

Our first child was born in 2001. On Wednesday the 7th, some of my wife's nursing coworkers came up to see our son Declan. One of the nurses, Jennifer Richert, noticed a strange, steady shaking of little Declan's left leg and arm. We noticed two more seizures like this before we were due to be discharged. Declan's pediatrician, Dr. Triantos, ordered an EEG (electroencephalogram) after the second seizure was observed to see what was happening in little Declan's brain and to see if these twitches were indeed seizures. His EEG was "markedly abnormal". Declan had at least one more visible seizure during the EEG and near the end had a choking attack that might have been associated with a seizure as well; he wasn't breathing initially and had an absolutely terrified look in his little eyes. Before I knew what was happening, a NICU nursing crew whisked little Declan away to the neonatal intensive care unit.

Declan was plugged into an IV and on two separate antibiotics, an antiviral and had started receiving Phenobarbital to treat the clinical seizures. As if this wasn't enough, the doctors had already ordered a cardiac echogram and CAT (computer-aided tomography) scan of Declan's brain. Still needing to rule out any form of spinal infection, Declan underwent a very painful lumbar puncture procedure by Dr Chen. While the heart echo came back clean and very normal, the CAT scan was anything but normal. Showing signs of a vascular accident (stroke), there appeared to be blood in both ventricles and the choroid plexus of Declan's brain. With two abnormal tests results, the doctors ordered a rush MRI (magnetic resonance imaging) scan which would provide much more detailed resolution on his brain and would hopefully shed some needed light on what was happening to our new son. The MRI was completed on a tranquilized Declan to make sure he remained still during the entire scan and confirmed what the doctors had believed from the first two tests: something was seriously wrong with our little boy. On top of the abnormal results seen in the EEG and CAT scan, both lumbar punctures ran bloody indicating that there was blood surrounding Declan's brain – a likely sign of a neonatal stroke.

Sturge-Weber Syndrome

Dr. Tan was the staff neonatologist on Thursday; he received the results of the CAT and MRI scans and had consulted with the hospital's radiologists before sitting Michelle and I down in a private room. Dr. Tan reviewed the actual MRI films with us and gently informed us that little Declan had suffered a stroke at or around the time of his birth, resulting in small amounts of blood within his brain. Worse, the MRI scans also displayed clear evidence of a variant of Sturge-Weber Syndrome (SWS) - a rare, congenital condition that affects the skin and in more serious cases (like Declan's) - the brain. As described in medical manuals: Sturge-Weber Syndrome (or disease) is a rare, congenital, and progressive condition that affects the skin and in more serious cases - the brain. Intracranially, there is abnormal circulation that leads to 1) cerebral dysfunction; 2) electrical instability (seizures); and 3) cerebral cortical atrophy. Seizures usually present within the first two years of life. Typically the occipital lobes are affected first, and most severely, but the disease may also involve the parietal and temporal lobes, and (rarely) the frontal lobe. Patients with SWS typically suffer from an abnormal number and size of blood vessels throughout the brain.

While some children with this syndrome can go on to lead normal lives, Declan had a very large number of abnormally large veins pervasive throughout his right cortex. Dr Tan informed us that we could expect potential learning and motor impairments, lifelong seizures, ophthalmic problems and the chance of mild mental retardation. If there ever was a difficult time to find and accept God's will - this certainly was it for me. While very happy that the doctors had not seen any evidence of arterio-venous malformations (AVMs) that could have threatened Declan's life, the diagnosis certainly was much worse than either Michelle or I was expecting. After holding what we believed to be a perfectly normal baby in our arms for two days, being told that the same little baby would likely go through life with several significant problems is not something any parent welcomes. It was in fact extremely difficult to find any positive sense at this time, but that is exactly what Michelle and I tried to do after talking with Dr Tan. We did spend a few minutes in each other's arms consoling each other, but we did realize that we would be parents to a very special son. Thanking God for sparing our son's life and for allowing us the opportunity to have such a special little boy, we knew that regardless of what happened as Declan grew, we were prepared to give him all the love and care that a child could receive.

Prayers for Declan Mark...

Cathy Kozachenko – Declan's Godmother - visited him very early Thursday morning after waiting patiently for permission to visit him in the NICU. She lovingly sat with him in the early hours of the morning and anointed Declan with the oil from the vigil lamp of St. John Maximovitch before she had to leave for work. To close the day out, Fr John – our parish priest – also paid Declan a visit late Thursday evening and held a special prayer service for Declan. Fr. John anointed Declan with myrrh from the miracle-working icon of St. Nicholas the Wonderworker before heading home. Needless to say, many, many prayers from friends, family and strangers were offered for our little son that day, along with anointing with holy oil from St. John Maximovitch and myrrh from the icon of St. Nicholas. The support Michelle and I received from both family and friends was nothing short of amazing.

More Testing

Still wanting to ensure that a stroke or clot did not cause these neurological problems formed elsewhere in Declan's body, the doctors ordered a liver/spleen ultrasound. Wanting to further visualize the extent of SWS in little Declan, his team of doctors ordered five additional MRI scans - essentially a complete neurological study that encompassed five separate foci. The arteriogram and veinograms focused on the vasculature of the brain, while the set of gadolinium contrast studies visualized the blood flow (both direction and volume) throughout these vessels in the brain. These films would be taken Friday morning and would hopefully be reviewed and available later that day. Dr. Koukkari strongly suggested that we consult with Dr. Jim Barkovich, a pediatric neuroradiologist at UCSF. We needed to get Dr. Barkovich's immediate attention to see if he could review the films before much more time elapsed.

Have you ever felt like time just stands still sometimes? Well, time sure decided to all but come to a grinding halt for us Friday. These hours of waiting to hear something...anything taxed everybody that was praying for little Declan. Fortunately, our wait was not indefinite: late Friday evening we received word from Dr. Koukkari that contradicted everything we had been through the previous three days – "it" was gone! That's right - the series of scans taken Friday morning – the day after all those prayers were said for Declan and after he was anointed with holy oil of St. John Maximovitch and myrrh from St. Nicholas the Wonderworker – showed no signs of the physical birth defects that were seen in the scans and tests the earlier two days.

To try to make sense of this completely illogical and strange event, Dr. Koukkari had even placed a special call to Dr. Ed Barkovich to ask him to examine the films as soon as possible. He did not want to say anything else about the new films – positive or negative - until he heard back from Dr. Barkovich.

Michelle and I were at the hospital bright and early Saturday morning and it was not long before Dr. Koukkari paid us a special visit. After thoroughly reviewing the films that were taken only the day before and consulting with Dr. Barkovich over the phone, he confirmed for us that the new MRI films displayed no sign of the physical birth defect that he had been positively diagnosed with only days earlier. After sharing this amazing news with us, Dr. Koukkari didn't stop there – he said there was no reason we couldn't go home today! He signed the orders around 9am that we could be discharged and was on his way. Elation! Overwhelming joy! I think that pretty much says it all.

Epilogue

Interestingly, when infants suffer strokes, the evidence of where the stroke occurred and how severe the stroke actually was becomes more visible over time – hence the reason for additional MRI tests four to six weeks after the initial incident. As one might have guessed, Declan was back in the hospital for this set of follow-up MRI scans five weeks after he was discharged, and while it was a bit surprising to some of the doctors, it was no surprise to us that all signs of cranial injury, stroke or SWS were nowhere to be seen. Some doctors later tried to explain this event in a number of different ways – most explanations we heard contradicted statements that these doctors had made earlier. Some doctors and nurses had the courage and wisdom to see this event for just what it was...a miracle of God. And, if anyone remains unconvinced, please stop by – we have the MRI films that clearly show unmistakable and irrefutable evidence of SWS in our son's brain one day and gone the next. In fact, Declan was tested at Good Samaritan hospital for cognitive and motor abilities and development at six months of age using some of the most conservative testing methodologies available – and scored ahead of where he should be in motor development and right on target for cognitive development.

Questions...& Answers

So what do you do when "your" life is turned upside down, then right side up again after being dropped in such a situation? First off, I can say it was not "our" life, but one that God entrusted

to us. It certainly was an interesting question that begged more questions: Why did this event happen the way it did? Why our son? Why us? What were we supposed to learn from it? Rest assured, these and many other questions came to mind during the first three days as well for many weeks afterwards. I fully believe that this did happen for a reason and I hope to one day understand all the reasons that God allowed it to happen the way He did. After much contemplation though, I can say that a few things have settled in my heart: 1. This event provided us with but a small taste of the love that God has for all of us. The love that was felt for our newborn son and the emotions that poured through me during those first three days – as intense as it was and still is – cannot even compare to the love that God has for all of us – especially if He was able to allow His son to endure crucifixion and death for all mankind. No matter how much we love our children, God's love is infinitely stronger, deeper, perfect, and eternal. 2. I know that God continues to bestow and pour this incredible, unique love on us as we move into this new chapter of our lives – surely as a reminder of how we need to love our son. 3. Never stop trusting or believing in God, especially in times when things don't make sense and when there appears to be little hope. 4. God clearly reminded us for as long as we live, that this child is His, not ours. No matter how much we have come to love this child, how much we care for him, no matter how much of our own love, energy, patience, etc. we put into this child - it is ultimately still God's child. He gave him life, He entrusted this life to us, He gave us the love, strength, patience, and endurance to bear the crosses that come with being parents - but at any moment He can take this life back to Himself. We, then, being God's babysitters, will answer to God at the Great Judgment concerning how we loved this child, how we cared for it, how we raised this child, what we taught this child. And this lesson shall inspire us to be better parents, and a better husband and wife team. Glory be to God and His Saints!