

thespin

SPINAL CORD INJURY BC

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the incomplete issue

Putting into perspective the
mixed blessings of life with
incomplete spinal cord injury

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STIMULATING Quality of Life

The recent media blitz we saw on a promising epidural stimulation research project focused largely on restoration of leg movement. We believe there are other implications that are more intriguing.

“**A** spinal cord injury treatment breakthrough moves legs!” cried the headline in the May 2 issue of the *Legal Examiner*. “This Might Be The Cure For Paralysis,” shouted the *Business Insider* on May 20. “Paralyzed patients successfully move legs after breakthrough treatment,” exclaimed *PBS NewsHour* on May 9th.

No doubt you read or heard at least one or two variations of these headlines in your own regular news sources. And, like us, you may have realized that mainstream media missed the mark when it came to the significance of the research in question.

Then again, maybe it’s hard to sell newspapers with headlines such as “Spinal Cord Injured Man Regains Ability to Take a Leak” or “Paralyzed Man Gets Erection” or

“Breakthrough Treatment Helps People with SCI Avoid Autonomic Dysreflexia.”

Regardless, it’s left to us to tell you about the most promising, real-life benefits that you might be able to enjoy one day as the result of the research project that’s been taking place at the University of Louisville in Kentucky.

To date, the work has centered around four young, spinal-injured American men who received a surgical implant of an electrical stimulation device in their lumbar spine. The device, known as an epidural stimulator, is made by Medtronic and is widely available off-the-shelf for pain relief. But for these four men, it yielded a completely different and unexpected result—it appears to have reawakened their spinal cords’ innate ability to control certain motor functions without direct input from the brain.

The premise behind the research is that our spinal cords are to an extent “smart” and, when properly activated (in this case, with electrical impulses), can remember and execute certain functions. Think of a baby suspended with feet on the ground—he or she instinctively begins to make stepping movements, even though his or her brain isn’t developed enough to direct this movement. This is the spinal cord’s “smartness” in action.

Rob Summers, who is quadriplegic and had no movement but some sensation in his lower body, was the first to receive the implant. The goal of the researchers involved was to answer some questions about nerve pathways after SCI. But to Summers’ surprise, he was suddenly able to stand three days after he had his array activated. With more stimulus and locomotor treadmill training, he began to take supported steps. You may remember that this created somewhat of a media sensation back in 2009 when it was reported. Then, seven months later, he realized he could move his toes when the stimulator was on.

All of this astonished the researchers overseeing the project, University of Louisville neuroscientists Dr. Claudia Angeli and Dr. Susan Harkema. No less surprised was UCLA’s Dr. Reggie Edgerton, whose groundbreaking epidural stimulus work in animal studies preceded Angeli’s and Harkema’s work in humans. Interest grew, and the University of Louisville was successful in finding funders to see if they could replicate the results they saw in Summers.

Over the course of five years, Andrew Meas, Dustin Shillcox and Kent Stephenson agreed to be participants. All three had no movement below their injury, and Meas had no sensation. Again to the surprise of the researchers, all three regained the ability to stand and take some assisted steps on a treadmill. The researchers clearly appeared to be on to something. The results from all four participants were most recently summarized in the April issue of the journal *Brain*, and that’s when you no doubt read about the work in the media, which had a field day with the research—particularly the idea that the four men

In their own words...

The work in epidural stimulation is being partially funded by the Christopher & Dana Reeve Foundation. Recently, the Foundation published firsthand accounts of the first four participants of the trial, and have graciously granted us permission to reprint those accounts.

ROB SUMMERS Portland, Oregon



On the third day in the clinic after the surgery, they said, “Let’s just see how it goes to stand.” They put me in a harness over the treadmill, my weight suspended 100 percent. They lowered it down and down until I’m standing, full weight-bearing. It was just an incredible feeling. I hadn’t moved anything in

four years. My legs were supporting me. There was nothing to help me balance. I could feel my legs working, I could feel my feet under me on the treadmill. At first I didn’t comprehend the significance, but I soon realized what an incredible thing this was. It was like a giant weight was lifted off my shoulders. I had worked so hard for so long, and to be standing for 15, 30 seconds, it was so emotional for me in many ways. After seven months we found out that while the stimulator was on, I was able to voluntarily control my toes, ankles, knees and hips, on command. This was something that was completely unexpected. There were other benefits, too. One day I realized I could sweat again, and regulate my temperature, feel hot and cold. I could also feel light touch. I regained control of my bladder, bowel and sexual function and my circulation improved. I’m not 100 percent but the changes really impact my quality of life. I’m happy to have been part of the experiment and be able to help the scientists streamline their techniques. After seven months I could take steps; Dustin, patient number four, could step in the first week. I joke with (lead researcher) Susan Harkema, “by the time you get to patient number 1,000, they will be running out

of the lab in five days.” If I were to address a person with a new injury I would say without a doubt, this will change the quality of your life. We are not quite there yet, but cures are just around the corner if we continue the research efforts and experimental trials.

KENT STEPHENSON Mt. Pleasant, Texas

On June 9, 2009, I was practicing and getting ready for my summer motocross racing season, which started the following week. But everything changed that day. Going off the face of an 80-foot tabletop jump, the motor on my dirt bike locked up, causing me to crash. I did several cartwheels and in my landing broke T5 and T6 in my back. I was paralyzed from the chest down—T4 Asia A. I went to Craig Hospital in Denver for my inpatient rehab and came home from there in August. I was home for a week, then went to Frazier Rehab in Louisville, KY to start Locomotor Training and therapy. I did the [Reeve Foundation] NeuroRecovery Network training and community fitness program for a year at Frazier before I became aware of the epidural stimulation research, which of course was being done right there. I went through the screening and was selected. The first time they turned the stim on I felt a charge in my back. I was told to try pull my left leg back, something I had tried without success many times before. So I called it out loud, ‘left leg up.’ I felt a sort of charge go down my leg and then a tightness. This time it worked! My leg pulled back toward me. I was in shock; my mom was in the room and was in tears. Words can’t describe the feeling that overcame me at that moment—an overwhelming happiness. I had been told by doctors that because I was an ASIA A I would never be able to move voluntarily. The feeling is amazing. It really gives you back that part of yourself you feel you lost when you became injured. When this all started, my injury was supposed to be a life-ending deal, really, that is how the doctors told it to



were standing and stepping.

Largely lost in all the media frenzy was the meaningful health and quality of life benefits that each of the four participants had experienced. Yes, it's true that they regained leg movement, and the ability to stand and step has helped them restore muscle mass and cardiovascular health.

Remarkable, yes. But it's highly unlikely that these men will ever walk on their own as a result of this research.

However, every person with SCI should be intrigued by the health and quality of life benefits that each participant has experienced since receiving the implant. These include measurably improved autonomic function and blood pressure regulation; improved bowel, bladder, and sexual function; increased mobility and trunk strength; and for one participant, an important gain in temperature regulation.

"All four individuals have seen improvements in these secondary functions," explains Dr. Claudia Angeli, a senior researcher at the Human Locomotion Research Center at

me. But in fact, it has been an adventure. Being a part of the stim program has really changed my life and enables me to do all the things I used to do, like deer and duck hunting, going off-roading, running heavy machinery at work, everyday 9 to 5. I wasn't 100 percent sure I wanted to give up two years of my life to go through the training and everything. But it has totally been worth it. I got a fortune cookie recently after my injury. It said, "Everything's impossible until somebody does it." I still have that note in my wallet, and always recite it in my head when I'm trying new things.

ANDREW MEAS Louisville, Kentucky



I broke my neck seven years ago. It was dusk, I was cruising about 35 miles an hour on my motorcycle. I got hit head-on by a car. I flew 100 feet almost to the other side of the highway; I did a superman dive, landed on my head. I broke my neck at C6-7. After complications with pneumonia—I almost died while

on the breathing machine—I was weaned and eventually transferred to Frazier Rehab, where I stayed for three months. Of course, I heard about Locomotor Training right away, it's done right here. I participated, but my insurance only paid for two weeks. I was put into the lottery, I guess you'd call it, for the research program there. Once I was picked, they had me do 80 sessions of Locomotor Training, to make sure I had no motor function below the lesion level. I did not. I got the surgery and waited a few weeks. Once the stim was turned on, I could stand on my own. It was amazing. I forgot how tall I was. It was very emotional to be standing after sitting in the chair for so long. Then, on command I was able to lift up my legs—pretty easily, even without the stim. I can't describe it, it was just incredible. Yes, leg function is a spectacular feature of epidural stimulation but for me the most important benefit is in managing my autonomic dysreflexia [AD, a dangerous blood pressure problem for

Frazier Rehab Institute who, along with Harkema, co-leads the project. "These changes seem to be long-lasting since they don't require the stimulation to be on, but they gradually improve as the individuals start and continue training with the stimulation. These changes are very gratifying to see, and are very important for the research participants because they have a direct impact on their quality of life."

In other words, Angeli and her colleagues understand that these quality of life impacts are a very important aspect of their work—perhaps even the most important. "We're starting to look at all these things in more detail and developing projects around these improvements," says Angeli, "because regardless of our success in obtaining independent stepping, quality of life changes might be sufficient for a faster translation of this research into clinical practice."

In fact, as this research moves forward in an effort to validate the results, Angeli says that the secondary health improvements will take on a greater prominence. "We currently have

people with injuries above T6]. Before the stim, I could sense when my bladder was full. If I waited too long to empty it, though, I would get a pounding headache, a sign of AD, and a painful reminder that this could lead to stroke. Now, I can hold my bladder longer and have no AD symptoms. Bowel function has improved a little bit. As far as sexual function goes, that has improved greatly – everything is possible now, and there is no AD.

DUSTIN SHILLCOX Green River, Wyoming

I was in a car accident on August 26, 2010, on the interstate near Green River, WY. I was driving a work vehicle when the tire blew out and the vehicle rolled. I was ejected from the car and paralyzed at level T-5, ASIA A. A few months after being discharged from the hospital, I saw a news report that researchers



had for the first time enabled a paralyzed person to stand on his own. Once I found out about Rob Summers, I called and had my name put in the pool so I might have a chance to be a part of the study. The following summer I got the call. I packed my car and headed for Louisville. The feeling I get when I turn the stim on is amazing; when I stand or work on walking I feel great because I'm doing things that I was told would never happen again. The ability to move my legs is awesome and it makes me excited for the future because the four of us in the epidural stim program all keep making progress. I have also had progress in improved bowel, bladder, and sexual function – this alone has given me a strong self-confidence. The stimulator makes me feel normal. It's like I'm back. If I talk with someone who has a new spinal cord injury I'd tell him or her about how exciting the research is and how important it is to stay healthy and keep involved with therapy. I tell people—and show them by my example—that scientists are making great improvements for people with a spinal cord injury.

funding to replicate the initial study in another four individuals—these will involve four individuals with matched clinical characteristics to the four already implanted,” she explains. “The basis of this will be replication of results. But we also have additional funding for four more participants with a focus on the secondary effects—specifically the cardiovascular function. These will be cervical injuries with significant cardiovascular deficiencies.”

While the research to date is intriguing and promising, Angeli cautions that the hardest work lies ahead. “There’s still a lot to learn and a long road ahead for us conducting the research, but we are working extremely hard to one day be able to translate this to the clinic. For me personally, it’s extremely gratifying—I get the benefit of being in the lab almost every day with these individuals, and seeing what we would have defined as unlikely milestones happening very frequently and how excited the participants get every time they can do something

more. Knowing that every day might be the day I get to see something amazing happen helps me get to work every day.”

Meanwhile, other offshoot projects of the research are moving forward. “We have a team of engineers working on improving the technology and developing new stimulators and interfaces to reduce some of the limitations we’ve found,” says Angeli. And while her team will continue working with surgically-implanted stimulators, the bioengineering institute at the US National Institutes of Health is funding research to develop non-invasive stimulators which can deliver electrical pulses through the skin.

Forgive us for speculating, but is it possible that all of this could eventually lead to a wearable device that would allow many people with SCI to stand and somehow achieve weight-bearing exercise, while yielding significant improvements in functional abilities that greatly improve health and quality of life? Obviously, this won’t happen

in the immediate future, and without a great deal of work. But it appears to be possible.

Finally, yet another exciting offshoot of the work is taking place at UCLA, in the labs of Edgerton and colleague Dr. Daniel Lu. The two scientists recently received a \$6 million, five-year grant to study the same epidural stimulation for restoring hand function in people with quadriplegia. In fact, experiments with five participants have already taken place, and while data have not yet been published, Edgerton is optimistic.

“Our hypothesis with the upper extremity,” Edgerton recently told The Christopher & Dana Reeve Foundation, “is that the cervical spinal cord probably will respond to interventions similar to what we have established in the lower spinal cord. Our results were better than we expected; we saw improvement in function including hand grip strength but also the ability to control that movement.”

Stimulating news, indeed. ■

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