It never occurred to Jan Scheuermann that she might lose the use of her legs and arms. And she certainly never imagined that her own mind would one day power the motion of robot parts. Now she knows that anything is possible.

A WHOLE LIFE

Written by Morgan Kelly  Photography by Ric Evans
And courtesy of University of Pittsburgh Medical Center

When the numbness in her legs made her lag behind the rest of her family as they walked or shopped or traveled together, Jan Scheuermann shifted the blame. She channeled the problem and her guilt for "holding the family up" to her weakened legs. Those heavy limbs became Charlie and George. If they would not work, what was she to do?

"It was Charlie and George having problems, not me," says Scheuermann. "I was doing my best."

In 1996, a neural degenerative condition began draining the strength in Scheuermann's legs. Before long, her arms were affected, too. Her limbs became increasingly useless. Within five years, the disease inexorably destroyed the connection between her brain and her muscles. By 2002, Charlie and George were lifeless, as were Scheuermann's arms. She was fully quadriplegic.

But, since then, remarkable advances in neurobiology and technology have offered new hope for the future—and may eventually transform the lives of others who have lost the use of their limbs.
Scheuermann, a Pitt graduate in non-fiction writing, has a longtime penchant for christening inanimate objects. Today, she has some new names that express independence and renewed abilities rather than limitations. For instance, Sven, a husky and strapping power wheelchair from Sweden, has taken over for Charlie and George.

And lately there’s Hector, a robotic arm controlled by Scheuermann’s brain. Her thoughts power Hector’s movements. This breakthrough technology developed by University of Pittsburgh researchers enables Scheuermann to move the arm, make a fist, and pick up objects purely by thinking about doing so.

The starting point for this advance comes directly from natural movement. “Specific movements begin as neural activity prompted by a particular thought,” says Andrew Schwartz, a professor of neurobiology in Pitt’s School of Medicine. Using functional magnetic resonance imaging and even experimenting with brain-computer interfaces such as the one that guides Hector, scientists are uncovering neural patterns that represent complex movement.

“For more than two decades, Pitt researchers have been tracing individual movements back to their neuro-origins, then determining how to tap into the communication route to power prosthetics. ‘Using natural movement is a newer way of looking at neural research,’ says Schwartz, who also is a senior investigator on the project. ‘It’s more exciting and allows us to discover things that are new and unexpected.’”

Two pedestals resembling plastic caps attach to Scheuermann’s scalp and tap into the electrode grids implanted in her motor cortex. She has dubbed them Lewis and Clark because of the new medical territory they blaze. The electrodes sense neuronal activity in Scheuermann’s brain, and the results are processed by a computer algorithm. This mathematical “extraction algorithm” formulates the particular limb movements that correspond to the specific brain-cell activity detected by the electrodes. Based on that extracted signal, electric commands are sent to robotic arm Hector—and the metal and plastic appendage performs the intended movement.

The physical robot arm, developed at Johns Hopkins University, is modeled on the human right arm from the shoulder down, fingers and all.

Last year, Pitt researchers witnessed the latest results of their work in progress. Shortly after her 2012 surgery to implant the electrode grids, Scheuermann moved a limb—Hector—for the first time in 10 years. Initially, the process wasn’t flawless, but the prosthetic arm moved in response to her thoughts about movement. Within several months, Scheuermann accomplished a feat with Hector that involved picking up, raising to her lips, and taking a bite of a chocolate bar. In December, the Pitt researchers published details of their advance in The Lancet, a leading international medical journal. Since then, Hector and Scheuermann have shared the spotlight in newspapers and on television, including a segment on CBS’ 60 Minutes.

“This interface of brain and machine—which, for now, occurs only in a laboratory setting—gives Scheuermann (A&S ’83) a satisfaction and sense of accomplishment that eluded her during the lowest points of her disease. As her degenerative condition emerged and progressed, she fought through it all. During those years, she tried to keep planning and hosting mystery-theater dinners, a pursuit that satisfied her creative and humorous nature. She volunteered at her children’s school. She also cried in secret, though she acted brave. ‘There’s a saying, ‘You are who you pretend to be,’” Scheuermann says, paraphrasing Kurt Vonnegut’s novel Mother Night. ‘I was pretending to be brave.’ But her exterior resilience failed to mitigate an internal sense of loss that worsened with every disappearing function, every new degree of fatigue and paralysis. She lost her characteristic optimism. At times she felt suicidal, she says, a hopelessness that lifted with the help of antidepressants.

“Every step along the way, there was a little bit more I couldn’t do,” Scheuermann recalls, “I was sure that, at the rate I was going, I would be dead in a couple of years. That was a very sad period.”

More recently, though, Sven, Hector, and Lewis and Clark have picked up where her biological body gave out, returning to her some of the functions she had at one time despised over losing.

“There’s a feeling of accomplishment and control,” Scheuermann says about regaining more than lost physical abilities. “When you can’t move your limbs anymore, you lose control over a lot.” Even simple household spaces slip into displaced territory. She felt a loss, for instance, about how her kitchen looked, how things were arranged and organized. Out of necessity, the kitchen became her husband’s domain.

“To move something, to pick up objects and move them,” says Scheuermann, “it’s a different kind of control, but it feels good to have control of something. To be able to use the technology feels very empowering. It’s a step toward independence.”

In the world of prosthetic research, scientists strive to make movement as natural as it can be, which might seem obvious until one knows how elusive that has been over the past several decades. At Pitt, making Hector work means researchers have devised an algorithm that looks at many elements simultaneously to allow intended movements to be reproduced by the robot arm with almost human grace, says Schwartz, a senior author of The Lancet article.

Today, the ease with which Scheuermann moves Hector is a significant improvement over the earlier method of controlling a prosthetic limb, which required a trial-and-error approach in determining the specific human thoughts that would produce desired movements in the device.

In 2011, Pitt researchers were working with Tim Hemmes, a man from Butler, Pa., who severely injured his spinal cord in a motorcycle accident nearly a decade ago. Hemmes was able to use his own thought to move objects on a computer screen and, with the help of a robotic arm, to touch his girlfriend’s hand for the first time in seven years. A video of Hemmes’ achievements inspired Scheuermann to volunteer for the work with Hector. Since then, more advances have occurred.

Prosthetic movements are getting smoother, more complex, and more natural as researchers better understand how the brain and its billions of cells communicate motor signals—and with which parts of the body those signals correspond. By tapping into those signals, prosthetic
The work with Scheuermann extends beyond just smoother, more effortless movement. It also has implications for understanding how action is related to a person's perception of, and relationship to, an object, says Schwartz. The goal is to express that correlation in a model and reproduce it mechanically to further improve prosthetic function. A discovery in the research with Scheuermann occurred when researchers found she could better grab certain objects with Hector when her eyes were covered and she couldn't see.

"That was really interesting to us because it seemed like there was something specific to the object buried in the neural signal, something we were missing," Schwartz says. "That suggests a new line of study—how objects are represented in this activity. Instead of thinking about how the hand is represented in the brain, maybe we should be thinking about how the object is represented and what is going to be done with that object."

For example, Schwartz says when a person reaches for a glass of milk, the brain also considers how much milk is in the glass and how much the glass can be tilted before the milk spills, among other interactive factors.

"All those things determine the way you grasp that object," he says. "That's among the implications of what this work is all about. What we're getting to, essentially, is cognitive processing."

A day after the one-year anniversary of her surgery, Scheuermann is attached to Hector. Over the whir of multiple computers and fans, and in front of multiple technicians and video cameras, Hector glides left to right, up and down as Scheuermann directs him toward targets on a board.

Jennifer Collinger, lead investigator on The Lancet article and a Pitt assistant professor of physical medicine and rehabilitation, says ongoing research with Hector suggests that ever-more natural movements will continue to become a reality. The near goal of the overall project is to introduce sensation. Beyond that, researchers want to make the technology wireless and practical for use at home.

Scheuermann's motivation in all of this comes from knowing that what she does now will resonate, that Hector and the circuitry that moves him will be refined and reproduced for the benefit of others.
“I see Hector completely differently because he’s not coming home with me, he’s not there to help me with my daily life, but he will be going home with other people in the future,” she says.

Notable about Hector is not only how Scheuermann moves him, but also where she moves him. “Degrees of freedom” refer, roughly, to the directions of movement a person can make to achieve a single task. The joystick on wheelchair Sven, which Scheuermann moves with her chin, has two degrees of freedom—it can be moved forward and backward, and left to right. Hector functions with seven degrees of freedom.

More remarkably, Scheuermann gained this control within only four months. Most other projects have taken one to five years to achieve much less, says Michael Boninger, professor and chair in the Department of Physical Medicine and Rehabilitation in Pitt’s School of Medicine. “What we’ve done has taken a shorter time frame and gotten more control for a person with this physical disability than has been done before.” For that, he is quick to credit the collaborative work of the project’s engineers, doctors, technicians, and, of course, trailblazing volunteers like Hemmes and Scheuermann.

Perhaps most significant is the fact that these two are exactly the people such new technologies are designed for—yet the very people for whom past research at other institutions has not been as successful, according to Boninger. The Pitt research proves that a requisite amount of movement is not necessarily needed for optimal results.

“The fact that neither one of them has any motion in their arms meant a higher bar for success for us,” says Boninger. “We put this technology in the target population—those people who we think in the future will most benefit from a clinical product.”

Commenting on the latest research, Boninger says that Scheuermann’s enthusiasm has played a large part in Hector’s advancing success. “She’s a pioneer. She’s like an astronaut, and what she’s saying is, ‘I accept all the tasks as an astronaut that I need to take, and I’ll do anything to push this forward.’”

Scheuermann undertakes speaking engagements to “spread the message that you are more than the body you live in.” Speaking earlier this year to middle-school students at Saint Elizabeth of Hungary Roman Catholic Church in Pleasant Hills, where she graduated from high school in 1977, Scheuermann explained how she overcame her initial despair with the help of her family, her faith, and ultimately her acceptance of her circumstance. She told the students:

“I never asked ‘Why me?’ because I thought ‘Why not me?’” Later, at a press event, she remarked: “This is who I am. I’m a quadriplegic. I don’t look healthy, I don’t breathe normally, but this is who I am, and I’m proud of it.”

Her sense of accomplishment is even beginning to seep into her language and her consciousness. Recently, her sister-in-law visited the Pitt lab to observe a session with Hector. Afterward, she noted that Scheuermann hadn’t referred to Hector or Lewis and Clark. Instead, she was using singular pronouns like “I” and “my” to describe her arm movements.

Increasingly, says Scheuermann, her shiny new limb and partner electrodes don’t feel mechanized. “They’re very much a part of me and how I move.” She continues to construct a new life, a whole life, with one name: Jan Scheuermann.