

Our Journey to Munich

On July 1st, 2017, our lives were forever changed. We were returning from our annual family vacation at the beach. My husband would always make the 11-hour drive back with the boys and the dog, and my daughter and I would fly back. Only moments after our plane landed, my phone rang. It was our son. "Mom, we are at a gas station, and we think dad had a stroke." Those words, and that moment will stay with me forever.

How was any of this possible? At 57, my husband had never been sick a day in his life. Regular check-ups and perfect health. A former professional soccer player. Strong and physically fit. Nothing made any sense. The doctors initially labeled the stroke as "cryptogenic", one with an unknown cause. We later learned it was a result of a birth defect, patent foramen ovale, a hole in the heart that didn't close as it should have after birth. He had gone his entire life and never any indication of an issue. What were the chances that a blood clot would slip through that hole? The doctors called the stroke a "perfect storm".

The stroke left him with right side paralysis and severe apraxia of speech. However, as a result of his physical strength, determination, and an incredibly intensive therapeutic program, he regained his ability to walk. His greatest challenges were severe apraxia of speech and his inability to use his right hand. Fortunately, we were blessed with the support of incredible medical professionals and a very "driven" patient. We were making great progress in therapy, although never fast enough for Dominic.

Suddenly, that progress was disrupted. He suffered his first seizure about 6 months after the stroke and went on to endure more than 100 seizures in the year that followed. As if the seizures weren't enough, he was hit with post stroke pain, a pain he described as unbearable. Both derailed our lives and his progress in therapy. To say that we were frustrated and scared would be an understatement.

Again, we sought out the support of the best medical professionals. His situation was complicated as the seizures occurred in the eloquent cortex, the part of the brain that controls function. In terms of treatment approaches, it would be incredibly important not to do anything that might jeopardize Dominic's progress. The recommendation was a series of surgical procedures to isolate and then treat/control the seizures. While the recommended surgeries felt promising, they were terribly invasive and would have a long recovery. Overwhelmed, we both decided to continue with our research for options, but this time we decided to look outside the United States.

Very late one night, I stumbled upon CBC Health in Munich and carefully read each word on the website. Sasha's story really struck a chord with me. I replayed the video several times. I listened to his words. I felt his pain and his joy. Intrigued by the prospect of cord blood treatment for ischemic stroke recovery, I sent an email on 8/17/2019. Two days later I received a call from Dr. Thoennissen. We had several consultations calls with Dr. Thoennissen and were incredibly impressed by his empathetic approach. He not only wanted to understand Dominic's medical history, but he genuinely wanted to know Dominic as a person, and he took the time to get to know our story. He was always available to answer our questions. He was candid, clear, and presented us with facts. He encouraged us to consult with our medical team about the approach, and to continue to do our research. He also shared that he would be willing to talk with our team to answer any questions. It was critical to him that we felt comfortable. He made no promises, yet he gave us hope.

We dug further into the Stanford and Duke studies where they utilized cord blood to treat ischemic strokes. Although limited studies existed, the scientific evidence was overwhelmingly positive. We consulted with our team of doctors and other medical professionals. There were no objections raised. Our biggest concern was we wanted to understand the risks. In the end, we concluded the greatest risk was not taking this chance.

We booked the trip and arrived in Munich on October 11th. Dr Thoennissen met us that evening at the hotel. He sat and talked with us for over an hour. We knew from the moment we met him that he held our health and recovery as a top priority. A brilliant man, with a gentle and empathetic heart. And his love of soccer created an even stronger bond between my husband and him.

We started the process on Monday, October 14th. The first day we spent doing preliminary testing. The next two days my husband received the cord blood infusions. Dr. Thoennissen sat with us the entire time, which gave us an incredible sense of security and peace of mind. There were no side effects other than my husband was a little tired after the first treatment, and he had an odd odor on his breath (DMSO) that lasted a few days. As a matter of fact, my husband came alive in Germany! And of course, Dr. T was an absolute gift! I cannot begin to explain the kindness and hospitality that he showed us. To be honest, we felt like he was family.... a lifetime member of Team Dominic!

It has been nearly 6 months since the treatment. My husband has not had a seizure since the treatment! As I shared previously, my husband had suffered over 100 seizures since his stroke. The longest period he had ever been "seizure free" prior to the treatment was 6 weeks. At approximately 4 weeks post-treatment, his pain began to subside. Although the pain isn't gone, it's manageable. And there are days when he is pain free! We've also experienced unexpected improvements with speech. At approximately 6 weeks post-treatment, friends, family and therapists noticed he was much more conversational, putting together two, three and four sentences at a time. His speech continues to improve with therapy. Finally, and most important, his spirits are better. He laughs and smiles more. He stands a little taller, as the constant burden of the seizures and pain has been lifted.

Dr. Thoennissen gave us hope. His passion for life is infectious. He puts his patient first....always. His constant pursuit of research and knowledge is mind-blowing. Without hesitation, we can say we have absolutely no regrets. The experience was something we will treasure for our lifetime. Often times we talk about wishing we had found Dr. T sooner, but then we both agree we found him at the exact right time.



***Much love and gratitude,
Dominic and Annette Barczewski***