

Patient: Chris

Diagnosis: Cerebral Palsy



*Chris*

When Chris was brought to me for treatment for his Cerebral Palsy, he was only 10 months old. At birth, he suffered from lack of oxygen for an extended period, resulting in multiple strokes and severe brain damage. The following is Chris's history as written by his mother:

*Chris was born December 18th, 2008 at 8:42am via repeat c-section. His cry was the most beautiful sound ever and then he was sent back to our room. On his way to our room he started grunting.*

*After checking him, the nurse immediately rushed him to the Neonatal ICU (NICU). When they let me see him, he was already on a ventilator. What a scary thought for any mom. Little did I know that was just the beginning.*

*I was told to go back to my room and try to get some sleep. I had no idea why I was having such trouble sleeping until a nurse came barging through my door saying the NICU needs to talk to you ASAP. I immediately called the NICU nurse. She said, "I just wanted you to know that he is not doing so well on his ventilator and we are going to have to switch him over to a higher powered ventilator, you don't need to come down here I just wanted to let you know what we were doing." Needless to say I had the nurse help me get down there right away.*

*When I got to the NICU there were 3 nurses working with Chris and you could just look at his face and tell he was not doing well. A doctor that I had never met came over to me and said, "Chris would likely need to be transferred to another hospital for a procedure called ECMO, which is a heart lung machine for newborns." He immediately ordered for med-flight to transfer Chris.*

*He arrived at the new hospital at 7:30am. He was 47 hours old. We were immediately greeted by the Pediatric Surgeons who informed us that Chris had "coded" on the elevator, but they were able to get his heart restarted.*

*We were told that his only chance at survival was to be immediately put on the ECMO machine.*

*Four hours later a nurse came out and simply said, "It is not good. He had coded 2 more times and suffered a large liver laceration from the CPR chest compressions and as a result he had a massive blood loss and to prepare ourselves." This was the first and last time I said to myself, "Are we doing the right thing? Should we stop fighting? Does he want us to let him go?" The priest was called to our room and I couldn't even speak to him. I was so angry with god.*

*About 1 hour later the Pediatric Surgeon came into our room and as soon as she saw us she wept. She explained that Chris would be a minute-by-minute little boy. That while they were putting the tubes into his Carotid and Jugular veins to hook up the ECMO machine, that he coded again and because of the blood pressure drop his Carotid and Jugular veins were shredded. (I couldn't believe she used the word shredded). She went on to explain "because of that they had to open his chest and put the tubes directly through his heart."*

*She then explained to us that we would have to prepare our-selves that his chest was open with tubes sticking out and that his abdomen was left open and that if he survived he would need several more surgeries to repair the liver laceration.*

*There is NO!!!! preparation for this.*

*When we arrived in the ICU he was swollen and purple. The metallic smell was horrifying. He was bleeding extensively. He was lying in so much blood, that the nurses*

*had to change his bedding every 15-30 minutes. He was lifeless. Our surgeon asked if we minded if she go to the chapel and pray for him.*

*We stayed by his bedside over night. The next morning we were just breathing a sigh of relief that he had made it through the night. The nurse said that his ultrasound results of his head were back and they were not good and that the doctors wanted to meet with us at 10:30 am.*

*At the meeting, we were told that we had two choices; either let him go, or try to put him back on the ventilator.*

*They said if he survived he would absolutely have CP and many developmental problems.*

*I looked at my son and said, "Chris mommy and daddy love you and we understand if you are tired and want to go home, but if you are willing to fight I do not care how many people in this room don't believe in you, Mom and Dad will fight as hard as we can."*

*Well evidentially he wanted to fight because even on all of his sedatives and pain meds, he opened his eyes real big and starred into my eyes for what seemed like an eternity.*

*The hospital called in the priest (my husband could not handle this. He screamed across the room when he saw him, "Get Out!!!") They also called the "post mortem photographer". She was to take pictures of Chris if he did not make it.*

*Needless to say he did not die. He lived. The photographer asked if we still wanted her to take pictures. I said absolutely not. In my mind it was bad karma. She was there to take a certain picture and if I gave in, perhaps Chris would also.*

*At that point, the surgeons came back into the room. To add insult to injury they never thought he would survive, so they did not think about what to do if he did make it.*

*Chris never looked back. He was off of all supplemental oxygen within the next 3 weeks. He had 6 more surgeries in the next week. Meaning in his first 10 days of life, he had endured 7 surgeries.*

*An MRI of his brain showed "Near complete replacement of bi-lateral cerebral hemispheres due to liquefaction necrosis from global ischemia". Words I will never forget. It meant: most of his brain had been destroyed. The doctors strongly cautioned us*

*not to take Chris home, saying that “He would be our sleeping baby until he died.” And they even had the nerve to ask us if we realized what this could do to our other two children, if we were to take him home.*

*We took Chris home and started our journey*

*Chris made no noise at all. He was only awake about 5-10 minutes every 6-8 hours. We were noticing more and more spasticity every day. He was fighting so hard but his little body was starting to give in to his brain damage*

*Every time I took Chris to the doctor I was questioned as to why we chose to take him home. I even said to my husband, “It feels like with each appointment I am punched in the gut.”*

*Chris was being treated by his doctor for his seizure disorder. One day at the doctor’s office we were saying how we know that we need to treat his seizures but we wanted to make sure that we did not over treat and sedate him, because we knew that if we were going to get any neurological function back, over sedating him would interfere with any possible recovery. She actually chuckled and said “You do not need to worry about sedating him; it is not as if he is going to learn anything anyway.” We immediately changed Neurologists*

*We received the results of Chris’s next brain scan. It was horrible. Chris’s strokes had spread and it destroyed more than 65% of his brain. Funny...my question to the Neurologist was, “Ok so now that the damage is done there is nothing that we can do, no surgery, nothing? Just watch him die?”*

*Ironically, the Neurologist said “Well, barring going to China.”*

*She assured me that “IF” it were proven to be a successful treatment, in just a matter of time it would be available in the”United States and that we should just wait.*

*I was NOT ok with waiting, so I started researching on my own, calling Wake Forrest University, Duke, Harvard, Stanford, St Jude Children’s Hospital and MD Anderson. Only MD Anderson would even talk to me. The doctor there said even if the U.S. were eventually going to do anything, they wouldn’t touch a patient like Chris.*

*Little did he know that what he said energized me even more. I kept researching and found MEDRA. The more I read the more excited I became. I spoke with your offices and the employees who themselves were parents of a brain damaged child. I knew this was our only chance.*

*Bob and I finally decided that worst case scenario...I would rather take a chance and nothing was to happen, than not take a chance and lose him.*

*Thanks to your generosity Chris got his first set of cells on June 27th, 2009 (his daddy's birthday). What a birthday present!!!*

*We did not see much the first 4 weeks. Then came 6 weeks post stem cells... Every day we were getting progressions. Chris started making noises (he was totally non-verbal before) he would fuss, his suck reflexes were stronger, his muscles were less rigid, we could actually open his hands and he could lay them flat, his was lifting his head from the floor using his arms. With each day came more and more.*

*He eventually started sitting up by himself, rolling over, trying to stand up and when put on his tummy, he would start moving his legs one right after the other and lifting his upper body trying to crawl. I could not believe this was the same baby.*

*Chris was initially diagnosed with Cortical Blindness, his pupils had been pin point and totally non-reactive ever since the strokes. About 2 ½ months after our first set of cells we were sitting at home and out of the blue his pupils were dilated and he became agitated. At first I was scared that it might be another stroke; however when I pointed a flashlight at him, his pupils reacted. I couldn't believe it. He kept this up for about 3 hours, before he ended up falling asleep. His pupils have continued to do this since.*

*Dr. Rader when you first spoke to us after looking at Chris's medical records, you said that Chris would be best served with 3-4 treatments spaced out every 3-6 months because of the degree of his brain damage. We returned for his 2nd set of cells only 4 months later. Pretty incredible that we saw that much progress in only 4 months...hah?*

*When we got to the hotel we called you because of how bad his seizures had gotten during the trip. It was amazing; you sent a doctor, a nurse and a medical assistant to our room, to take care of Chris within minutes. They all stayed, continually checking in with you, for more than 2 hours until Chris's seizures calmed down.*

*Within days of that second treatment, Chris's seizures had gone from 50 plus per day to 10 to 20. Within only 4 weeks we went from 10 to 20 per day to on most days none and on a bad day a maximum of 5. We started weaning him off of one of his 3 seizure medicines on day 27 post cells. It took us about 3 weeks to get him completely off of his medications. However he handled it flawlessly, with NO increase in seizures. He is now having days with no seizures at all.*

*His suck and swallow are getting better. He is even taking a pacifier. Chris is getting so vocal that he has even woke us up at night on a couple occasions. He is fighting off his own infections and illnesses.*

*For the first time in his life, he is now able to see. He even strained his head back to see the Christmas tree that was behind him. His vision therapist when asked what to get him for Christmas said, "Anything that he can see, he is definitely not blind." Last week he reached out his hand to touch a green balloon. This was his first time ever, to reach out towards something.*

*Chris met our biggest goal on December 18th, 2009...He had his first birthday! Back when Chris was 4 months old and we got his CT scan, we were told his life expectancy was only 9 months to 1 year max. One of his nurses came to his 1st birthday party. She sat there for almost 2 hours holding him. When I sat down with her she said, "I am just in awe over him...He just shouldn't be here, he is truly a miracle." She went on to say that "Chris is the talk of her shift. She of course is not allowed to recommend stem cells. However she has been telling parents of her patients to remain determined to make the best of their child's life no matter what the doctors say."*

*We are so excited to see what he will do in the weeks to come.*

*I have been exposed to the most amazing people through this incredible time in our life.*

*Needless to say...YOU HAVE GIVEN US OUR BABY BACK!!! But most of all YOU HAVE GIVEN MIKE AND JACK THEIR BROTHER BACK!!!*



*Thanks to you and your company we were able to have a Christmas with our baby. Also thanks to you, we were able to look in the face of one of the doctors who offered no help and only limitations, a doctor who said Chris would never make it to 1 year and hold our tongues, while we giggled at his 1 year WELL CHILD check up.*

*You have a special place in heaven; I hope that you know that.*