

Prepared for Scottie's site on December 21, 2021.

Journal

Monday, July 22, 2013

July 27, 2013

Around 11:15am, I (Scottie's Dad) was in our house getting ready to run some errands. Scottie had worked very late, the previous night, and was sleeping in, but I wanted to make sure he was up and about before I left the house.

When I went into his room, and called his name, he did not respond. I thought he was just in a deep sleep, so I approached where he was sitting up on his couch and shook him. I realized that he was trying to breathe, but they were short gasps more than breaths. I immediately called 911, and they told me to begin CPR, while the EMT's were en route.

I got Scottie on to the floor, and started chest compressions. Within moments the first of the "Help" began to arrive. We got Scottie out in to the living room, and at that point, I was escorted outside, while a flood of emergency responders began arriving.

After what seemed like an eternity, Scottie was brought outside on a stretcher, and taken up to Kalispell Regional Medical Center. The Police gave me a ride up to the Hospital in their car, and our neighbor Dee and Chaplain Drew rushed over to Sonja's (Scottie's Mom) work, where they picked her up and drove her to the Hospital.

We learned very early on, that Scottie had gotten a virus that attacked his heart, and that his heart was only functioning at between 5 - 10% of normal capacity, which was not life sustaining.

Many tests were given on this day. Things seemed to stabilize somewhat as day turned into night, or so we thought.

That evening, we all took turns visiting Scottie in the Intensive Care Unit. Later in the night, I took my laptop down to Scottie's room, and sat next to him, while we watched some of his favorite cartoons. He was under sedation, but I figured it might calm him, if he could hear the sound.

Scottie's ICU nurse, Amanda, was walking around, checking his monitors and IV's, when

she looked up, just in time to see his heart going into cardiac arrest. She immediately laid his bed down, and "Code Blue" was announced over the intercom. Within seconds, it seemed like the entire Hospital had arrived, and CPR began, while they were charging up the defibrillator. The shock was administered, and Scottie's heart began beating again. We were told that his heart had slipped into the same rhythm that they found him in at the house, and this rhythm would quickly lead to death, if not corrected quickly.

Things slowly returned to normal, or so it seemed. Within a short time, Scottie again began to arrest, but this time, Amanda got him laid down flat, and his heart recovered by itself.

Scottie went into cardiac arrest yet again, not very long after the last event, and this time, he did have to be shocked into a "good" rhythm again.

At this point in time, the Cardiologist indicated that Scottie had to get to a facility that had a transplant team, preparing for the worst case scenario. Dr. Mitchell called Sacred Heart in Spokane, and began making preparations for transport.

Brain damage was a huge concern at this point, as there was no definitive answer as to how long Scottie was not breathing. However, there were several times that Scottie came out of sedation, and tried sitting up, and that was proof enough for Dr. Mitchell, that there was not any serious brain trauma.

Sometime, around midnight, the flight crew from Life Flight showed up, and they began prepping Scottie for his flight to Spokane.

Due to the amount of life support that Scottie was hooked up to, it seemed like an eternity before they were ready to move. In the midst of these preparations, Scottie again began coming out of sedation and moving around; again, his heart arrested, and again, they shocked him back into a normal rhythm.

Finally, they got moving, and en route to the ambulance that was waiting outside. The Life Flight had room for one additional person, so I accompanied Scottie, while his Mom and Grandpa Scott, Grandma Christy, and Brother Duncan, went by car, to meet us in Spokane.

After a short ambulance ride to Glacier International Airport, we arrived at the hangar where the Life Flight was waiting. Amanda (the ICU nurse from KRMC) was accompanying us, and there were 2 flight medics- Justin and Darryn, as well as the pilot, Howard.

Again, it seemed like an eternity to get loaded on the Life Flight, but eventually, we were all in, and airborne, with a 45 minute flight time to Spokane, WA.

By the grace of God, there were no further cardiac events, and we landed at the airport, and loaded into another ambulance, that would take us to Sacred Heart.

Tuesday, July 23, 2013

July 27, 2013

Early in the morning, we arrived at the Sacred Heart Medical Facility. While the medical staff was getting Scottie situated in the Cardiac Intensive Care Unit, I met with Dr. Kwasman, for an initial consultation.

As we already knew, Scottie was in very critical condition. He was hooked up to every type of life support that the hospital had, and had an Aortic Balloon Pump installed in his heart. Doctor Kwasman basically gave us best and worst case scenarios, and explained to me what actions he wanted to take to treat Scottie. Heart transplant was discussed, as well as Scottie walking out of here on his own, with his own heart; only time would tell, and we had a tremendous fight ahead of us.

At around 10:45 am, Scottie was taken down to surgery to have a heart biopsy performed. He was also to have a CT scan, and the surgeons wanted to remove the aortic balloon pump that was in place, and install one that was larger.

A couple hours later, we were in the conference room talking, when the 2 heart surgeons and Cardiologist came into the room. They explained that while they were installing the larger balloon pump, things began to go bad, so they had to quickly install a VAD (ventricular-assistive-device) that would do the work that the heart was not able to do, with the benefit of giving the heart some time to try and heal. At this point, Scottie has been stabilized, but we have never seen a human body hooked up to so much life support, so many IV's, so many monitors.

What we did learn on this day, however, was the amazing competence of the people working on our son, and not only that, but the tremendous caring they demonstrated, while tending to him.

Grandma Cathy arrived late this night, and Grandma Ruth and Dave got in, very early

the next morning.

Wednesday, July 24, 2013

July 27, 2013

Today, we got a little bit of good news. During the night, Scottie was able to be weaned off most of his 4 blood pressure medications. In addition, his medications were able to be fine tuned, and thus far, there have been no further cardiac events.

We had another conversation with Dr. Kwasman, and in essence, he told us that there is nothing that this ICU can not handle, with one exception, the brain. A brain that had been deprived of oxygen for too long, is something that cannot be repaired. I told Dr. Kwasman of how Scottie was trying to sit up and move around while at KRMC, and that gave him hope, but he wanted and needed to see proof in the upcoming days, and they began cutting his sedation back.

A couple other things that we learned today, was that Scottie was on dialysis. Apparently, through all of this, his kidneys and liver took a real beating, so he needed some help in the form of dialysis. Dr. Kwasman told us that he believed there was no permanent damage, and because of his age, he should rebound in time.

Later that evening, I was sitting in the Hotel room that we had for the night and Grandpa Scott came walking in the room, after visiting Scottie. He told me "I don't know if this is important or not, but the kid just tried sitting up, and was moving all over the place, while the nurse was touching him and adjusting things." The most important part of that information, was the fact that none of his vitals spiked, meaning that he was slowly getting stronger.

I went into Scottie's room to visit, later in the evening. I tried explaining things to the best of my ability, and a couple times, I could see he was trying to open his eyes.

This was a great day, and Scottie showed us what a fight he is putting up!

Thursday, July 25, 2013

July 27, 2013

Sonja and I got down to the Cardiac ICU early in the morning, with the hopes of talking with the Cardiologist.

We met up with Dr. Kwasman, and he told us that he was able to get a response from Scottie, via verbal commands, and he now had his proof positive that Scottie was all there, mentally.

Today, Scottie got the last of a drug called anti-thymocyte-globulin. This is injected into his body, with the expectation that it will tear down his immune system and the antibodies within. Apparently, his own immune system is doing more damage than good, with this virus in his body, so they want to stop it. Very soon, they will begin injections of Rituxan, (which is a chemotherapy drug) that will be performing the same task as the Thymo, in tearing down his immune system. His room is now classified sterile, so anybody coming or going has to scrub up, and put on a gown, face mask, hair net, gloves, etc.

Once these immuno-suppressant injections are completed, Scottie's body will begin a several month process of rebuilding his immune system, and there is a very good likelihood that he will be getting all of his original childhood immunizations again.

Today was the first of 3 days of plasmapheresis. Each session will last for 3 hours, and my understanding is, the blood is circulated out of the body, filtered, plasma removed and replaced with donor plasma, then put back in the body.

In the evening, Grandpa Scott went in to visit Scottie in his room. While in there, Grandpa took his hand, and asked Scottie to squeeze; Scottie immediately squeezed his hand. The nurse came over and asked Scottie to squeeze her hand; he squeezed her hand as well. Scottie opened his eyes, and looked like he was trying to talk, so the nurse turned up the sedation, and he went back to sleep.

Friday, July 26, 2013

July 27, 2013

Last night, Scottie had a very good night. Early in the morning, Grandma Cathy saw Scottie moving around, and he appeared to be motioning for somebody to remove his ventilator tube.

The morning started with another stellar conversation with the Cardiologist, Dr. Kwasman. He reminded us that Scottie is still very critical, however, the echocardiogram showed his heart functioning at 15% as opposed to the 5 - 10% from the days before.

The second round of Plasmapheresis was performed.

A very good day. The staff warned us that there would be many steps backward, along with forward progress. It almost seems like we got all of the backward steps out of the way in the beginning, because every time we talk with the Doctor, we hear nothing but good news!

Tonight, I scrubbed up and went in to the room, to visit with Scottie. I had a wonderful conversation, and Scottie was awake and aware for most of it. I asked him if he was comfortable, and he nodded yes. I also asked if he was hot or cold, and he shook his head no, in both instances.

The hospital staff brought a cd player in Scottie's room tonight, and we gave them some cd's of bands that he likes, to play.

Saturday, July 27, 2013

July 27, 2013

The morning started again, with a conversation between Dr. Kwasman, and Sonja and I.

There is talk of possibly removing the aortic balloon pump from Scottie's heart, as well as taking him off the ventilator soon.

The exceptional news is that Scottie's heart is pumping twice the amount that the VAD (ventricular assistive device) is doing. Because of this, Dr. Kwasman is talking about possibly removing this in the very near future, as well.

As each day goes by, and Scottie's heart appears to be getting stronger, the possibility of a transplant becomes less and less.

Dr. Sandler, one of the cardiac surgeons who is treating Scottie, made the decision today

that the aortic balloon pump will have to remain for at least another day. Scottie is on many blood thinners right now, and after a test revealed a very low platelet count, the risks outweigh any benefits of removing the pump today. Removal of the ventilator will also be on hold for at least a couple more days.

The final round of plasmapheresis was completed today.

Today they began round 2 of blood transfusions. These transfusions were necessary to replace the blood that was lost these past couple days, due to the blood thinners. The main reason for these blood thinners, was to ensure that the VAD did not throw a clot, while helping circulate Scottie's blood.

Sunday, July 28, 2013

July 28, 2013

Today started with a debriefing from Scottie's nurse, Deb. She gave us more good news, that the previous night was uneventful, with all of Scottie's vitals remaining stable. There was also more discussion about the balloon pump possibly coming out today.

At around 11:30 am, the aortic-balloon-pump was finally removed, without incident.

Throughout the morning, preparations were made and tests administered, in anticipation of the ventilator being removed.

At around 1:00 pm, the ventilator was finally shut off, and Scottie was allowed to breathe on his own. The ventilator tube was left in, and there was a small amount of positive pressure continuing through the tube, but Scottie's lungs had no problem kicking in and doing their thing.

At around 1:45 pm, the ventilator tube was completely extracted and Scottie is now breathing again, completely unassisted.

The sedation has ceased at this point, however, there is a lot of residual from the drugs in Scottie's system. We are seeing the effects of the sedation beginning to wear off, and

as a result, Scottie's awareness of the equipment he is hooked up to, is increasing.

A lot of this equipment is attached to Scottie, via IV needles and the large gauge tubes entering his leg, that are connected to the VAD.

As would be expected, these needles and tubes are painful, and at the very least, uncomfortable; the nurse is doing her best to keep Scottie comfortable and resting, but as would be expected, he is getting restless as the sedation wears off, and becoming more and more cognizant of his situation.

All of us are taking turns calming him as he is becoming more and more lucid.

Kidney functions are stellar at this point.

When I last saw Scottie this evening, the only thing on his face, was one small feeding tube. As a side note, nurse Deb informed us that it would be some time before Scottie will be able to eat and drink, but not to worry, as his body is getting all the liquids and nutrition he needs, via IV and feeding tube. After organ failure and rebound, no risks will be taken with food and water until absolute stability is demonstrated.

The VAD could very possibly come out tomorrow, depending on what the echocardiogram shows in the morning.

Monday, July 29, 2013

July 29, 2013

This morning, we had a small "pause" in Scottie's recovery.

Nurse Jennifer called Sonja this morning and told her that Scottie had been taken

downstairs for a CT scan. During the night, they were not seeing as good a response, as they had seen the previous day. The CT scan was ordered by Dr. Sandler as a precaution. Jennifer indicated that this could very well be a result of the medications that Scottie is on.

Another issue they had through the night, was that Scottie was thrashing around quite a bit. This is to be expected, and would normally be tolerated by the staff, however, this type of activity poses a huge risk of interfering with the VAD (ventricular assistive device.) The VAD has very large gauge, rigid lines, entering the femoral artery in the leg. The legs absolutely have to remain still while the VAD helps his heart heal, by taking over the blood-circulating function. Scottie keeps trying to sit up and move his legs, so the doctor's elected to have him intubated again, and allow the ventilator to take over breathing, so that he can be sedated again.

Echocardiogram will be performed this morning, and with those results, the doctor's should make a determination on whether or not the VAD will be removed.

At around 12:30 pm, the mechanical heart nurse, came down to the waiting room, and gave us an update.

Dr. Icenogle had made the decision to have the aortic-balloon-pump reinstalled. Along with the balloon pump, they reinserted a sensor in the carotid artery, to monitor pressure in the heart.

At 1:45 pm, Scottie returned from the cath lab, with the new balloon pump.

We have had such good progress with Scottie, over the past couple days, that these new developments were emotionally hard to hear. We were made to understand that there was nothing "bad" about Scottie's situation, but instead, to view it like this: all of these pieces of equipment are aids in helping Scottie heal his heart. They were removed to see how his body reacted, and after he showed the most minute sign of still needing them, they were quickly (and very easily) reinstalled.

A new PICC line was inserted into Scottie's other arm, this afternoon. PICC stands for Peripherally Inserted Central Venous Catheter. There was a PICC line installed in Kalispell, but nurse Jennifer stated that it was not working very well anymore, so it was removed, and a new one installed in the other arm. The PICC line is used so that there is a readily available "port" to the bloodstream, for injections.

At around 5:00 pm this afternoon, Sonja and I went and visited Scottie one last time for the day. He is resting very soundly; he looks very good, blood circulation is great, kidneys are functioning very good and circulation is very good. Nurse Jennifer indicated that she believes the doctors will try weaning Scottie off the Tandem Heart VAD

tomorrow.

Tuesday, July 30, 2013

July 30, 2013

The morning started with a meeting with Dr. Icenogle, and David, the mechanical heart technician. They have scheduled for the Tandem Heart VAD to be removed from Scottie's leg today. No other news from the Doctor, other than things are progressing slowly. The echocardiogram was performed today, and the results indicated that Scottie's heart is now performing at 25%. As explained to us, a normal, healthy heart, functions at 60%. While 25% is obviously not anywhere near where Scottie needs to be ultimately, to come from 5 - 10% that first night, up to now, we are so thankful!

At 9:45 am, the Tandem Heart VAD was successfully removed from Scottie's leg. This was a huge step today, because now the only thing assisting Scottie's heart, is the aortic balloon pump and a very minute amount of medication. Dr. Sandler will return within the hour to suture up the area that was incised for the insertion of the VAD line into the femoral artery.

Scottie's leg was sutured up on schedule, and a small transparent, plastic cup is now over the area of the incision. This device is called a Femostop, and it has a little hand pump attached, and uses a certain amount of air, to hold direct pressure in the exact

area that the artery was penetrated by the VAD line.

We got to see Scottie finally, and he is looking very good. All vitals are stable. He is heavily sedated for now.

The evening went by very peacefully, and without incident. Scottie remains sedated in anticipation of the possible removal tomorrow, of both the aortic-balloon-pump, as well as the ventilator.

Wednesday, July 31, 2013

August 1, 2013

Yesterday and night was very long, but very good.

Running a little late on this entry; apologies to those who have been following this journal, and watching the updates.

To say that this day was huge, would be a complete understatement,.

The morning started with us going to Scottie's room at around 8:30 am, and when we approached the window to his room, we realized his eyes were open. We hurriedly washed up, put a mask on, and entered the room. Scottie's sedation had been completely turned off, and even with a ventilator still installed, we were able to communicate with him.

I am pleased to say, that I was able to make Scottie smile two times, when I retold a couple stories, and we had a chuckle at the expense of Scotti's Brother and Grandfather.

After a quick visit, Scottie's room began to get quite busy, as the staff began making preparations for removal of the aortic-balloon-pump. Scottie also got hooked up to the dialysis machine for one last treatment.

Around 1:30 pm, the balloon pump was removed without incident.

This afternoon, nurse Beth informed us that they were looking at an approximate ventilator removal time of approximately 6:00 pm. At this point in time, the ventilator is merely providing a minute amount of positive pressure. Scottie is completely doing all the breathing on his own, they just want to make sure that there is absolutely no further

need of the ventilator, before they pull it out.

At around 3:00 pm, one of the critical care doctors came in to check on Scottie. He and nurse Beth had a quick chat, and they agreed to do one last, quick breathing test, and the ventilator would be removed, ahead of schedule.

At 4:00 pm, Sonja and I came back to Scottie's room to check on him. I am happy to report that the ventilator has been removed. Scottie had a small plastic mask on, with a nebulizer hooked up to it, which was the beginning of breathing treatments that Scottie will get 4 times a day. Essentially, the plastic mask has a small reservoir attached to the bottom of it, where liquid medication is added. With a small pump providing air flow, the medication appears to be vaporized, and inhaled out of the mask.

Scottie is very hoarse, due to the stress that the ventilator put on Scottie's throat and vocal cords. However, we could completely understand what he was communicating by getting close to him.

For the first time in 8 days, the nurse was able to give Scottie some water, in the form of ice chips. He was very pleased to have that.

We are now making sure that one family member is present in Scottie's room at all times. The kid just will not go back to sleep! He has many questions, and because of the high amounts of sedation for the past week, there is a little confusion, as well as short term memory lapses.

Huge progress today, and now we wait for Scottie's heart to heal.

Thursday, August 1, 2013

August 2, 2013

Because of the long term sedation, Scottie is suffering from a good amount of psychosis. As a result of this psychosis, there is an inability for Scottie to fall asleep. A bit scatterbrained, but you can ask him anything that happened up to the day that he went to the hospital, and he has complete and total recollection. Ask him something from 30

seconds ago, and he has a very hard time remembering. We have been assured that this is short term, and it is often seen with patients that have been sedated for several days. Unfortunately, the lack of sleep is causing some hallucinations and delirium. Sonja and I have been splitting the night time hours, and making sure to be in the room with Scottie, and my 2 Moms and Dad are helping us in the day. Scottie is very restless, and is also obsessed with fidgeting with his lines, tubes, sensors, etc., so we make sure that somebody is there to help him occupy his mind until he gets over this.

Scottie went from only having ice chips every couple hours, to now being able to drink water, every so often.

We visited with Dr. Icenogle this morning, and he had many good comments about Scottie's condition.

Grandma Christy spoke with Dr. Sandler this morning, and he too had good comments.

Even with all these good comments, the doctors keep reminding us that Scottie will still be here at the Hospital for a while yet, and while he is doing well, there is nothing definitive on how good his heart will rebound.

The heart pressure probe was removed from Scottie's neck today, which was nice to see, as this was a large gauge device, that was inserted into Scottie's neck. Slowly but surely, lines, tubes, probes, etc., are disappearing.

This afternoon, Scottie got a visit from two physical therapists. They got Scottie to do some simple exercises, while sitting in the bed, and they told us they are going to get Scottie on his feet tomorrow.

After the physical therapists, we received a visit from the speech therapist. She was there mainly to have Scottie do some trial runs, eating some different foods, and making sure there were no issues with chewing and swallowing. After many days of living on Intravenous solutions, and a bag of mush that was hooked directly to the small intestine, Scottie got to experience some "real" food. Fruit, pudding and some graham crackers was what Scottie was given, and he ate everything without any issues. Tomorrow, Scottie will be back on a regular food diet.

Fevers seem to be showing up at regular intervals, and are usually treated with a Tylenol solution that is dispensed into the feeding tube that goes into Scottie's nose. The fevers are not a huge concern of the Doctors; the blood labs are done every day, usually a couple times each day, and so far, nothing has come back showing an infection. The main concern is the compromised immune system, due to the anti-thymocyte-globulin injections along with the Rotuxin, that was administered earlier.

As the afternoon passed without incident, we went into the night, Scottie still not being able to fall asleep. A whole lot of crazy talk, but we keep his mind occupied, and keep reminding him where we are at, and why we are here. He is in very good spirits. A lot of cuss words being dropped by our young man, but we get after him, and even tolerate the smaller ones. We were doing okay until he began regurgitating many of the more colorful lines that Gunnery Sergeant Hartman used during the first half of Full Metal Jacket when the recruits were all in basic training.

At this point, the psychosis is going to be dealt with, by letting it run its course. The main reason for this, is they do not want to administer any drug that could possibly interfere with the medications they are using to try and heal his heart. It is the opinion of the hospital staff, that eventually, he will get so tired, that he will have no choice but to fall asleep. We shall see.....

Friday, August 2, 2013

August 3, 2013

Another very long night, with Scottie unable to get any sleep. He is in very good spirits, and the nurses keep telling us that he will fall asleep, eventually. The psychosis caused from the days of sedation, combined with the sleep deprivation, make for some interesting conversations.

Dr. Icenogle stopped by and spoke with Grandma Christy, this morning. He informed us that Scottie's care would be turned over to a regular cardiologist very soon, and he would be relocating from Intensive Care to a regular hospital floor.

The feeding tube that was going into Scottie's nose was removed today, as well as one of the large IV lines.

Later in the morning, nurse Sean came into Scottie's room, and brought him a breakfast tray. Finally, real food again, albeit not a whole lot.

Dr. Ring, the cardiologist that will begin seeing Scottie as soon as he is moved out of ICU, came by and visited with us today. Dr. Ring reiterated what Dr. Icenogle told us, regarding moving out of ICU and to a regular hospital floor.

Two occupational therapists stopped by today, to work with Scottie. By the time they left, they had him out of bed, standing and sitting upright in a chair. 2 weeks of being

confined to a bed, and laying on his back could not beat this kid down; he has plenty of strength!

We are trying to familiarize ourselves with medications that Scottie is getting, and what they do. Nurse Sean told us that the doctors are prescribing different medications in different doses, in an attempt to get Scottie's heart rate and blood pressure to the best numbers, with his condition.

Later in the evening, Scottie was finally given a pill (Seroquel) to help him get to sleep. It did do some good, and he finally got about a 4 hour nap.

Saturday, August 3, 2013

August 3, 2013



A fairly uneventful night, last night. The psychosis has still not abated much, but we are constantly assured that it is completely normal.

Scottie's cardiologist, Dr. Ring, stopped by this morning. He checked in on Scottie and let us know that transition from ICU to floor #6 in the hospital, would be postponed one more day.

A very busy morning, we had the privilege of receiving visits from the Kidney Doctor, Infectious Diseases, Cardiac Surgeon and cardiologist. The consensus is that Scottie is doing well, and there are not any major concerns, presently. It was reiterated to us that it will be weeks, if not months, before we know what the ultimate effect from the different medications will have on Scottie's heart.

The nutritionist came by today, and told us that Scottie is essentially on an unrestricted diet, at this point. As a matter of fact, they want him to eat as much as he wants, due to the fact that he has lost so much weight during his time in the ICU. We are now keeping track of caloric intake, as requested by the nutritionist, so that she can monitor his diet.

Dr. Icenogle visited with us today, and had for a chat. He basically echoed what Dr. Ring told us, about moving out of ICU. He also was very firm in letting us know that because

of this heart illness, Scottie's heart will never be the same as it was before. It may very well heal enough to be managed with medications, but the devastation caused by this virus was so severe, that the most important thing in his life, from this point on now, is taking care of his heart, and to become lacsadaisical about treatment and medications, would be deadly. Half-way through this conversation, I had to interject, and point out that Scottie was quite delirious, and short term memory was not very good, as he was still suffering from psychosis. The semi-glazed look in his eyes and bit of slobber in the corner of Scottie's mouth confirmed this..... I did tell Dr. Icenogle that I am his greatest advocate, and rest assured anything he told me, would be stomped into Scottie's brain relentlessly.

Today, Scottie appears to have an unquenchable thirst. The flavor of the day was root beer, and we got Scottie 2 bottles of Barq's, first thing today. He drank the first one rather quickly, and got half way through the second, before nurse Chris came in, and took it away for the time being, and offered him water instead. The kidneys are functioning very well, so there are no limitations on fluids at this point in time.

Scottie tries to get naps during the day, and just when he seems to be out, another doctor comes in to do a checkup. Scottie will be getting another dose of Seroquel tonight, to help him sleep.

I found out today, that we can order Scottie's meals for him, by calling the hospital kitchen. After careful consideration, and Scottie's input, dinner tonight will be chicken bake, grapes, banana cake, apple juice and vanilla shake.

This afternoon, when I went in to visit Scottie, after returning from a lunch break, there was a humorous exchange; as I walked over to Scottie, he put his hand out for me to shake. As I took it, he informed me that he appreciated the job I have been doing, but he is going to nonetheless, have to let me go. I informed him that fortunately for me, there is an unwritten rule that Dads cannot be fired except under the most extreme of circumstances. I pulled my face mask down, that we have to wear while in the ICU, and he realized that it was me. He then apologized and explained that he had mistaken me for somebody that worked with him at the Montana Club.

Sunday, August 4, 2013

August 5, 2013

Kind of an uneventful day, and we are always pleased to have uneventful days.

Grandma Christy got the morning update from the doctors.

Kidney doctor gave his assessment and indicated that the kidneys are functioning at between 40 - 50% of a healthy kidney. I keep having to remind myself that when he came in here, he was in kidney failure, and on complete dialysis for some time. Even functioning at 50%, Scottie's kidneys are kicking butt!

Dr. Ring, the cardiologist, came in and gave us his morning assessment: progress is very good. Dr. Ring says that Scottie is slightly anemic; Anemia is a condition that develops when your blood lacks enough healthy red blood cells or hemoglobin. Apparently, they will attempt to counteract this with iron supplements. If the supplements do not do the trick, then they will do a transfusion.

Scottie is able to sit upright in a chair for extended amounts of time, now. He eats his meals sitting, and standing up is absolutely no problem. He is getting from the bed to the chair by himself.

Trying to get Scottie to eat as much as possible. The nutritionist says that he is way behind on calories. Not a huge appetite, but he also gets fevers frequently, which I imagine is part of why he is not hungry.

Scottie got to bed at around 10:00 pm and was able to get a full night's sleep, with a little help from our friend, Mr. Seroquel (the little pill.)

Psychosis is slowly but surely abating, and short term memory is coming back like gangbusters.

Monday, August 5, 2013

August 5, 2013

What a change a couple days have made, combined with good sleep! Psychosis issues have all but disappeared. And short term memory is roaring back. Scottie got around 8 hours of sleep last night. A couple interruptions from the nurses, but he was able to fall right back asleep each time.

Chest X-ray was performed at around 3:00 am.

Had a very nice conversation with Dr. Kwasman and Dr. Sandler, this morning. Dr. Kwasman had been out of the area for the past week, and the last time he saw Scottie, Scottie was under heavy sedation, had the Tandem Heart, aortic-balloon-pump, multiple IV's, dialysis machine and ventilator. There were questions as to how long Scottie may have been without oxygen, before I found him, and Dr. Kwasman had only seen a response in the form of squeezing a hand, etc.

When Dr. Kwasman came in, Scottie was sitting upright in a chair, eating his breakfast, and conversing with us. Dr. Kwasman asked Scottie some questions as to where he was, how he was doing, etc. His final question, was if Scottie knew what had happened to him. Scottie basically rattled off a textbook answer as to what his condition was, how he got it, and what his present condition was. Dr. Kwasman was left a little befuddled, and his reply was: "That is a very advanced understanding of things...." Dr. Sandler looked at Dr. Kwasman, and said, "Are you happy now?"

Echocardiogram was performed at around 4:00 pm. We should get the results tomorrow sometime.

Still waiting to move to floor #6. Fever keeps returning, so doctors are hesitant to to make the move just yet. Safe than sorry seems to be the theme.

Saw Dr. Redding (kidney doctor) this afternoon. Kidneys are getting better every day. There does not seem to be any issues with fluid retention. You know things are going well, when the doctor spends 30 seconds giving a health update, and spends the next 15 minutes comparing his watch to Scottie's, which are apparently very similar models.

Appetite still slowly coming back, but still need to be taking in way more calories.

Heart rate is still in the 120's - trying to get that lowered with medication.

Breathing seems to not be so labored today. Have not seen any real shortness in breath, unlike the past few days.

Tuesday, August 6, 2013

August 6, 2013

Morning went by without incident. Shayne stopped by for our daily chat, and to check in on Scottie. The results for the echocardiogram were back, and he rated Scottie's injection fraction at a 15. A few days ago, they gave his injection fraction a rating of 20, but Shayne explained to us that this test is extremely subjective; if 10 cardiologists were asked to look at the results of the test, probably get 10 different answers. Shayne also told us that the right side of the heart looks very good, but the left side is what sustained the most damage. Scottie has nothing but time at this point; to rest, let the medications work their magic, and let his heart get healthy. We are so pleased to see consistent forward progress, ever since he arrived at Sacred Heart. Heart rate seems to be calming down some, which would indicate that his medications are working. Scottie is now getting iron supplements, in an attempt to counter the anemia. Physical therapists showed up this afternoon to work with Scottie. Exercises for today, consisted of walking around the nurses station and balance. Temperature seems to have remained normal today; doctors are still uncertain of what is causing these fevers. Blood labs are being performed twice a day, and have shown no infection. Finally got to move up to floor #6 this afternoon! Floor #6 is the Advanced Cardiac Support floor. Despite it's scary name, this is the step-down floor where patients go after they no longer need ICU. Scottie has a nice, private room, with bathroom, and shower. At this point in time, Scottie has a portable receiver hooked up to his sensor leads, which transmit his vitals to the central nurse station. 2 IV's are currently going to his arm, and these are hanging on a mobile tree. Scottie will now be able to take extended walks, now that he is free of so much equipment. The nurses were nice enough to bring a comfy, portable bed, into Scottie's room, for his mom to sleep on at night, if she wants to. Tonight is the last night that I will be updating this journal for a while, if not for good. Since Scottie is out of ICU, and into a regular room, I am leaving Spokane, to return to work, in North Dakota for a couple weeks. Sonja will continue updating until I return, or until Scottie is sent home. Scottie is in very good spirits. His biggest concern at this point, is getting back home in time to start his senior year of High School.

Wednesday , August 7 2013

August 7, 2013

Scotty had a pretty good day today despite a restless night of sleep. He has been walking around the unit quite a bit and doing as much exercises as he can manage before tiring out.

Dr. Ring came in early in the morning and said his kidneys are almost back to normal range although His hemoglobins are much lower then they like so there was talk of a 4 hour blood transfusion. In the afternoon after a consultation with Dr.Sanders the decision was to forgo a transfusion because he is still a candidate for a transplant. He still has half the amount of blood so he is getting iron so they are tryong to stimulate Scotties bone marrow.

Hopefully we will hear tomorrow or Friday from Dr. Collette and Dr. Alexander after they check his progress whether or not he will need a defilibulator because his heart is still pumping much lower then it should. If he gets a defilibulator it will be replaced every 6 -7 years .

Scottie has had no fever today, his blood pressure was great, and his heart rate has pretty much stayed around 104. He is getting ready to do stand ups and walk around the unit so all in all its been a wonderful day! Scotty is in a great mood, and anxious to go back to school.

Sent from CaringBridge Mobile

Thursday, August 8, 2013

August 8, 2013

Scotty had a pretty uneventful, restful night. He started the morning pretty happy because his nurse checked his vitals and informed him that all of his vitals are FINALLY staying constant and within normal range including no temp, even blood pressure and heart rate staying the same.

Dr. Reed came in after that and told Scotty that as of right now he will not need a transfusion because overnight his hemoglobin levels jumped from 7.1 8.2..otherwise mom would be the potential donor if needed.

Dr. Collette told Scotty that for at least 6 months he can have no canned food including soda or fast food because of the sodium, and as expected he will be getting a defibulator but right now they are waiting a week to rule out any infection. He will have that plus pills for life and will go home with a pump that will be carried inside a fanny pack that is attached to an iv which will be inserted in his chest. He will hopefully have that gone by

Christmas if all goes as planned.

Scotty also has not been sitting in bed feeling sorry for himself; he has been walking, exercising and eating healthier and trying to push himself a bit more each day. He has been very calm, upbeat and proactive in asking the doctors what he should and shouldn't do and eat when he leaves and we have heard nothing but praise for now polite he is with everyone he meets. Very good day!

Sent from CaringBridge Mobile

Friday, August 9, 2013

August 9, 2013

After a very restless sleep last night for Scotty..due to faulty machines beeping all night..he woke up in a good mood that was VERY improved by Dr.Ring informing him he could take a shower. Ahh the smiles! He also told Scotty..who asks after every so gale vital taken..that his temperature is normal and there is no sign of infection. There is also no scarring on his heart although its still pumping a bit weaker then they would like.

After a good lunch of turkey BLT the dietician came in informed Scotty that his calorie count is now done although he has to watch both his sodium and sugar intake.

Dr. Colette visited In the early afternoon and said that Scotties kidneys are now back to normal, and the wait I g time to make sure there is no lingering infection is already almost halfway over. Hopefully he will get his defublator next week. His magnesium is still low so he is getting that along with iron and something they call rocket fuel, which is Milrinone. He will go home in this medicine and hopefully be done with by Thanksgiving. Milrinone is a medication used in patients who have suffered from heart failure. It helps to alleviate increased pressure on the heart.

Scotty also has been doing some pretty intense physical therapy, and has a little more energy and strength as each new day passes. He is very motivated to get better so he pushes himself to do more and is doing great.

Sent from CaringBridge Mobile

Saturday, August 10, 2013

August 10, 2013

Today was pretty quiet and restful for Scotty. His main doctors weren't here but basically he kept busy doing his cardio exercises..i.e. walking stairs, stand ups, and walking around the unit quite a bit, not to mention his breathing exercises along with O.T. arm and strengthening exercises.

He slept great last night and Was pretty encouraged when, early in the afternoon Dr. Sandler came in and told him that he was working on trying to find out when he could ho home because his partners are off on weekends. He is going to have a meeting next week with Dr. Icenogle and Dr. Klasusman to schedule the defibulator and to find a small pump for Scotties iv foe when he comes home.

So, in essence, today has pretty much been resting, exercising, and taking it easy. Scotty is just hoping to start his first day of senior year and is pretty much passing any expectations and goals that they give him. Good job, Scotty!

Sent from CaringBridge Mobile

August 11, 2013

August 12, 2013

Today was a very slow, peaceful day with doctors off until Monday. Scotty rested white a bit due to a very sore and aching leg but pushed himself to continue his cardio and walking. He had great night of sleep and was pretty hopeful of heating from doctors.

Sent from CaringBridge Mobile

August 12, 2013 Monday

August 12, 2013

Scotty started his day early on the morning when Dr. Rice came in to check his heart, vitals, and progress so far. He was very pleased to see how well Scotty is getting Around, and said that his heart has improved slightly with no scarring.

Later in the afternoon Scotties physical therapist came in to check his progress and put him through an intense session walking the stairs repeatedly, monitoring his heart rate and oxygen levels, and walking around the unit. He did very well although he did get a bit tired. His right leg Has been bothering him, but we are told that is because a nerve may have been touched when the balloon pump had been installed and he is now feeling it.

About an hour ago, Dr. Alexander came in to inform us that the defibulator surgery is scheduled for this Wednesday at 7:30 am. It will last about 2 and a half hours, and he will get to go home Thursday! Dr. IceNogle will be in soon to talk with us. Scotty is thrilled! He is doing wonderful, happy to get the defibulator and go home

Great day!

Sent from CaringBridge Mobile

Tuesday, August 13, 2013

August 13, 2013

Today Scotty woke up to a steady stream of doctors and nurses, checking his vitals and preparing him for surgery tomorrow morning. His magnesium levels are very low so he is getting twice the amount he has been, but that is mainly due to the fact that his body is trying to heal and mend within so its sucking up all the magnesium it gets.

In the early afternoon, his physical therapist had him running through his cardio exercises and walking quite a bit, then Dr. Ryan came in to explain again exactly what the defibulator is, how it will work, and where it will be placed. A nurse then came in with

a defibulator to show Scotty and to have him feel it.

Scotty is not nervous in the least merely anxious to go home. He has been sleeping, eating and resting well along with taking an enormous amount of kills without any complaint. Wish him luck, because tomorrow is surgery!

Sent from CaringBridge Mobile

Wednesday, August 14, 2013

August 14, 2013

Today started off with Dr. Rice coming in to check on Scotty early , then a few minutes later the patient transport team came in to get Scotty ready for surgery at 7:30. I was able to walk with him, and believe it or not he wasn't nervous in the least, just calm, cool and collected. The surgery only lasted an hour and a half then he had to go to recovery for 45 minutes. St. Kwazman said Scotty did great, and no complications even when they deliberately put his heart in a quicker rhythm to test it before and after the defibulator was out in.

Scotty then came back to his room to rest because by this time his pain meds had Worn off so he was in quite a lot of pain. After resting for a few hours, a nurse came go show him what the small pump looks like, how to use it, and answer any questions He is going home with quite alot of medicine plus ivs but Scotty is unconcerned and happy.

Tomorrow morning, as soon as we can GWR discharge papers plus his pump, we will head home. He will have numerous weekly follow up appointments not to mention a nurse coming to the house and physical therapy but he is doing great!

Sent from CaringBridge Mobile

Thursday August 15, 2013

August 20, 2013

Scotty went home! (Sorry this is late). After waiting..literally..all day for the discharge papers, then undergoing training on how to use his portable pump and change the iv bag, not to mention training on how to care for his heart, such as low sodium diet, exercise, sect..at 6:30 finally..the patient transport brought Scotty out in a wheelchair to feel the sun on his face that he hadnt felt, only seen from his hospital room after almost a month. Scotty was all smiles! After a long drive home , arriving about 3 am, he slept very well in his own bed. He has a nurse that visits throughout the week and once a week visits back to Spokane, but he's doing great! He starts senior year august 28th and hopefully if all goes well he will be off of the l've by thanksgiving. He has a long road of recovery but he's working hard, resting and ready for the future. Thank you to all who have been following his journal, and please feel free to post.

Sent from CaringBridge Mobile

Back in Spokane, Sacred Heart Medical Center!

June 5, 2014

A message for our friends and family,regarding our son Scottie, and his struggle with his heart condition. Very early in the morning on Thursday, Scottie came to our bedroom door, and told us there was something wrong. He believed he had been shocked by his implanted defibrillator, and there was a problem with the pump that provides his 24 hour iv infusion of heart medicine. His heart rate was off the charts, and his breathing was very erratic. Sonja and I immediately took him to Kalispell Regional Medical Center, and had him admitted through the ER. Within an hour or two, he was back to "normal" with the only sign that there had been anything wrong, being tenderness in his chest, where he believed his defibrillator had fired. The ER doctor basically thought he was okay at this point, but did not want to release him until the cardiologists could see him in the morning.

Sonja stayed with Scottie throughout the night, and I came back up to relieve her in the morning. As it got later in the morning, a gentleman came into the room to do a device interrogation, which is fancy talk for saying that he used a computer to wirelessly connect to Scottie's ICD (implanted cardiac device)defibrillator.) After a few minutes of doing systems checks, a very concerned look came over his face, and he turned his monitor around, and explained what the interrogation revealed.

That night, Scottie's heart went into v-fib and v-tach which essentially means the heart just kind of quivers and is not conducive to life. The data showed that his heart rate had reached 300 beats per minute at one point.

Now, the real frightening thing; his defibrillator, which is implanted in his chest, did what it was supposed to do, and fired. Not once, not twice, but six times. The problem with these devices, is they are small, compact, and have a limit to what they can do. In this case, the device can only fire 6 times, before it stops. It fired all 6 times, and on its final shock, Scottie's heart converted back to a normal rhythm. There are no alarms that go off. Nobody is notified after the device stops, once it reaches its maximum output. He was shocked 6 times, at maximum voltage each time, his heart finally responded, and he finally woke up.

The technician told us all this, and then took off down the hallway to confer with the cardiologists that arrived.

Shortly after, they came back in the room and told us, in no uncertain terms, that they are making preparations to life-flight him to Spokane.

I arrived at Sacred Heart Medical Center in Spokane, WA, with my son, early this afternoon. He is settled in, on the 6th floor, which is the main cardiac floor. He looks and sounds completely fine on the outside, but he is far from that. His amazing, inspiring attitude is so damn deceptive to what he is actually having to deal with. The good thing, is that he is exactly where he needs to be. He has already saw his heart failure team, and these are the people that brought him back from the brink of death, more than once, during those first days he was life flighted here, in July of last year.

There will a lot of discussions tomorrow, but essentially, we are here until Scottie gets his LVAD surgery, which should be very soon. This was pretty much the plan of attack all along, to finish High School, enjoy the graduation ceremony, and prep for surgery. He sure gave it hell!

LVAD stands for Left Ventricular Assist Device. This is a not-so-small titanium pump, that is installed under the rib cage, and essentially plumbed into the parts of the heart, to take over the function of the left side of the heart. This is a very serious, very complicated, very dangerous, long surgery, that typically takes all day to complete, with a 2-3 week, average recovery time, in hospital. Once the pump is installed, it has a power line that is fed down to one side of the body, and exits through the skin. The skin eventually heals over the power line, which is connected to 2 large battery packs.

Once the LVAD is implanted, Scottie will be listed for heart transplant. He is of the less common blood type, so he will enjoy the benefits of his LVAD for possibly a couple years. The pump is a good thing. It will give him that quality of life, and while leaving him partially bionic, there is no reason why he cannot continue to live out a completely normal life.

Although Scottie missed many days of his Senior year of High School, due to continuous checkups, appointments, and routine clinic visits in Spokane, he still managed to keep caught up with homework, and passed all his classes with flying colors. He finished his final day of school on Wednesday, and was preparing for his graduation ceremony on Friday. I was so angry to see how his situation was turning out, knowing that the one thing he was so looking forward to, had been yanked out from underneath him.

As final preparations were being made for the flightcrew to take custody of him, one of the cardiologists came up to me, and told me that the principal of Scottie's High School, along with one of the counselors, were on their way over to present Scottie his diploma. I had not even thought of that! I begged the flight crew for a few extra minutes of time, and they accommodated. When the principal and counselor got to the doorway, I stuck my head in, and told Scottie that he had a couple visitors. When they walked in, his eyes lit up, and I had never seen a smile that big and beautiful! They brought a cap and gown, as well as his diploma, and helped him into it. Right there in the hospital room, the principal did an expedited version of the ceremony, right there in front of me, and Grandma Ruth, along with the flight crew, and some of the nurses. They all cheered when Scottie flipped his tassel to the other side, and we were able to get the absolute second best thing to being able to participate in the full ceremony.

So, to kind of wrap things up, we are waiting for tomorrow, to get some better ideas of the scheduling for the LVAD surgery. I would not be surprised if things happen some time early this coming week. I will be here for surgery, and will have to get back for my work rotation as soon as I know Scottie is out of immediate danger. Sonja will take on the responsibility of care-giver after surgery, when I can not be there to help out, due to work.

At the risk of exaggerating this procedure, LVAD implantation is pretty high up on the list for the biggest, baddest, most complicated surgery that a hospital participates in. The surgeons that will be participating in this, have already proven their ability when they saved Scottie last year, on more than one occasion. This is a huge step for Scottie to take, and a positive one, as we prepare for his eventual heart transplant. He has a huge advantage over many people afflicted with this, and that is his youth.

Comments

If either you or Sonja need anything please don't hesitate to call me. I am just a few minutes from the hospital. You all will be in my thoughts and prayers.

—Marsha Randall, June 5, 2014

Scott & Sonja~

Our thoughts and prayers are of course for your family. Our actions too- we want to help in any and all ways that we can. Scottie is SO fortunate to have such dedicated parents- that in and of itself is a true blessing. Love from our family to yours- God is Good.

—Kim Kearney, June 6, 2014

Stay strong my precious Tinman...you have more people than you can imagine that love you and are praying for you. Soon you will have this behind you and on the road to feeling normal once again. I understand completely how you feel about working once again and doing all the things a young man should be doing...it drove me nuts when I was sick and couldn't work...drove me nuts...lol...just remember...this is all temporary and soon you will be back on your feet again and working again....and busting everyones chops...including your grandma....which I may add...you have not lost that!!!! LOVE YOU OODLES OF NOODLES!!!!

—Ruth Ann Lint, June 6, 2014

Get well as soon as you can. We love you and think about you all the time. Let us know if we can do anything at all. Your Uncle Jeff says to be strong...I guess that's a guy thing. Last but not least, congratulations on your graduation. My love to you also, Aunt Mary.

—Mary and Jeff Smith, June 7, 2014

Hang in there! Stay strong! We are all praying for you here in Michigan! One goal down and a few more to go, like college! <3 Aunt Charlie and G-ma!

—charlie lint, June 7, 2014

Many prayers for our great nephew Scottie. We love you Scottie. I know we don't keep in touch the way we should but that does not mean we don't think about you often. Hang in there and God bless you and our family out there in Montana and in Michigan. We love you!

—Aunt Mary and Uncle Jeff, June 18, 2014

Some Important Updates

July 29, 2021

It has been 7 years since anything was added to this journal. There has been some major updates to this ongoing story, so without further adieu, here we go!

Wednesday July 14, 2021- A "Minor" Problem

July 29, 2021

Today, Scottie had a pretty good scare, while at work- the LVAD shut off, for a brief moment. When this thing has any sort of power failure, the alarms go crazy, and you know there is something wrong. He checked a couple things, hoping it was just a loose battery connection, from the LVAD controller, but no such luck. He dropped his co-worker back off at their shop, and got himself to Sacred Heart, with the quickness.

Upon arrival, he was promptly admitted, and up to the 6th floor he went. 6th floor deals with everything cardiac, and unfortunately, we are not strangers here.

The LVAD did not have any more power failure issues. A call was placed to fly in a couple repair technicians, from California, and they would be arriving the next day. The hope was that the external driveline (power and control cable) had a minor break in the wires somewhere, and these guys could just cut and splice a new line in.

The repair was scheduled for the next day, in the afternoon.

Thursday, July 15, 2021- The Repair Technicians Cometh

July 30, 2021

Approximately 2:30 this afternoon, the technicians from Boston Scientific arrived, to attempt to repair the LVAD driveline. This was done in the Cardiac Intensive Care Unit, just in case there was any type of emergency with the LVAD; mainly it shutting off when they were working on the wires, and fail to start back up.

Procedure only took about half an hour. After a brief inspection, there were no obvious signs of the wire being damaged, but we were hopeful that the new spliced-in power/control cable would be the fix. The doctors orders were to stay in the hospital one more day, and move around as much as possible, to try and get the LVAD to shut off again. If the LVAD did not shut off again, then it would be assumed that the driveline was successfully repaired.

Fingers crossed!

Friday, July 16, 2021- Murphy's Law Strikes Again!

July 30, 2021

Got through another uneventful night at the hospital.

Looking like an early-afternoon discharge from the hospital, as the LVAD seemed to have been repaired.

While signing paperwork, packing up belongings, and getting ready to return to regular life, the gut-wrenching sound of the "No Power" alarm began sounding off from the LVAD controller. This could only mean one thing- the wire problem was somewhere internal.

The LVAD promptly came back to life, and the alarm went off. Nowhere to go, but back to the CICU.

Sonja and I (Dad) were called in to the hospital, so we could sit down with Scottie and the doctors to discuss options. We are really only moral support at this point, as Scottie is well past 18 years old, and makes all his own decisions, obviously. The only "good"

option, was to get settled in to the hospital, and get uplisted on the heart transplant list. Once a patient that has had heart failure, has a major device failure such as this, it is pretty much, standard operating procedure.

There is no way of knowing how long a stay this will be. The doctors got Scotties verbal agreement that this is the plan they would go with, and now the wait begins. The doctors indicated that there was a 1600 mile radius that a heart could be "pulled" from.

Saturday, July 17, 2021- Getting comfortable in the hospital.

July 30, 2021

Spent Saturday, Sunday and Monday, hanging out in the CICU.

A little good news on Tuesday- since there were no more problems with the LVAD, they were moving Scottie back up to the 6th floor where there was some privacy and the most important thing- a private bathroom!

Wednesday, July 21, 2021- Another boring day

July 30, 2021

Sitting in the hospital, waiting for something to happen. Food is pretty terrible, but that seems to be par for the course.

No more than 2 visitor per day, so we are all taking turns going up to visit.

Thursday, July 22, 2021- By the grace of God, they found a heart!

July 30, 2021

I (Dad) was at home doing yardwork when Sonja approached me and handed me the phone- it was Scottie. I could tell by the look on her face that it was something big.

"They found me a heart," Scottie told me.

I had to stop and brace myself against something, as my damn legs just about went out.

"What? When?" I asked.

He did not have a lot of details, only that they were looking at surgery, early in the morning on Sunday.

Scottie politely told me he had to go, so he could make some more phone calls.

I will now quote Mr. Spongebob Squarepants, and proclaim "Best Day Ever!"

It was a feeling of elation, followed by numbness. This was the call we had been waiting on, for the past 7 years.

Saturday, July 24, 2021- A quiet meeting with friends and family, before the big day

July 30, 2021

At 7:30pm, myself (Dad,) Sonja, Duncan and Scottie's 2 other roommates, Frank and Lance, all met up at Sacred Heart Medical Center, for an awesome little get-together, before surgery took place the next morning. One of the cardiac nurses accompanied Scottie, and got him sat down at a table with us. She left us alone, but made sure she could see the monitor that accompanied Scotty, displaying his vital signs.

We all commenced to carrying on like a bunch of knuckleheads- happy, scared,

optimistic. We were just wanting to get this surgery over, so the long recovery could begin.

We were given one hour. It was a beautiful afternoon/ evening, and when that hour was up, we saw Duncan, Frank and Lance to the doors, and met Scottie back upstairs in his room. I did my best to provide witty banter, but quickly realized that we needed to let the kid try and get some rest. We made our way down to the empty hospital lobby, and found a chair to take a nap in.

At some point during this day, we found out that surgery had been pushed back 2 hours, so instead of a 2:30am "go time," it was going to be 4:30.

Sunday, July 25, 2021 - The day has finally come

July 30, 2021

4:00 am, Sonja and I (Dad,) left the hospital lobby, and went upstairs to the cardiac floor, where Scottie was sleeping in his room. We quietly slipped inside, and sat down in the chairs, waiting for the nurses to arrive.

Transport people showed up, around 4:30 and we went downstairs to the OR.

I am now going to cut and paste the update, that I provided for friends and family on Facebook:

Just wanted to send a quick note to everyone: Scottie had his transplant surgery successfully completed this afternoon. There was nothing simple or easy about this, due to the fact that there was a mechanical pump that had to be removed, a pacemaker, and all it's associated wiring. I don't think that you can ever have a surgery this complex (12 hours,) and NOT have any complications. This surgery was no exception. Nothing these amazing people can't handle. As of now, Scottie will remain intubated and hooked up to some other equipment, for the next couple days, while his new heart adjusts and settles from the trauma of being transplanted. We are getting ready to see him for a brief moment, before we leave for the night. He will also remain "asleep," so that there is no added stress to the new heart. We will be back in the morning, and pulling "watch duty," so we will be able to pass along information as time goes by. Thank you to everyone for your love and support.

Just a few other bits of information:

Right before Scottie was wheeled in to surgery, we met all the OR nurses and the surgeon (Dr. Reynolds.)

Dr. Reynolds casually strolled over to us, and greeted Scottie. Asked how he was feeling, then simply said, "Let's Get'r Done!"

One of the nurse's cell phone rang, and she answered. It was a quick conversation, and she hung up. She looked up and simply stated, "the heart is good." My assumption is that this was Dr. Smith who was picking up the donor heart, along with the other transplant surgeon. This was the cue that the team needed, to begin the surgery and be ready just as soon as the new heart arrived.

We hugged our son, and watched as he disappeared in to the OR.

Sonja and I were escorted down to a small, private waiting room.

We later found that the transplant surgeons landed in Spokane, with the new heart, at approximately 10:30am, and were raced back to the hospital in an ambulance, with all lights and sirens going.

We received updates, as the surgery progressed, either by phone or person. Dr. Moody (surgeon) came in, at some point, and sat down. In her own words, the surgery had gone quite well. The new heart was an amazingly good fit, and immediately began pumping, as soon as it was stimulated. Everything was going along amazingly well, but at some point, the new heart began to struggle.

This is something that is not uncommon at all. The donor heart had been out of a body for hours, at that point, and now just needed some help, while it "adjusted." This is the purpose of the ECMO which is the heart/lung bypass machine- it will help take up the slack from the heart.

Later that afternoon (some time around 4:00pm,) surgery was complete. Dr. Smith (lead transplant surgeon,) entered the waiting room and talked to us, at length, about the surgery. After our conversation, she indicated that we could join Scottie upstairs in his CICU room.

We went upstairs, and saw our son for just a minute, then decided to leave for the day, and give all the nurses and doctors the room that was needed to do their work.

Monday, July 26, 202- Day 2, After Transplant Surgery

July 30, 2021

No phone calls during the course of the night, so Sonja and I were extremely happy!

We arrived when the CICU visiting hours began at 9:00am.

Scottie is hooked up to lots of equipment, the 2 main things being the ECMO machine (Extracorporeal Membrane Oxygenation Machine) and the ventilator.

****In extracorporeal membrane oxygenation (ECMO), blood is pumped outside of your body to a heart-lung machine that removes carbon dioxide and sends oxygen-filled blood back to tissues in the body. Blood flows from the right side of the heart to the membrane oxygenator in the heart-lung machine, and then is rewarmed and sent back to the body. This method allows the blood to "bypass" the heart and lungs, allowing these organs to rest and heal.**

Plasmapheresis is another procedure that will be continuing for the next few days

****Definition of plasmapheresis from Hopkinsmedicine.org:**

The antibodies in a person's blood help protect our bodies from foreign objects. Typically, your antibodies protect you from viruses and bacteria. However, in the case of an organ transplant, your antibodies may mistake your new organ as an invading object and try to defend your body from this intruder.

Plasmapheresis is similar to dialysis; however, it removes the plasma portion of the blood where the antibodies are located. Plasma is the almost clear part of the blood which carries red cells, white cells, platelets and other substances through your bloodstream. During plasmapheresis, you will need to have a working native fistula, graft or dialysis catheter. If you have a catheter, one line of the catheter is attached to tubing and takes blood to the plasmapheresis machine. A second line of the catheter is used to return the blood. If you have a fistula or graft, needles will be placed as they are for dialysis. You may feel some minor discomfort when the needles are placed in position. This is similar to what a blood donor experiences.

Transplant patients may need to have multiple plasmapheresis sessions before

and after surgery to remove antibodies. In addition, the patient's spleen, which produces antibodies, may be removed.

There are no immediate plans to take him off the ECMO or the ventilator, as of now. The doctors are very cautious to do anything too soon, and they are simply in no hurry, as he is stable, and healing.

Doctors and nurses at Sacred Heart are simply the best! They welcome Sonja and I to come up together, to visit with Scottie, whenever we want, during visiting hours. The 2 of us made our own agreement that only one of us would be in his room at a time, to make sure that the staff has plenty of room to do their work. Whoever is up visiting has to text the other, of anything significant.

Tuesday, July 27, 2021 - Day 3, After Transplant Surgery

July 30, 2021

Healing is continuing. Scottie is still intubated and continues to receive help from the ECMO machine.

Doctors and nurses are all very happy with his progress.

He is still under varying degrees of sedation. Responds very well to Sonja and I (nonverbally.) We get plenty of eyerolls, when he is getting annoyed about something.

One of the chest tubes had been removed earlier that morning. About 50 more things to go!

New heart is working well. As time goes by, the ECMO machine is adjusted down, incrementally, to make sure there are no surprises. If he continues recovering this well, the consensus is that he will be taken down to surgery within the next couple days to be completely disconnected from the ECMO as well as removal of the remaining piece of driveline, from the old LVAD. With those 2 procedures completed, then the ventilator tube can be removed, and life will be exponentially more comfortable.

Bonus good news: A medical reporter from the local paper (Spokesman Review) had previously interviewed, myself, Sonja and Scottie, right around the time that he was initially admitted for the LVAD failure. She wanted to do a story on him, focusing on life with an LVAD and being on the waiting list for transplant surgery. The three of us were very adamant that the story emphasized how important it is for people to sign up to be an organ donor. Arielle (the reporter,) did a tremendous job, in my opinion. The article can be found here: <https://www.spokesman.com/stories/2021/jul/27/waiting-for-a-heart-transplant/>

Wednesday, July 28, 2021 - A Shocking Situation!

July 30, 2021

The morning was pretty uninteresting. I went up first and saw Scottie, for a little bit. Sonja went up after me, and stayed until lunch time. We were told that the doctors were going to have a little powwow in the early afternoon, to determine whether they can take Scottie down to surgery to remove the remaining piece of driveline from the LVAD that was recently explanted, as well as take him off the ECMO machine.

We were eating lunch when my phone started ringing from Sacred Heart. "Oh no, I thought....." It was one of the nurses. She asked if we were close by, as Scottie was "really awake" and kept wanting to tell Dad something.. We jumped in the car, and drove back up to the hospital. Sonja waited while I went upstairs. In the words of the nurse, Scottie was very rambunctious, and getting worked up about something. By the time I walked in, he had gotten a couple doses of valium (or something comparable,) and was quite calm. I approached his bed, and asked if he had been misbehaving, with a huge smile on my face. He kept trying to talk with that tube going down his throat, and I reminded him not to try talking, and keep still. I was trying to figure out how to communicate; I grabbed the "alphabet tablet" they had sitting next to his bed, but that was not going to really work. Then I started to do a process of elimination. I quickly determined that he wanted something from home.

"Are you wanting something to do with your LVAD equipment?" I asked. He shook his head yes.

"Batteries for your LVAD?" I asked? Again, he shook his head yes.

I had to explain to him that he no longer had an LVAD, and no longer had to worry about batteries.

Sonja told me that he was probably constantly hearing different sounds and alarms, and associated that with the alarm that his LVAD would make, when the batteries got low.

The ECMO machine has been dialed down to its lowest setting- a good sign that he is ready to be removed from this piece of equipment.

It got a little scary for a moment, when the doctors were doing some final checks and testing, and they started messing around with something called a Swan Catheter.

****Swan-Ganz catheterization (also called right heart catheterization or pulmonary artery catheterization) is the passing of a thin tube (catheter) into the right side of the heart and the arteries leading to the lungs. It is done to monitor the heart's function and blood flow and pressures in and around the heart.**

The doctors thought this Swan catheter was not positioned properly, and when they went to manipulate it, it rubbed against the heart, causing negative stimulation and, sending it into ventricular defibrillation. His pulse went from 90s to the 250s, in the blink of an eye. Of course all the monitors were flashing and alarms were going off. A crash cart was rushed in, and the defibrillator pads were positioned on Scottie's chest. I'm thinking that "this is really bad," but all the doctors and nurses were completely calm, cool and collected. They gave him a shock, and the heart immediately went back to a normal rhythm. Dr. Smith explained that electricity is the best way to get the heart back in to a normal rhythm when something like this happens. She further explained that this had nothing to do with the health of the heart or its function.

A couple specialists came back up with this big x-ray looking machine, and I got out of the way, while they put a new Swan catheter in.

I took this time to go back down to the lobby, and have Sonja switch out with me. The last couple hours of the day were incident-free.

Thursday, July 29, 2021 - A Minor Surgery

July 31, 2021

Sonja went up to visit first, today. Upon arrival, we learned that Scottie had been taken down to the OR, in order to get the remaining piece of LVAD removed, and that was the driveline. This was the power cord that entered his side, and went up to the mechanical pump, that was recently removed. Surgery went off, without a hitch, and they brought him back up to his room, a short time later.

Scottie is mostly sedated, with moments of lucidity, here and there. Sedation is the best, as he is still hooked up to ECMO and the ventilator. Today, a feeding tube was inserted, and now nutrients can start to be administered.

Plasmapheresis is also continuing.

Friday, July 30, 2021 - Bye Bye ECMO!

July 31, 2021

Both took our turns visiting the CICU. When I went up to take my turn, Scottie was wide awake and kept trying to tell me something. I asked him to quit trying to talk, since the ventilator was still stuck down his throat, but he would not listen. The nurse finally figured out that his legs were uncomfortable, as he nodded his head vigorously, when she touched his legs and asked if that is what he was trying to tell us. We believe it was just pressure from some fluid retention. They moved him around a little bit, and he

appeared to be okay.

Dr. Smith, the transplant surgeon, came in and said they were taking Scottie down to the OR at 1:00 pm, and get him taken off the ECMO. It would probably be at least a 3 hour procedure. Removing the input and output lines of the ECMO was relatively easy. They would then stay in the OR and monitor how the new heart handled having zero help functioning. Dr. Smith also indicated that the right side of the heart still seemed to be a little weak, so if that trend continued, after being removed from ECMO, then she would install an RVAD, which stands for Right Ventricular Assist Device. Without regurgitating some definition that is full of medical jargon, my understanding is that it is simply a large diameter tube that goes into the neck, and assists the right side of the heart with blood flow.

Surgery went to about 4 hours, and finally we got to go back in to see Scottie. He was completely out.

In Dr. Smith's own words, this afternoon was very "eventful." She went on to explain that they did indeed install the RVAD. When the ECMO was detached, the right side of the heart apparently started misbehaving. Nice thing is, when they decide to remove this RVAD, the Dr. indicated that it was a very simple procedure that could be done right in the room. He can eat, drink, talk, move, even walk and go outside with this device. They simply affix a support brace to the tubes, so that nothing gets dislodged.

Dr. Smith told that overall, she was very pleased with the progress being made. When she is happy, we are very happy!

Tomorrow (Saturday,) they are going to possibly remove the ventilator.

Saturday, July 31, 2021

August 1, 2021

Nothing significant to report, today.

Continuing to try and wean off the many medications, which are delivered via IV.

Scottie is awake more and more. He is a little frustrated because it is really hard to communicate with the ventilator. We have a couple papers that are used to help: essentially they have pictures of common things a patient is trying to communicate, plus an alphabet sheet and number sheet.

One more round of plasmapheresis is scheduled for tomorrow, and the doctors are going to tentatively take him off the ventilator after that that is complete.

Sunday, August 1, 2021 - Wide Awake

August 1, 2021

I (Dad) got to the room at 9:00 am to check on the kid. He is quite awake, and much to my liking.

Completed the final round of plasmapheresis. Was hoping to get the ventilator tube removed today, but doctors did not feel comfortable doing it just yet, so it stays.

Had one of the kidney dialysis doctors come in and speak with us. They are going to begin dialysis immediately, simply to help take the strain off the kidneys, because of the huge amounts of fluids and medications that are being administered.

Sonja pulled afternoon watch, and we are now at the 1 week mark, post transplant.

Tuesday, August 3, 2021 - Challenging Times

August 4, 2021

This morning was spent getting ready for a trip to the OR in the afternoon, to have the temporary RVAD (right ventricular assist device) removed. The doctors had suspicions that this pump was doing more harm than good, by causing irritation, due to its close

proximity to the heart. About 1pm, he was wheeled down to the operating room. At about 5pm, after not getting any updates from anybody, Sonja made a call and found that Scottie was back in his room on the CICU floor. We casually made our way up there, to either go see him or get a face-to-face update from the nurse that was in charge of him. Instead of "buzzing us in" through the doors that go back to his room, the charge nurse came out and met us in the hallway. In his words, he said that Scottie "was critically ill," and there were many many people working on him, right then. After a little more waiting, one of the nurses that works on the CICU floor, came and got us, and let us sit in one of their small conference rooms. This was about 7pm. Essentially, the RVAD was removed without incident. They stayed in the OR room for another half hour, to monitor his vitals, and when everything appeared to be holding steady, the slow trek back upstairs to the CICU began. Along the way, his blood pressure began to drop slightly, so medications were delivered to offset this. It started dropping further, as they continued back to CICU, and by the time they got him back to his room, his blood pressure had plummeted. It was quickly ascertained that the right side of the heart was failing.

His heart was going in and out of the quick (bad) rhythm, and at one point, I believe he flatlined. They were able to get his heart back in to a good rhythm again, and there was a race to get some mechanical support for his heart, and that would end up being our old friend, the ECMO (heart-lung-bypass.)

They let us walk in and quickly see him, before they began their work. We could tell by the looks on everyone's faces, that this was very serious, so we got to tell our son that we loved him, and touch him for a second, and then quickly got out of the way, and returned to our little hideout.

It was an incredibly long night, but the people doing the actual work, were down the hallway with our son. We simply had to sit there, and occasionally sign consents, as needed.

By the grace of God, they got him hooked back up to the ECMO, and immediately, things began to stabilize. This ECMO essentially takes over the function of the heart, and it can be adjusted up or down, as to how much work they want this machine to do.

Heart failure is a very tricky situation- as the heart struggles, it affects the rest of the body, rather quickly. For instance, when the right side of his heart was having difficulty, it causes the body to form acids in the blood, and in turn, this causes the medications that are being delivered via IV, to be less effective. Knowing that, a kidney dialysis machine was brought in to help filter the blood, and lower these acidic levels.

One of the main doctors came in around 3am and gave us a final update, and have a quick question-answer session. For unknown reasons, the right side of the heart was simply not performing well enough to sustain the body. In the doctor's own words, this heart was "baffling," and "acting quite unpredictably." Neither of which is conducive to a successful recovery. She told us that she was going to give this heart 1 week, to show definitive signs of proper function, or Scottie would be listed for a second transplant. She reiterated that while organ donation is a precious gift, not to be taken lightly, she was not going to risk his life any further, hoping that this particular heart would eventually

function correctly.

The thing we have to remind ourselves of, is that with heart failure and heart transplantation specifically, there are a plethora of unknowns and obstacles and challenges. When I asked one of the doctors if the problems that Scottie is having, is common, he simply said that every single person has a different recovery. Some recoveries go flawlessly, and some are riddled with problems, and challenges. It seems that Scottie falls in the latter category. I think I can paraphrase my son and say "if there was not a such thing as bad luck, I wouldn't have any luck at all."

At 3am, our amazing heart doctor told us that Scottie was stable, and that we should go home. So that is what we did.

As we were leaving the hospital, it was clearly evident that our son was being treated in the best facility by the best people. During the past week when all the bad stuff has happened, never once, did a doctor talk to us, and insinuate that they were facing problems that they were not in control of. In my humble opinion, the people treating our son, have the expertise, knowledge and equipment, to tackle any problem that is thrown at them. They keep proving this, over and over again.

This night, Scottie was clearly in dire straits. By the time all remediation efforts were completed, he was stable, sleeping, and being treated for any of the setbacks that occurred. The nurses and doctors constantly ask if Sonja and I are doing okay, and if there is anything we need.

Now we watch and wait. 7 days to show if this new heart is going to work out, or not. More than likely, Scottie will be taken off the ventilator, and he will be much more comfortable. As soon as he is alert enough, and able, I am going to bring his cellphone up, and encourage him to try calling friends and family.

Comments

My prayers are coming your way. Keep fighting Scottie and do as the nurses tell you. As a nurse myself I know they are fighting fir you too.

—Debbie Coon, August 5, 2021

Dear Lord God! We beseech you for Scottie this very minute! We ask that you make his new heart start working properly and perfectly. Thank you for guiding his doctors, please continue to give them great wisdom and discernment in Scottie's treatment and give them vison to see even beyond what the scans and tests are showing. Please Lord, help his body accept his new heart and touch the right side of his heart and make it work perfectly. In Jesus name we pray, Amen Scottie-I am Chere's step-mom and will continue to pray for you and your family!

—Peggy Rowe, August 5, 2021

Father in heaven, thank you for this amazing gift of Scottie. We pray for his care team that they continue to have wisdom, skill, compassion and love for Scottie. We pray for their perseverance and dedication to this incredibly precarious and difficult situation. As we understand more of how intricately our bodies have been created, we are reminded of the miracle of your creation. We pray that Scottie's body embraces his new heart and that the heart grows in strength and function to its fullest ability. Father, we also pray for Scott Russell, Sonya and Duncan and ask that you continue to hold them tightly as we know you are infinitely strong. We prayer for Scottie's extended families and friends as they wait for Scottie's health to improve, and especially Scott and Christy, Scottie's grandparents. Thank you for your mercy and love. In Jesus' name we pray, Amen.

—SteveCarolyn Cottrell, August 5, 2021

August 7, 2021 - Resting and waiting

August 7, 2021

The past few days have been relatively uneventful. Not really possible for anything catastrophic to occur, with the amount of equipment that the kid is currently hooked up to. He has pretty much been under sedation, with brief moments where he opens his eyes and looks around, but he is not really reactive to anything, due to the degree of sedation.

Currently, there are zero blood pressure medications being administered, which is a small victory, because when he was requiring this, it was not allowing the heart-lung-bypass machine to work as efficiently as it should.

Heart doctors are pleased with how he has turned around, since last Tuesday. Monday, we will probably start seeing lots of testing beginning to occur, which will shape the path forward. The ECMO (heart-lung-bypass) will slowly be turned down, which will force the new heart to have to do some work, and they will monitor how it reacts. If it cannot respond and perform accordingly, they will probably relist for a second transplant. From initial conversations we have had with the doctors, it has historically been rare for a young, healthy donor heart, to NOT be able to regain all its function, post transplant. As I mentioned in an earlier journal entry, these doctors are a little baffled, and quite disappointed by what was initially looking like a typical recovery, in a young healthy adult, but turned completely upside down. The word that was used to describe the donor heart, in its current capacity, is "unpredictable," and they are not happy with that, at all.

So, hear we are, almost 2 weeks post-transplant. Best case scenario, is that this new heart keeps working and can continue to do so, as the different pieces of machinery are slowly dialed down and removed. If it does not show the indicators that the doctors are looking for, Scottie gets relisted. A second transplant seems unfathomable, but we are happy that the doctors have that option.

Comments

Praying that hopefully this is the corner that he needed to turn and continues each day with small victories!☐☐

—Ruth Ann Lint, August 7, 2021

Sending love, hugs, and prayers for a miraculous complete healing!

—Peggy Rowe, August 7, 2021

Many prayers for Scottie from Uncle Jeff and aunt Mary. You are a Smith and Smiths are fighters.

—Mary Smith, August 9, 2021

August 14, 2021 - More procedures- 2nd transplant is inevitable

August 15, 2021

This journal has not been updated recently, simply because these past few days were spent trying to manipulate medications, and get this new heart to start functioning properly. Scottie is still under enough sedation so that he is not lucid. Unfortunately, the possibility of disaster is very clear and present, between the ECMO pump and all of the other devices and IV's, should any of it be disturbed.

11am, he was taken down to the operating room, where the doctors would take him off

the ECMO machine, and at the same time, monitor heart function in real time, via TEE (transesophageal echocardiography.) As the name of this procedure suggests, a large probe/ camera is sent down the esophagus, and can get a really good look at how the heart is functioning, because it only has soft tissue to "see thru."

They removed the 2 cannulas coming from the ECMO (think of an input/output,) and waited to see what the heart would do. Unfortunately, almost immediately, they could see signs that the right side of the heart was beginning to falter. At that point, one of the heart surgeons (I do not want to use names, in the interest of their privacy) came out to where I was sitting in the waiting room, and we had a quick discussion. She indicated that the right heart was not doing good, and she wanted to do open-heart surgery again, to install an RVAD (right ventricular assist device) to help the right side function properly. The irony here, is that for the past 7 years, Scottie has lived with an LVAD, because the left side of his old, native heart, was damaged beyond repair.

I agreed with the doctor, and she returned to the operating room, to install the RVAD. Once this was complete, the same doctor came out to tell me that she was all finished, and that there a couple vascular surgeons doing some work, to fix up some problem areas, from some of the many procedures that he has undergone, in the past few weeks.

9pm, I got a call, and the nurse on the CICU told me I could come up and see Scottie, before I left for the night. I met one of the other heart surgeons in Scottie's room, and he told me how glad he was, that the RVAD was installed. Unfortunately, like the old LVAD, this pretty much cemented the path forward, and that was for a second heart transplant.

At this point, the doctors want to see a little rehab, before he is relisted. The popular opinion, is that once relisted, he probably will not have that long of a wait, due to his current situation. They would like to see a week, possibly 2, of him moving, walking-living and functioning without being sedated to oblivion. Now, the worst part of this entire ordeal, is when he wakes up, and one of us has to tell him all that has happened. We were able to communicate with him, shortly after the initial transplant, and he understood that there were complications. The medications and sedatives that are given intravenously, do a phenomenal job of scrambling memories, to the point, where he will probably not have any clue as to how long he has been in the hospital, or even what has happened thus far.

Comments

Hang in there Scottie. We are praying and hoping for the best. Love, Uncle Jeff and Aunt

Mary

—Mary Smith, August 16, 2021

August 20, 2021 - Waiting for liver and kidneys to wake up

August 20, 2021

Today started with Scottie being taken down to another floor, for a CT scan. The primary reason was because the doctors saw some uneven dilation in his pupils, and wanted to rule out any brain trauma. The scan was completed, and did not show any issues.

He is still physically unresponsive, for the most part. Although his eyelids were more open than I have seen in some time, and he appeared to be following me, when I would get close to his face, and move back and forth.

The brutal realities of dealing with heart failure, is that the rest of the organs in the body, begin to fail as well. The left side of this donor heart has never had any problem, the right side is a different story. That is the reason the RVAD was implanted. Unfortunately, liver and kidney functions are also severely impaired, at present time. The kidneys can be supported by dialysis.

Because the liver is having problems, this causes the levels of ammonia in the body, to be elevated. When they tested Scottie's ammonia levels, they were extremely high. The course of action is to treat with a couple different drugs. The consensus among the doctors, is that these high ammonia levels are the culprits behind the lack of responsiveness, and is contributing to other issues.

So, it is a waiting game. The nurses and doctors continue to do an amazing job, taking care of Scottie, and react to the plethora of problems, that he continues to have thrown his way. Sonja and I continue to pull "watch duty," on a one day on/ one day off, schedule (due to the 1 visitor per day mandate.) It is a long and brutal game, and we dream of the day he can walk out of the hospital.

Comments

Jeff and I are praying for a miracle. We send our love.

—Mary Smith, August 21, 2021

Continued prayers for a miraculous healing and recovery!

—Peggy Rowe, August 21, 2021

Keeping you all close in prayer. ☺☺☺☺☺☺

—William Troutman, August 25, 2021

Sunday, August 22, 2021 - A scary situation

August 25, 2021

While we were waiting for Scottie to "wake up" from the tremendous amount of sedatives he has been under, a new problem has arisen, which is seizures. Nobody knows how or why, as nothing has really changed with the care he has been given. There has been no major incidents, either.

The first seizure happened around 4 pm today, when I (Dad) was reading a chapter from "The Hobbit," to him. I noticed Scottie start shaking, then quickly realized it was a seizure. The nurse came in, saw what was happening, and they immediately got a doctor. Something was injected, and they eventually got the seizure to stop. After he was resting, visiting hours were just about over, so I left for the night.

August 25, 2021 - A very sad goodbye

August 25, 2021

Today, at 9:19 am, our beloved son, Scott Michael Smith, passed away, at the Sacred Heart Medical Center, in Spokane, WA.

Many hearts are broken today, but we find solace in knowing that we shall see him again, eventually.

Our son's body has been to hell and back, as the doctors tried to help him recover from heart transplant surgery, over a month ago. He has been ran through a gauntlet of surgeries, procedures, and life support. In the end, it was essentially uncontrolled brain swelling, that ended his life. The question is, what actually caused the brain swelling. The only thing the doctors deduced, is that this was all caused by an undetectable bacteria. By the time that they came to this conclusion, too much time had passed, to negate the effects, and the outcome was not able to be changed.

I cannot stress enough, how much we appreciate all of the love and support that has been given to Scottie, Sonja and I. With that, this will be the last entry into this journal, and a farewell, to one of the most beautiful souls that I have ever had the honor of knowing.

Until we meet again, son.