Julie Elander's Story

I was born in Indianapolis in 1960 and of course in those days no one knew ahead of time that their baby had SB until the baby was delivered. I was my parents' first child and there was no history of SB in the family. I have a brother 3 1/2 years younger than me without SB.

I was born with lipomyelomeningocele at L5/S1. A couple of very good doctors were called in and they closed my small lesion and removed a piece of skin that was hanging by the opening. Unfortunately, I got meningitis and was very sick for a number of weeks, spending about a month in the hospital. At one point, when they weren't sure whether I would make it, one doctor at the hospital told my mother would be just as well if I died because with the SB and the spinal meningitis, my brain would not function properly--and I'd basically be a vegetable. Yes, those were the words they used back in those days, and I cannot imagine a mother hearing that about her firstborn child—or any child!

Needless to say, SB kids are fighters, and I survived. As an infant I wore shoes with a bar to turn my feet straight, but I eventually started crawling and pulling myself up and walking (without the bar, of course) at about 13 months. My own daughter, who does not have SB and is also a firstborn, started walking about this same age.

I had a bladder/ileal colon surgery when I was barely age 5. I won't go into all the details, but I remember being VERY happy about it, running around and telling all the neighbors about it when I got home from the hospital, lol! This type of surgery has been improved upon over the years, but it worked for me, and has served me well for 46 years. So take heart about that, moms of SB kids!

I had an unusual gait, of course, and over the years I had numerous surgeries, a metal leg brace, and even a cast at age five to try to turn my foot straight (no surgery—just a cast!). I wore the leg brace from 6th to 9th grade. I attended two public grade schools and both times my mother marched me to the principal's office before school started to show the principal I was just fine

on my own. In those days, disabled kids weren't really attending public school, so I know my mom had to try to convince the school I would do fine. I was indeed the only "handicapped" kid at both of my schools, so I got a lot of comments and, sometimes, rude or teasing remarks about the way I walked or about my brace. However, I also had a lot of nice friends at school, so that called less attention to my being "different." A lot of people asked if I'd had polio, even though polio had basically been eradicated in the U.S. by the time I was born. But people knew about polio; most had not heard of Spina Bifida or knew almost nothing about it when I explained what I had.

Through grade school and high school, I had surgeries every few years: tendon transfers, bone rotations, foot corrections, spending time on crutches, full leg casts, walking casts, and wheelchairs. Since I have little sensation in my legs, the surgeries didn't hurt all that much, and I actually felt in some ways unique (in a good way) with my cast, crutches, or wheelchair. I did have achy legs for a number of years on very rainy or snowy days. At 25, I had my four hammer toe bones fused straight (left foot). Funny story: I fell down the stairs in my lovely wooden hospital shoe and toe pins after the surgery, bending my pins! So, I DO have fused bones, but they are anything but straight, lol!

My teen and adult life has been pretty normal: I went to public high school, got a part-time job at age 15, drove at 16, won awards for art and writing, graduated 5th out of 287 in my class (Take that, Spina Bifida!), went to college out of state for my BS in Graphic Design, did internships in various states, backpacked Europe (alone) for three months, moved far from home for my first job after graduation (IBM), got married, had three kids (very easy to deliver babies when you have SB, btw--#3 was accidentally born at home!!), worked for various companies at each of the five places we've moved to, taught adjunct at a college, and started my own freelance editing business.

The only really major SB event in this time was at age 40, when I realized my walking was getting worse (well, it actually started when I realized I was having trouble getting up from a squat). I had an MRI and learned I had a tethered spinal cord. Like a rubber band, it had been stretched for all these years and was finally giving out. They didn't usually check for TC back in the day, so I had never known! I had TC surgery in Chicago at age 41 (after much doctor hunting). My balance was pretty bad by this time, and I was starting to use a cane (which I still do). The surgery had some complications that required a revision and then four months lying flat in bed trying to get a pinhole leak to heal (it was leaking spinal fluid). It healed, I went back to work, caught West Nile Virus—a spinal fluid condition of all things!—and the pinhole reopened. Three more months in bed and then just about the time they were going to put me in the hospital to try drain my spinal fluid away from the pinhole for awhile, it healed! Woohoo!!!

Having a good sense of humor, and parents who encouraged both independence and trying a variety of things to see what I was good at (and encouraging me to develop those things--like my art and writing) were some things that really helped me get along with all kinds of people despite my SB. That is not to say I never felt (or feel) different, or that people never felt uncomfortable around me (at least subconsciously). It just meant that growing up I was able to laugh (at least later!) at most awkward situations caused by my SB, and that I rarely thought much about my physical limitations, instead focusing on things I enjoyed doing and felt I had a special talent for. Guess I've done OK for a "vegetable." :)

Thank you to Julie for sharing her story with SBANT!