
Prepared for Emily's site on March 22, 2014.

Journal

Mar 22 2014

Written 5 hours ago

Today is going to be one of those days. Emmy has some immunosuppressants that she takes today that is going to make her feel extremely cruddy. She has already woke up with quite the attitude. Em wasn't happy that she had some pills to take. After much discussion she finally got them down. I'm not sure who is going to feel worse today Emmy or Linda.

Linda had a little scare last night while I was out of the room. Just a few issues with heart rhythms. A bit sporadic which caused the floor Dr. to visit. The communication wasn't so clear regarding her status. So, I'm sure Linda was a little tense for a bit. However, when I got back all was normal.

Today her chest bandage should come off. Currently discussing whether or not to place a wound vacuum on her cannula sites. Pretty oozy right now. The wound vac speeds the healing process.

Step by step we travel the path but never alone!

Sent from CaringBridge iPhone app

9 PM

Written 17 hours ago

Emily has awakened a couple of times asking for water and solid food. She also commented that she was so confused. How can it be 8 o'clock? Definitely has lost some time.

No plans for the night other than rest. She did have an additional blood test as a result of a positive test (2 of 4 positives) for something from the donor heart. So Em is currently receiving treatments of Vancomycin as a precaution. In a couple of days if the test is

negative than Vanc will stop. Also giving isotropes as the heart is slumbering from being preserved and stopped. Since the heart hasn't fully awakened - a pacer is used to control beats @ 110 per minute. Not expected to be a permanent problem. She had an Echo and everything looks good. Electrolytes and everything looks good.

Em has asked for water and solid foods. She just can't understand why ice water or food is not allowed. Hopefully tomorrow clear liquids can start. She is very vocal about positioning and required changes of position. Em is making it clear to everyone around her Don't Touch My Back! She also is negotiating the number of breathing exercises. Her nurse requested 10 and Em said 2. The nurse settled for 5. Maybe she's picked up negotiating skills from Pawn Stars. Afterwards she asked how long she needed to stay in ICU. An hour or so?

Linda & I are happy that Bernie is gone. We patiently and eagerly wait for necessary progress to leave ICU. A big achievement so far. But just a small step in the overall scheme of things. Now comes the regrowth and fine tuning.

Continued prayers greatly appreciated!!

Sent from CaringBridge iPhone app

11:50

Written Mar 21, 2014 11:05am

Having WiFi connectivity issues. (May see double posts???)

Got to visit Em at 11:00. She looks swollen and heavily sedated. Emily was able to follow commands for hand squeezing & toe wiggling right & left. She has awakened a little and complained about the breathing tube and pic line in her neck. Looking forward to talking with Miss Em this afternoon.

Dr.T has told us this heart is a real Banger. Then later Dr. R who advised against the last heart popped in to say - This is a really good heart.

Mom & Dad are extremely happy and look forward rehabbing at Ronald McDonald & learning our new nursing & dietician duties in order to get back home.

All praise to God for guiding the medical team and carrying us through these life challenges and those yet to come. Especially for being with the donor family. At some point in the future we will have an opportunity to send a card through Riley's transplant coordinator to the donor family which remains anonymous.

Thank you all for the prayers and continuous support.

Sent from CaringBridge iPhone app

9:30

Written Mar 21, 2014 8:35am

Learning great patience. Still waiting to meet Surgeon and see Emily.

Sent from CaringBridge iPhone app

Mar 21 :6:30 am

Written Mar 21, 2014 5:37am

The new heart is in and Emily is doing fine. It will still be a couple of hours before Linda & I get to visit. The surgeon's want to watch and seal up bleeding which is normal due to her blood thinners.

Sent from CaringBridge iPhone app

Mar 21 12:01 a.m

Written Mar 20, 2014 11:22pm



Emily was taken to OR right at midnight. This one looks like a go. We passed a group of 3 with an igloo cooler on the way down. Procurement team? Emily was very calm and peaceful as she left us for OR. Her biggest fear of transferring to the OR table went smoothly.

Next update most likely dawn.

Sent from CaringBridge iPhone app

March 20, 2014 Thursday

Written Mar 20, 2014 6:56pm

I'm happy that God has forgiven me for yesterday. He has provided a donor heart that was accepted by my cardiologist & surgeon. All indications is this is the special one! God willing I will have a new beginning tomorrow. Right now I'm getting frozen plasma, heprin, celcept, and IV fluids to prepare me for OR. I'm happy to know God is continues to be with me and fam.

Dad or Linz will keep you posted when we actually go to OR. ???!

Sent from CaringBridge iPhone app

March 19, 2014

Written Mar 19, 2014 9:40pm

As Forest Gump says "Life is like a box of Chocolates - You never know what your going to get" Well I'm tired of this box and ready for a new one.

Today I got gagged on my capsule and threw up which went on my pic line. So my Cardiologist & Surgeon decided I needed a new one because the other one could of gotten infected. Then I find out I can only take Loritab and Benedryll orally for pain. While waiting to go into the OR type room with ultrasound and contrasting for precise placement. The longer I sat waiting the more sick I felt. Then suddenly up comes my lunch and probably my meds.

I went in in a not so good mood. I pray forgiveness for my thoughts I was thinking before and after the procedure. I was told that I should be nicer to people because I was very vocal in telling people not to touch my back and really wanted to cuss because my back hurt so bad transferring to table and off the table. At least I have a precisely placed pic line. After coming back to my room I was given some Ativan and slept for a couple hours. Dad wasn't too happy either since they wouldn't let him in during the pic line change. For a minute I didn't think he was going to sign the papers.

Tonight I'm feeling much better and look forward to tomorrow. At least until I have my dressing change tomorrow. Now I'm enjoying Duck Dynasty and getting ready to FaceTime mom and Linz.

Love,
Emily?

Sent from CaringBridge iPhone app

March 18, 2014

Written Mar 18, 2014 9:09pm

Daddy surprised mom and I by coming up today. Him and mom are switching out for a few days so mommy will get mother-daughter time with Lindsey and much needed rest. Dad can't believe how fast I've gotten at taking my pills.?

Today was an eh day, but I did walk more than yesterday. It seems like my side/waist/hip has hurt the worst today. In P.T. I walked half a lap, came in the room and did some leg stretches, then walked the hallway and back. My P.T. instructor tried to lay me flat in bed like she used to for my posture, but that really hurt so she didn't put me all the way flat. After P.T. I had dressing change and I seemed more tired than silly and sassy. After I woke up from my nap, I was still tired.

One of my therapists that come on Tuesdays came today and we played UNO and mom played too. The therapist won the first game, I got 2nd, and mom got 3rd. The second game we played I won and I'm not sure who got the titles for 2nd and 3rd.?????

Now I'm just hanging out with daddy and I will very much enjoy my time with him.?

Oh, and now I'm off my heparin drip meaning I'm not hooked up to Ivy anymore. (My IV pole)

Love,
Emily?????

Sent from CaringBridge iPhone app

March 17, 2014

Written Mar 17, 2014 7:42pm

Happy St. Patrick's Day everyone!!!!??????????????????

With every upside, there's a downside. On that note, today was the luck of the

Irish...haha....NOT!!

We all thought I was getting better, and just this morning I was PERFECT: Sitting in my chair, eating breakfast, watching TV, and I didn't even move and all of a sudden I started screaming "Mom!! My lower back my lower back it HURTS!!" She told me to calm down, breathe in through my nose out through my mouth and say a prayer, and sing my song. We think it was a spasm again.

Since I was having spasms again that were even worse than last week, daddy came up. It was good because he was there for P.T., helped me to the bathroom, held my hand, went to a conference care meeting, and went down to x-ray with me. I don't know who decided it, but I went downstairs for an x-ray on my chest and back which was really hard because I had to stand and lift my arms up. But daddy, mom, my nurse, and my P.T. instructor were all there with me so it was OK. They wheeled me down there in a wheelchair and gave me Attivan for my pain. This morning I got Vallume, which helped just a little bit. Tonight when daddy left he believed that mom and I could handle it, so now he's home with Lindsey. Also tonight I got Loritab and that seems to be helping. I have pillows on both of my sides, I'm in the chair, I have my stuffed animals sitting here with me, and hot packs on my lower back which feel SO good. Mom and I are sitting here watching Duck Dynasty and enjoying each others company. Even though I'm in pain, we both love to see each others smiling faces right there. Oh, and in P.T. I didn't do much, but at least I moved my muscles around. I walked the hallway and back and that was a major accomplishment even though it wasn't much.

P.s. I'm hooked up to my IV pole because I'm on a heparin drip because my INR was a little below 2 this morning. So hopefully that will raise it back up.

Hope everyone had a great St. Patrick's Day, mine is determined to get better...

Love,
Emily?

Sent from CaringBridge iPhone app

March 16, 2014

Written Mar 16, 2014 9:25pm



Cuz we're just cool like that. No caption needed. (Look at the picture I posted to understand) #SisterlyLove?

This morning started out by getting out of bed and going to the chair, listening to the Immanuel Lutheran Church Service with dad???, working on Confirmation???, and taking an early 2 lap walk with daddy.

Today went by fast, but fun. When mom and Linz got here...Lindsey and I played games on the iPad (Deal or No Deal, Wheel of Fortune, Family Feud, Hay Day, and took selfies) and we did some crafts.? This afternoon I took another 2 lap walk with mom, Linz, and dad, though this time we were jammin' to music.???????????? After my walk mommy and daddy washed and dried my hair before dressing change.? ? my hair now feels all soft and clean.? Around 3 or 3:30 I started taking my Loritab and got Adivan through IV for pre meds for dressing. The Adivan (which makes me silly) kicked in very quick today. So I went ahead and used the bathroom and got into bed. Since I was being silly and funny I was taking pictures and videos of Lindsey and I and I wanted to show Linz and dad what I did with Teddy my last dressing change....but I couldn't find him. I said, "Where's Teddy?!?!"...he was right beside me. Before dressing when I was laying in bed mom, Linz, and I got 2 games of UNO played. Both times mom won, I got 2nd, and Lindsey got 3rd.????? I said bye to dad and Linz even though dad stayed with me during dressing because after dressing I would be taking my nap.

When I woke up, I saw that daddy put up my Final Four mini basketball hoop that a nurse practitioner got me. I was excited I got this gift because I can do it sitting or standing throughout the day by myself or with mom, it works my arms, and it will give me something new to do in P.T. instead of just doing arm/leg exercises.?? Also a few minutes after I woke up I got surprise visitors, the whole gang: Uncle Kevin, Aunt Kendall, Kaiden, Kole, Mur, and Uncle Jon. Today was Kole's 5th birthday and he said he wanted to see me.? How sweet!! #CousinLove??? We all sang Happy Birthday to him and even though they didn't stay long (because of school tomorrow) I loved seeing them.????????????????5?

Happy Birthday Kole and Happy St. Patrick's Day Eve!!!!????????????

P.S. When I had my Adivan I was in major lala land and when I had my Fetynol today I was in super sassy mode. hahaha?

Love,
Emily?

Sent from CaringBridge iPhone app