

Millie Dunn

My health challenge journey began at birth, in 1966. I was born premature at weighed 4lbs., and was born with club feet and a heart murmur. My feet were corrected early on with casting and leg braces. My mother had suffered four miscarriages before I was born.

At the age of 16 years I had surgery for bilateral ovarian teratomas, which possibly could have been from the high amount of hormone injections my mother had with me to keep the pregnancy viable. The teratomas were very large and took over most of my ovaries. During imaging for this issue and stomach reflux issues my scoliosis was found. My curve was over 40 degrees at that time. I saw a scoliosis specialist who followed my over the course of a year while I healed from ovarian surgery. At the end of the year my curve had progressed very rapidly and surgery was recommended. I had my first scoliosis surgery at age 18 years old. My family history is such that my paternal grandmother had severe scoliosis with a curve close to 90 degrees. My youngest brother had scoliosis-he tragically passed away at the age of 29 years from flu and heart complications. He left behind an 11 month old son, my nephew Alex who also has scoliosis. My own son, Daniel has scoliosis as does my paternal cousin's daughter who had surgical correction in her teens as well.

Following my scoli surgery, I did very well and had no issues with my back until age 42 yrs old when my fusion broke apart. Most likely due to early onset osteoporosis which I have, as well as erosive osteoarthritis.

To back up a bit, at the age of about 33 years old I developed a neurological illness suddenly. I thought it was a strange viral type illness, but many of the symptoms persisted and progressed such as muscle pain and spasms with walking. I also developed severe hyper reflexia. The weakness and fatigue, double vision and spasms in my muscles continued to be a problem. I had many neurological assessments from neurologists at the Texas medical center and never really got a clear diagnosis other than severe spasticity/ Upper Motor

Neuron syndrome (or it is referred to as Spastic Quadriplegia) indicated by EMG testing. I was recommended for an implanted Baclofen pump to assist with walking. Baclofen is a muscle relaxant drug that via the pump is delivered directly into my spinal fluid. I have had pumps now since 2004.

In 2008 is when my spinal fusion developed a pseudo-arthritis, or non-union. The pain was very bad and I could not stand or sit without severe pain. I had surgery right away by a neurosurgeon and had a very poor outcome. While he repaired the fusion area and some herniated discs, he mal-aligned my spine and my scoliosis worsened again rapidly. He also failed to remove my old fractured hardware and instead cut off the bottom half of my Harrington rod which caused tremendous problems down the line for me. Harrington rods are stainless steel and contain nickel. I am allergic to nickel as I found out at age 16 when I had my ears pierced and had a severe allergic reaction. The mal-alignment also caused me to have a condition develop called Flatback syndrome which is a forward bend of the spine and loss of the needed normal lumbar lordosis curve of the spine. He had pulled me straight without restoring any of the natural curve needed to remain upright. Flatback is something that continues to worsen as one ages and by 2013 I had severe forward flexion, burning and all over severe itching and electrical type taser severe pain in my legs. I feel as though the itching and burning and possibly electrical pain came from the sawed off steel rod containing metal dispersing nickel into my bloodstream.

In 2019, I began researching the internet, reading about allergies in spine instrumentation, making calls to doctors, and read everything I could about scoliosis, metal allergies and Flatback syndrome. I had the fortunate luck of finding a website understandingscoliosis.org and wrote to them. This is how I met Becky Dutton. She has been a brilliant advocate giving of her valuable time helping people like me. She wrote to me and told me of the MELISA testing for metals, and also wrote to a friend of hers who is a scoliosis expert and sent him copies of my CT myelogram. He explained to us the complexity of my Flatback syndrome and mal alignment and recommended reaching out to the number one

spine reconstruction specialist, who does only the most complex of revisions named Dr. Lawrence Lenke in New York. After reviewing my CT myelogram films he had a telemeds conference with me telling me my case is severe enough that he would do my repair and reconstruct himself and not refer out to one of his spine colleagues. This was very good news as he developed the technique and instrumentation used to repair my issues.

Between the years of 2019 and 2021, my spine pain, thoracic curvature and other symptoms progressed rapidly. During these years I also had four incidents of my husband finding me unresponsive and barely breathing. My heart rate and pulse would be barely registering and each time I was transported by ambulance to ER then to critical care ICCU unit, with on one of the times in 2019 my being placed on a ventilator for life support for 2 days. I was treated with cardiac and breathing medications. One of CT scans done in 2019 picked up that I had suffered a stroke. The cause of most of these incidents is thought to be from Dysautonomia. One of the incidents is thought to be implanted pump related.

Regarding my symptoms of itching and allergic issues, Becky Dutton taught me of the benefits of Phosphatidylcholine to help detox the system of heavy metals. I have been using PC for the past month and it has helped with the systemic itching. Dr. Mark Drzala the spine surgeon who helped get me to Dr. Lenke, is also a metals allergy expert re: spine instrumentation and has developed Sensibands metal testing wrist bands that test for a variety of different metals allergies. I used the Sensibands prior to my reconstruction surgery, specifically to know if I reacted to Titanium as that is what Dr. Lenke was replacing my stainless steel hardware with. I did not show a reaction to it thankfully.

In March of 2021, I flew to New York with my husband from Texas and had surgical reconstruction from Dr. Lenke. He restored my sagittal imbalance, repaired everything, corrected the scoliosis curves and Flatback forward hunching and removed all stainless steel hardware rod, hooks and misplaced pedicle screws. I grew 3 inches immediately after surgery and now, 6 months later all my

spine pain is gone and I am able to walk without my walker for short distances. I need the walker still not because of spine pain but because of leg muscle

weakness from the spastic quadreparesis. Complications can occur easily with this type of intensive reconstruction and I had a severe form of allergic reaction to the antibiotics which caused liver failure. The liver failure was caught right away by Dr. Lenke and it reversed completely. I can never have many different types of antibiotics again, though and see an Infectious Disease specialist and allergist. Post surgery I had a left partial lung collapse (my new curve developed where my left lung is and Dr. Lenke had to work extensively in that area). I also had a post surgical abdominal ileus from pain medicine. All was caught right away by his team and treated aggressively. He and his team were incredible.

About 3 months after spine surgery I began to have heart and breathing issues as I was healing. I ended up back in the hospital and was diagnosed with Dysautonomia and Inappropriate Sinus rhythm Tachycardia. I had in the past had issues with blood pressure, temperature regulation and heart rhythm all prior to surgery as well but finally got a diagnosis following a two week heart monitor test. I am doing very well now on medicine to control the Dysautonomia. Dysautonomia is common in patients with spine disease and neuro muscular disease patients as well.

I have had recent updated Genetic testing from Baylor Genetics Dept. last month in Houston and currently awaiting to see if it sheds any additional light as to why all of this.

I thank you for taking the time to read my story and I thank so much my precious friend and advocate Becky Dutton with understandingscoliosis.org. She is a true angel.

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