

My Story in a nutshell!

I'm a wife and a mother of two young girls. It was a beautiful mother's day, May 13th 2012. That was the day that changed my life forever. I had a motorcycle accident that left me paralyzed in the T4/T5 area, basically chest level.

I was in the ICU and the rehabilitation center for 5 weeks. I have always been a driven person and felt with hard work things will get better. I did physiotherapy four times a week at the beginning and then twice a week to help me increase my ability to function as best I could. I ended up in Detroit, Michigan driving back and forth every week. There I was able to work with a physiotherapist that used Functional Electrical Stimulation Bikes (FES) as part of the therapy. I knew this would help me to stay strong and help me to get back as much function as possible. During this time I continued to look for more options. That's when I found out about the Estand trial. I was accepted into the trial and had my surgery on October 18th 2017.

Being a busy mom and working full time, I was hoping that through this trial it would reduce my nerve pain and help me with functional movement. Dr. Darrow asked me if you could improve 10% would I feel it was worth it. YES, I would take anything to help me live more functionally and that doesn't just mean movement. It was the very next day that we turned it on and could see that there was an immediate response. I couldn't wait to get working.

During this process, what I didn't realize was how much my autonomic function was suffering. Dr. Darrow introduced me to Dr. Andrei Krassioukov (Dr.K) and Dr. Aaron Phillips. They work with patients that suffer from Autonomic Dysreflexia (AD). In my case I didn't know how much it was affecting my heart rate, blood pressure, and blood flow to my brain. After some testing we realized very quickly that the stimulation was also helping me in this area.

With the simulator my blood pressure and heart rate is under control. I don't find that mid-afternoon I am having big drops in my blood pressure and if I do. I increase the stimulator. I'm able to work full hours with ease. My bowel and bladder routine has reduced from an hour and a half to about 15-20 minutes at most. My pain has reduced and I don't have the amount of toning or stiffening I used to have. This allows me to transfer without worry of falling and sleeping through the night. My body temperature is under control now before I would normally be overheating in the morning and freezing in the evening. Prior, I had had 3 incidences of Autonomic dysreflexia because of overheating. I have been able to gain control of my hips and glutes, pulling myself up to a stand while holding on to a bar. This allows me to pull my pants up and down with much more ease than in my chair. While I have my stimulator on, my swelling is reduced. My core has gotten stronger so much so that I have been able to lift a 20 pound weight off the floor without help. This has increased my quality of life more than I could have imagined.

I leave the simulator on all the time. I reduce or change the programs depending on what I am doing. It has become my new norm. It has allowed me to be more independent. Reducing the time spent with a physiotherapist. I'm able to do my own work outs and get myself on and off my own equipment (standing frame, FES Bike and bed for core workouts) Swimming, skiing and Kayaking are just a few more activities that I am now able to do. Doctor appointments have reduced because my overall health is excellent. I take no medication. In fact, I went for a follow up with my Respiriologist and he said that my numbers were so good that instead of every 2 years he moved me to 3 and now to 4 year follow ups.

At the beginning of this year my battery died. (Depending on the amount of use will affect the length of time the battery lasts) It didn't take long for me to realize just how much I rely on this for every moment in my life. I wasn't able to sleep through the night from all the toning my body was going through, I ended up with headaches and soreness and using a heating pad to keep my body temperature under control. My evening bowel and bladder routine increased in time with every day and my inconstancy started to act up again. Burning pain increased with more tone in my legs with nerve pain. I wasn't able to work as much and found myself having to put my feet up for a better part of the day.

I was so thankful for the day to have my battery replaced; I couldn't imagine life without my stimulator. I am so thankful to have been a part of the Estand trial and only wish that more could have this opportunity. This is a huge game changer. I really believe it should be available to everyone; I have yet to hear of the down side. I am so grateful to Dr. David Darrow and the Estand team. But I know if it wasn't for organizations like Unite 2 Fight Paralysis these trials would not be possible. THANK YOU to all that build awareness and fight for us and our families with paralysis.

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