

Bronte progress
1-5-09

Hi Everyone, - Beth report

Let me first start by saying Bronte is doing well. Brent and I got off to an emotional start as we watched Bronte being wheeled away from us around 8:00am this morning. We received lots of good news/updates during her surgery and her room was well staffed with about 10 people in her operating room including a visitor, the chief of neuro-surgery from UC Davis. She came out of surgery around 12:00 and we checked into the ICU (room 678 for those of you who are stopping by this week). She has 128 probes inserted into her brain to monitor her seizure activity for the next 5 to 7 days. The process to connect all of these wires coming out of her brain to the EEG monitors took approximately 3 hours. She slept most of the day and seems to be in little pain. Now we just wait and pray for a lot of seizures and that the seizures are coming from a part of her brain that can be safely removed. Thanks for all your support and prayers. We appreciate all of you being there for our family right now.

Beth

1-9-09 progress – Beth report
Hi Everyone,

Bronte is doing well. She slept all day Monday, Tuesday and Wednesday. She has had about 15 seizures which has given her doctor great news....THEY ARE ALL STARTING AT THE SAME SPOT!!! Not only are they starting at the same spot but it's in a safe spot to operate. I never thought I would ever hear these words. We went from 15 years of non stop seizures and 7 different neurologists telling us her seizures are uncontrollable, all over the brain and there is nothing that can be done to today's great news. She is scheduled for her second surgery on Friday night from 5:00 to 7:30pm. Her grids will be taken out of her brain and her right side frontal lobe will be removed. She will recover in about 3 to 5 days so we should be getting out of the hospital on Monday, Tuesday or Wednesday of next week. I really appreciate all your prayers, emails and visits.

Love to you all!
Beth

1-9-09 later pm update Brent report

To My Family and Dear Friends:

OK, we are at crunch time and Bronte goes into Surgery at 3pm to remove the grids and a large portion of her front right lobe. I asked Dr Chez last night if the data garnered from the EEG met his expectation, and he said the information he gained exceeded his expectation. Dr Chez strongly feels Bronte is a PERFECT candidate for the surgery. Dr Chez believes that Bronte will be successful on many fronts. Worst Case reducing the seizures to minimal "Partial Seizures," where maybe only her left hand twitches. Best Case, (i feel he was watering down his expected outcome) Bronte will have a 70% chance of **not** having seizures in the future. Dr Chez does not like to over promise and under deliver!! But even Dr. Edie Zusman, who has been the "Doubting Thomas" within the team of doctors feels Bronte has a great chance. Edie (who is very close to Bronte and has been heavily involved in Bronte's foundation) brought in another Doctor (I believe his name is Dr Rob Berman) in to review Dr Chez findings and Dr Berman feels very confident about Bronte's outcome. The front right lobe controls a person moods and emotions. Dr Chez feels the team will not need to remove the emotional piece of the lobe. If the team does gets in there during the surgery and feels strongly about taking out the extra section to increase her likelihood of not having seizures. The impact to Bronte should be minimal given that section of the brain is "sick" and is not working properly in its current state. So as I sit here typing this information to you, I feel like a child getting ready to walk out the door for my first day of School. I am excited, yet I am very nervous, very nervous to say the least. **SO SAY YOUR PRAYERS FOR A LITTLE GIRL THAT HAS NEVER BEEN GIVEN A CHANCE AT A BETTER QUALITY OF LIFE AND IS GETTING THAT CHANCE TODAY.** Sincerely yours,
Brent

Subject: Bronte Saturday Morning

> Date: Sat, 10 Jan 2009 10:42:55 -0800

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> Bronte is resting soundly, she had a night without seizures or any
> events. Dr Chez and Dr Zusman both stopped by to check on her this
> morning and she seems to be doing well, given she JUST had major brain
> surgery. Bronte does not seem to be able to move her arm or leg on the
> left side. Dr Chez says that is normal within the first 48 hrs of
> brain surgery, because of the swelling and trauma to her brain. I
> believe in my heart of hearts that Bronte is going to come out this as
> a new little person with a new world open up to her smiles and
> infectious personality. Like Dr Chez said this morning she might be a
> completely new person free of battering of seizures. So to my loving
> beautiful caterpillar of yesterday, I patiently wait for the waking
> of my beautiful butterfly of tomorrow.

>

> Brent

1-10-09 Saturday

Bronte status

Hi Everyone,

The surgery was PERFECT. It went exactly according to plan. The doctors gave us the best news we could've asked for. They removed part of her right side frontal lobe and cut part of her corpus callosum to prevent the spread of any future seizures if they were to come back. She had a look of relief after the surgery. Her eyes were open and she gave us a look of "don't worry, it's over and I'll finally have some calmness in my life. Our little girl will be in the hospital until Tuesday. If she goes without seizures for 6 months we have a pretty good chance they may not come back. If she is seizures free for two years, we can take her off her medication and continue on with a life we were told we could never have. Thank you to Dr. Chez who stepped out of the box and put this amazing miracle together and to my mom..... YOU didn't give up, YOU fought hard, YOU found Dr. Chez and this surgery would not have happened if it wasn't for YOU! Thank you every one for your prayers, emails and kind words. Please keep Bronte in your prayers over the next couples of months as she is healing and her little brain starts a whole new beginning.

Lot's of love!

Beth

1-13-09

Bronte Status

Good Evening:

Bronte is eating better, but still shows an affinity for softer foods. I might have burned her out on yogurt and jello. It appears Bronte will be staying in the hospital for a few more days, we have ran into a snag with her ability to walk. Bronte had two physical therapy sessions today, and made stronger advancement in the later session. The first session she would only walk with the aid of the therapist about 5-10 steps. The second session, where she walked 25 ft a few times (while I was holding her at the elbow for support), provided us with some insight as to what her limitation are. Bronte's left side is still not up to full speed yet, almost reminiscent of an individual who might of suffered a minor stroke. Her left hand curls under as she attempts to walk, and she struggles to plant her left foot firmly on the ground. Bronte's knee appears to hyper-extend as progresses in her forward motion and her hips are not providing much trunk strength. Dr Chez says this is all fairly normal because of the swelling and bruising on the brain. Beth and I would like to get back to the tranquility of our own homes, but will have to remain patient for a few more days. Especially given she is only 96 hrs out of surgery. On a good note, Bronte has greatly increased her accuracy in giving Dad hits of defiance... so other than the light bruising (jk) I am happy to see the spunk back in the little girl. I hope all is well and I will keep you updated as events progress.

Brent

1-14-09

Bronte Status

Bronte's hospital journey is over, and now it is time for her to heal and show progress in the comfort of her own home. Bronte made huge strides today, she was able to walk up a set of stairs at the hospital with a little support from mom. After physical therapy this morning, Dr Chez felt it was OK for Bronte to return to familiar surroundings. So Beth and I packed up all of Bronte's wonderful gifts and brought her home around 2pm.

Bronte is still weak on her left side, but seems to be getting stronger by the day. Bronte is 5 days post op and is so far seizure free. The Dr will take her off her anti-seizure medication if she remains seizure free for about two years. That will be a beautiful day and a day I never thought possible, but a day I strongly believe we will celebrate. After several days of silence from Bronte, she is now starting to use her words... like hi, bye, NO!! By the way, NO was the first word that broke her silence. So we are extremely happy so far, and we thank you so very much for all your warm wishes and prayers. Brent

1-16-09

Bronte Status

Hi Everyone,

Bronte was released from the hospital on Wednesday...yippee! We had such a smooth 10 days and no seizures. Wednesday night while sleeping she had a couple of little seizures. A little upsetting considering what she just went through but not unexpected. After spending 15 years of almost nightly, uncontrollable grand mal and petit mal seizures we went into this surgery hoping for a seizure free life but willing to accept any improvement we could get. I know she will be better in the long run, but only time will tell the ultimate outcome. Thursday was another surprise. Bronte started her day throwing up for several hours. We had to go to the ER for a CAT scan and we ended up getting checked back into the hospital. We still are not sure what caused all the throwing up but the CAT scan revealed some blood on the brain which could account for her seizure activity. The blood on her brain was not much of a concern so we were released again and back at home. I know we will continue to have our ups and downs and as most of you know life has been a rough road for us. I never understood why God would put my little Bronte through all the difficulty she faced through out the years but as I grow older I realize God has a purpose and a reason for the life we are given. I now know I am on a journey that has finally taken me to a place of appreciation for life. Bronte has helped me discover that life is about the real things...my relationship with God, my time spent with my family, enjoying each day and the wonderful gift of friendship....thank you my dear friends! Life is great and now you all know why most things don't bother me, why I am so patient and why I love people more than things. It's all from this journey with my precious little Bronte.

Love to you all!

Beth