to the top of Little Mountain to spend the day with Deb. It was a great day and I know Deb was just loving us as she watched us hike up that big steep hill. I know she was very happy. I was able to be happy yesterday as well.

Tanner turns four on June 27th. He is Deb throughout. He looks like her. He is

very mellow and relaxed as Deb was and he has her eyes which provide me with a picture of Deb every time I look at him. Tanner is a blessing. We have spent a number of days on Tam having lunch with Mom and will continue to do so for years to come.

He speaks of Mom quite a bit and we remain open to speak about her anytime. He saw a lot in 2006 and I'm always watching to see if anything will come of it. At this time he seems to be adjusting fine and is the highlight of our family.

Again, I want to thank all of you for your support and loving words over the last four years. Your actions inspire me to be there for others who are experiencing what we did.

You have reached the end of Deb's Story.