

In October of 2006, I suffered a T8, ASIA A spinal cord injury from a fall during sleepwalking. At the 2016 W2W (Working 2 Walk) Symposium Minneapolis, I listened to a presentation about an epidural stimulation clinical trial starting soon at HCMC (Hennepin County Medical Center) called ESTAND (Epidural Stimulation After Neurologic Damage). I met with Dr. David Darrow to discuss what the trial would entail and about the surgery itself. After looking through my medical records and discussing with the clinical trial team, Dr. Darrow told me that they were not sure this would work for me, given the severity of my injury, the length of time that had passed since my injury and my age-52 at the time of surgery. I went into this clinical trial with no preconceived notions of success. If it didn't work, then we knew what the limitations were. On September 27, 2017, I had the epidural stimulator implanted! 2 weeks later, on the 11th anniversary of my spinal cord injury, we turned the stimulator on. It worked! There was quite a bit of excitement in that room and yes, I did shed a few tears of joy! As the trial progressed, I noticed that my shoulders didn't hurt anymore. My left shoulder was so painful before the trial, I was worried that I may need surgery. I am able to sit up straighter in my wheelchair and that has allowed me to push more efficiently. My gray area of nerve sensitivity has disappeared and the pins and needles nerve pain has gotten much better! My legs don't bounce around anymore. I can ride in a car without becoming stiffer than a board and being thrown back in my chair. I can

maintain a more even body temperature. It is nice not to take 2 hours to warm up. My bowel program is shorter. My bladder is still a work in progress. I didn't expect all of these changes. In the past few years, our community has made it clear that while walking again would be great, it is all of the other stuff that affects our quality of life.

Without the Minnesota Spinal Cord Injury/Traumatic Brain Injury Research Grant program, the ESTAND clinical trial would not have happened. Why deny people a good quality of life after injury? Let's prevent shoulder injuries due to overuse, drug use for spasms, nerve pain, bladder leakage, long bowel programs, poor temperature control. The list is long. Please do your part to help advance Spinal Cord Injury research! Thank you for reading about my experience!

Kathy Allen-SCI survivor
Cross Lake Minnesota