

Now assist deep brain stimulation patients and families

WITH DETERMINATION AND SURGERY UCH VOLUNTEERS FORGE NEW LIVES

They've carried their fight beyond the walls of the hospital, becoming powerful advocates for disease research and education, locally and nationally.



Graham (left) and Kelsall display the programmers that regulate neuron firing and help keep their Parkinson's symptoms under control.

"When life gives you lemons, make lemonade." So goes the well-worn instruction for making something good from something bad. But whoever coined those words looks like a downright pessimist compared to a pair of University of Colorado Hospital volunteers.

Kate Kelsall and Valerie Graham both suffer from Parkinson's disease, a progressive, debilitating disorder of the central nervous system. They have spent years literally in the grip of Parkinson's, which causes tremors and muscle rigidity and severely impairs the body's very ability to move.

There is no known cure for the disease, which affects an estimated 1 million people in the U.S. But thanks to a complex neurological procedure and their own determination, Kelsall and Graham have, for the time being, at least, fought it to a standstill. And far from merely savoring their respite from Parkinson's, they're using their reclaimed lives to battle against it.

A commitment to service. The two provide tireless support for patients and family members considering, preparing for and undergoing deep brain stimulation (DBS), a procedure that uses electrodes implanted in targeted areas of the brain and a pulse generator to stimulate neurons and block the irregular electrical activity that causes movement disorders (*Insider*, February 12, 2008).

They are co-founders and leaders of a DBS support group, now in its fourth year, that includes around 200 members. They also volunteer as liaisons between patients and family members considering, preparing for and undergoing the procedure, and the hospital's DBS medical team, headed by neurosurgeon Stephen Ojemann, MD, and neurologist Olga Klepitskaya, MD.

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They've carried their fight beyond the walls of the hospital, becoming powerful advocates for disease research and education, locally and nationally. Kelsall writes a well-regarded blog about her disease. Graham coordinates activities for Colorado's 6th Congressional District on behalf of the Parkinson's Action Network (PAN), a Washington, DC-based national grassroots advocacy organization.

In October 2009, moreover, the Parkinson's Disease Foundation invited Kelsall and Graham to New Jersey for the Clinical Research Learning Institute (CRLI). The gathering aims to stimulate additional research into new Parkinson's therapies and treatments and to encourage more participation in clinical trials.

Those examples merely scratch the surface of their activities, which have brought them in touch with many other leaders of the Parkinson's research and advocacy community. And along the way, they've found time to engage in physical activities that they once assumed were distant memories.

Their accomplishments have not gone unnoticed. Last fall, Denver's Channel 7 bestowed its "Everyday Hero" award on them.

Surgical success. It's heady stuff considering the predicament Parkinson's put Kelsall, 60, and Graham, 56, in for years. Both women say they owe their present vitality to their successful DBS surgeries.

"I'd likely be bedridden without it," says Kelsall. She was initially diagnosed in 1996 after fellow Toastmasters noticed that while she exhibited no other signs of nervousness, her voice fell low and her

hands shook. Her worsening symptoms eventually forced her to depart her seven-year position as coordinator of volunteers at UCH in 2006.

Today, she says, the tremors and involuntary muscle spasms that plagued her for a decade are "minimal." The proof of that is in her legs and fingers: she's part of a dance troupe, the Rockyettes, that performs Broadway tunes. She also plays the accordion, although she quips she's not yet up to doing them at the same time.

A tough opponent. The disease forced Graham to end her nearly two-decade career as a private-practice attorney. The powerful anti-tremor medications she took caused stomach problems so severe that she required tubes in her stomach and upper intestine. Sustained muscle contractions eventually made it impossible to take more than a couple of steps without spasms.

Diagnosed in 1992, Graham says the disease first appeared in subtle ways. A tremor in her right leg tended to show up in stressful situations, such as court appearances. She loved outdoor activities, but one day as she climbed a 14,000-foot peak, she was seized by muscle tightness.

An experience both physically and emotionally painful some time later drove home her plight. Hurrying from the downtown law firm where she practiced to a light rail station to return home, her body froze.

"I was two steps from the stop," she says, "but I couldn't get on the train."

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Reluctantly, she recalls, she called her husband to pick her up. In 2002, having lost 40 pounds and her health failing, she stopped practicing law. Needless to say, she also found it difficult to keep up with the toddler she had running around at home.

“I had no quality of life,” Graham remembers. That stark fact made even the prospect of brain surgery seem palatable.

She underwent DBS in 2002, the first year the Food and Drug Administration approved it. Today, she’s doing better at keeping up with her now nine-year-old daughter and enjoying roller-skating, horseback-riding and bowling.

“These are things I thought were gone forever,” she says.

No miracle cure. Encouraging as its results may be, DBS is anything but a cinch – as both women’s cases demonstrate.

Candidates go through a lengthy evaluation process before they are selected for the procedure, which requires the neurosurgeon to drill holes in the patient’s cranium, through which they thread thin wires with electrodes that they attach to structures in the right and left sides of the brain. The wires, in turn, attach to separately implanted pulse generators, one for each side, which fire electrical signals to the targeted sections of the brain.

After the surgery, providers spend several weeks to a year with the patient programming the pulse generator to deliver the optimal amount of stimulation to the brain. Graham says the programming proved difficult in her case. A broken lead wire on the right side

required a separate surgery to replace the electronics.

In 2004, she received a referral to Ojemann, who later replaced another faulty wire. Ojemann also implanted a dual-pulse generator capable of accommodating electrical leads from both sides of the brain.

She credits both Ojemann and Klepitskaya for helping her through the difficult post-surgical periods.

“Both are terrific,” she says. “Dr. Klepitskaya gives patients realistic expectations. She reminds us that [DBS] is not a cure. But it can improve symptoms, and help decrease pain and the number of medications that we have to take.”

A partial procedure. Kelsall faced a different sort of challenge after her DBS surgery in 2005 at a Sacramento hospital. After returning home, she found her health care provider didn’t know how to program the pulse generator.

Without proper programming, the surgery could not address her debilitating symptoms, Kelsall explains. “I didn’t see anybody for about a year,” she says. “I had lots of involuntary movement.”

In 2007, however, she met Klepitskaya, who gave her a thorough evaluation, with and without medications and with the stimulation on and off. After six such sessions over the course of a year, Kelsall says, her tremors and involuntary movement tapered off to “minimal” levels.

A helping hand. The hard-won successes of Kelsall and Graham make

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them ideal choices to help Parkinson’s patients through the DBS experience. They first met in 2006 through the “friend of a friend,” Graham says. Before long, they’d started the DBS support group. Then it was on to creating volunteer positions that would allow them to work directly with patients and families through the lengthy pre- and post-surgical period.

They meet with the patients while they are still candidates – the evaluation process alone may take six to eight months – giving them brochures and their phone numbers if they need additional information.

On the day of the surgery, they meet with the patient, then wait with the family. They’re available to answer questions and

help family members get in touch with the patient’s physicians.

“We often help the families even more than the patients,” Kelsall notes.

“We formed this position in part because our husbands had nothing like this,” Graham agrees, adding she and Kelsall have so far helped about 25 patients and families through the entire process, from evaluation to surgery to programming.

The work all adds up to a schedule that would be busy for anybody. Their husbands “worry we do way too much,” Graham freely acknowledges. “But it’s hard not to do it,” she adds. “It’s more work than I ever dreamed I’d be doing, but it’s infinitely rewarding.”