



At our 21-week pre-natal appointment for our twins, Spina Bifida entered our lives. It was supposed to be a routine appointment to find out the gender of our little ones, but instead we left confused and in tears with an appointment scheduled with a high-risk Ob/Gyn the next morning. Our families were already coming to our house for a small gender reveal party, but we all gathered with more questions than answers.

We were lucky to have an amazing Ob/Gyn. He went through the ultrasound meticulously with us. He told us how each spina bifida case is different and we wouldn't know specifics until she was born. He explained that the placement of her Myelomeningocele would make walking questionable, but how individuals with spina bifida grow to have independent lives and many are gifted with above average intelligence. We were still very scared, but he gave us an outlook of having a child with a very full life ahead of her. I'm thankful every day for a realistic and at the same time optimistic delivery of our diagnosis, which is contrary to what many SB parents receive.

A few months later, Rory Mae and her brother, Declan Edward, joined us on October 13, 2014. Both babies stayed in the NICU and were only allowed a short list of visitors. With no babies to see, there weren't a ton of hospital visitors, but no visit was more welcome than from SBAK. They came with a baby gift, tons of information and an invitation to come to their events. I was a mess and pretty much cried during the whole visit. Heck, I was a new mom of twins in the NICU, Rory was recovering from her Myelomeningocele repair surgery, and I was worrying about another possible surgery for a VP shunt. SBAK provided me a caring and welcoming hand when I needed it the most.

As new parents of twins we pretty much hibernated during the winter. One of the first places we had the courage to venture to with both babies was an SBAK Play Pals group. In that first visit I learned so much about spina bifida and knew how blessed our family was to have SBAK in our lives.

The SBAK parents are open and willing to answer any questions that arise. I find so much value in the knowledge of those parents who have navigated this spina bifida road before me. We all feel the same fear and frustration with the medical world, but we also share in the joy as our little ones hit milestones that seemed nearly impossible.

This past summer Rory faced her third surgery. This surgery was on both legs, and her first since her days in the NICU. SBAK's outreach made us feel like we were never alone.

Rory is an active two-year-old. She loves playing with her brother, watching Elmo, dancing, singing and drawing. She keeps up with her brother in her ZipZac that she received from another SBAK kiddo who outgrew it. She has incredible endurance and is able to ride it on the sidewalk the length of our street. Everyone is amazed with her ability to maneuver it around tight corners. She is a daredevil, and her only frustration with the ZipZac is that her grandmother will not allow her to ride it down the stairs.

Rory is living proof of our doctor's diagnosis of a full life. She is a feel-good natural. Rory lives every day with an infectious smile, the best back-rubbing hugs and the ability to crack not only herself up, but all of us around her. Her biggest gift to us is the blessing of being loved by her.

