

Stuart's story

Lisa Butler*

When I picked Stuart up from school on Wednesday, he had just fallen on the playground and had a large bruise on his leg. He limped on it a lot. By soccer practice on Thursday night, he was running in slow motion and shuffling his feet. On Saturday, he was still limping and actually collapsed to the ground a few times. We saw a friend of ours who is a doctor and he looked at Stuart's leg and doubted that there was a fracture, but said to "keep an eye on it...and that children can't fake a limp". When Stuart collapsed walking down the stairs at church on Sunday, exclaiming "Woah", it was time for an x-ray, but it showed nothing. Despite the results of the x-ray, Stuart continued to collapse that day. We were beginning to be concerned. Was something wrong or was Stuart just being a goofy 5 1/2 year old boy? Monday came and we kept Stuart home from school due to an intestinal virus. His stomach was calm by mid-day, but his gait was now more like an awkward stagger. Our concern changed orry, because we knew something was not right!

On Monday, January 28, I took Stuart to see our pediatrician, the last appointment of the day. Our doctor examined Stuart and concluded by asking Stuart to walk down the hallway, a distance of 40 feet. Stuart could not walk this distance without using the walls as support. Whatever was happening, it was rapidly progressing! Our doctor explained that at this point, Stuart had an ataxic gait and felt that he should be hospitalized for a series of tests to confirm a more specific diagnosis.

A neurologist was called and saw Stuart that Tuesday afternoon. He performed a brief exam and strength test, we were amazed to observe that along with the problems in his legs, Stuart could not raise his arms above his head. We were equally shocked that Stuart had no responsive reflexes in his upper or lower body. Stuart was immediately diagnosed with Guillain-Barré Syndrome. Unfortunately, we were well aware of GBS as Stuart's paternal grandfather suffered with GBS, a short time after undergoing chemotherapy for Non-Hodgkin's Lymphoma. We were assured that there are not genetic connections, and that this was a rare coincidence.

Within minutes, we were on our way to the intensive care unit for a spinal tap that confirmed elevated protein levels in Stuart's spinal fluid. We then learned about the risks of respiratory failure and that GBS was now accelerating through Stuart's body. A series of four gamma globulin treatments were to begin at 24-hour intervals.

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Grandparents flew in immediately as we began to build our support team. Our friends began cooking our meals. We accessed the Internet and discovered the tremendous resources of the Guillain-Barré Foundation. Our education was beginning! We prayed and prayed.

Stuart's GBS moved quickly. By Wednesday, not only could he not walk but he could not use his arms or hands to feed himself. Although by Thursday, the IVIG began to do its job. As quickly as the GBS moved up his body, it began to dissipate from Stuart's upper body.

While we watched this phenomenon, every breath was monitored. When Stuart began vomiting, his ability to breathe was in question. Although the GBS never did affect his lungs, at that point we had another scare. A lab report revealed that Stuart had typhoid fever. Although this diagnosis was later refuted, what next?

Eight days after entering the hospital, Stuart was released to return home to his family. His brothers Peter, 3, and Walker, 6 months, eagerly awaited his return! We had quite a load to bring home. Stuart's friends on our street created a poster size photo collage. His classmates each made him a book of pictures based on "When you return, we will . . .". Stuart had pictures from his cousins, books, videos and finally, his own Game Boy! He came home to room-size hand-painted banners, balloons, baskets and many, many prayers! Stuart left the hospital in his shiny new wheelchair and carried his shiny new walker. Although seeing our little boy wheel himself around the halls seemed so wrong, we were hopeful that with these devices and intensive therapy, Stuart would be just fine.

For the first week, Stuart did recover each day. We saw some limited progress. We knew we had to be patient. This would be a long process that involved physical and occupational therapy five days a week. But within ten days of returning home, we were scared again. The signs of progress seemed to be slipping and Stuart seemed worse. What did this mean now? We contacted the family and child support group from the GBS Foundation. We spoke with previous GBS patients and were convinced Stuart needed help. We rushed back to our pediatrician who agreed, indeed, Stuart had grown weaker since his hospital discharge. Our neurologist was contacted immediately, and EMG and nerve conduction tests were scheduled to follow. These tests were extremely painful for Stuart. Due to lack of nerve or muscular response, the tests lasted close to three hours. The immediate results indicated Stuart's GBS may be the axonal form of GBS, often associated with poor results. Two days later was Stuart's class play. He had not attended school in one month, but was invited to visit for rehearsals and the performance. It was Grandparents' Day. As I carried Stuart on the stage and sat him in his wheelchair, his smile was constant. He was so happy to be reunited with his friends! Yet his smile would soon be replaced with tears. Following the play, we drove to the neurologist's office to discuss the results of the EMG and Nerve Conduction. On February 28, the results of the tests confirmed that Stuart's rare condition, Guillain-Barré Syndrome was now even more rare. Instead of typically damaging the myelin sheath that coats the nerves, Stuart's actual nerve axons or cores showed damage. Immediate hospitalization was

ordered. The possibility of the GBS as a chronic condition was discussed as well as the possibility of more permanent deficits or damage. At this point, we again contacted the Foundation for a GBS pediatric specialist. This doctor was contacted and collaborated on Stuart's status and treatment. Grandparents returned and we prepared for five IVIG treatments. The morning after the first treatment, all of the doctors attended to assess Stuart's prognosis. It was incredible! Stuart was able to lift his legs from a prone position. We were thrilled. Stuart continued to improve and once again left the hospital in a wheelchair, with his walker.

A vigorous routine of physical and occupational therapy followed. Stuart's attitude was tremendous. He never asked us why this happened, but only asked the time frame for his very confident and assumed recovery. He wanted to walk by Easter when his grandmother and cousins would arrive. At this time, this goal looked highly doubtful, but we were all motivated by his enthusiasm. His condition improved as he kneeled, sat unsupported and crawled. His preferred method of in-house transportation was pushing with his hands and feet while seated on a 'scooter board' ordered from a physical therapy catalog. Stuart and his three-year-old brother played catch around the house with our six-month old in his baby walker! The evening of his grandmother and cousins arrival, Stuart's Dad left for the airport. I stood in the kitchen washing dishes when I looked over to see Stuart stand up and begin to walk. My first thought was that I was experiencing a divine miracle! Stuart continued to walk around and around the room with pure glee. When his Dad returned from the airport, we requested they all stay at the front door. Stuart walked to greet them. He had actually reached his own goal! Our tears of joy, relief, thanks and love continued into the night as neighbors appeared in pajamas to see Stuart walk.

Stuart still had a way to go in therapy. We had even added aqua therapy. Although he missed almost six months of school, the support was unending. When Stuart turned six, we exchanged the wheelchair for a shiny new bike. That summer Stuart swam on the swim team and attended day camp. Stuart was rarely frustrated. He worked hard, maintained a sense of humor, learned about people with worse conditions than him, began to understand empathy and believed in himself. We are so proud. Although our experience was life changing, we feel so thankful. Our love and faith have grown and we celebrate each new day.

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