

Rogers' dystonia painfully contorted her body, pushing her head and neck to the right.



# BENT BUT NOT BROKEN

by Rogers Hartmann

**Dystonia was twisting me in knots until deep brain stimulation gave me back my life.**

**B**rain surgery is not for the faint of heart. Then again, neither is living with the effects of severe dystonia.

Although the disorder is classified as a rare neurological condition that is related to Parkinson's disease, it's an equal opportunity affliction that affects men, women, and children of all ages, ethnicities and backgrounds, and estimates of those who have it are greatly underreported

and undiagnosed. According to research we've conducted at Beat Dystonia, the nonprofit foundation I started in 2009, more than 500,000 people are afflicted with dystonia in North America alone. And we believe that is a conservative estimate.

Dystonia presents itself in multiple ways. Mine first presented itself in my neck. The medical term for that brand of the disease is cervical dystonia or spasmodic torticollis. In layman's terms, it was the painful kind. But then it transformed into generalized dystonia, which meant it was no longer focal. It affected my entire body.

## Rude awakening

I was 37 years old before dystonia turned my life upside down—or sideways, to be more exact—but I didn't know that's

what it was called then, nor did the first series of doctors I visited. It was May 2008.

Having grown up in Dallas, I attended The Hockaday School and later the University of Texas at Austin. I was living in Los Angeles after graduation, working for the actress Geena Davis following the success of *Thelma and Louise*. It was the beginning of my now 25 years in the film and television business. Life was good. But one morning I woke up with what felt like a really stiff neck. It didn't go away. Very much to the contrary, it got worse. Soon, friends were asking me why I looked "crooked." Every night as I fell asleep I prayed that I would not wake up with the crick that had made itself at home in my neck, but soon it made its way down the right side of my body.

Dystonia is a movement disorder. I initially conducted my daily business, but I was constantly moving and thus in increasingly unbearable pain. Spasmodic torticollis causes twisting and tilting of the neck and torso. My variety was pushing my head and neck to the right. By the summer of 2008, my neck officially hit a 90-degree angle and some days my head was below my waistline. On those days, my perspective was literally upended.

## Painful interval

Needless to say, dystonia changed my life forever. It was exhausting, but I was determined to keep a positive outlook. As the disorder contorted me further and further to the right, I felt as if my ribs were separating from tendons and muscles. Doing the most

ordinary tasks—feeding and walking my dogs—was draining. Even brushing my teeth was a challenge.

After too many misdiagnoses to mention, things improved when I finally told my parents back in Dallas about my condition. They were dismayed but also very proactive and quickly got a referral from a specialist at UT Southwestern for me to see a neurologist at USC Medical Center in Los Angeles. That's when I finally got my diagnosis and at least knew what to call it.

Through that USC referral, I began receiving regular Botox injections, pain medications, and physical therapy. Botox is used as a nerve blocker, and the idea was to stop my muscles from twisting me in knots by silencing the signals being sent to the injected muscles. That went on for a number of years.

But after 25 years of living in LA, I'm happy to say I listened to my parents and returned home to Dallas so they could help me get back on my feet, literally and figuratively speaking.

## Home is where your neurologist is

Not long after returning to Dallas, I had the good fortune of being referred to UT Southwestern neurologist Dr. Pdraig O'Suilleabhain. In more ways than one, it felt like coming home, and the increase in my level of care was palpable.

We continued the regular Botox injections, medications, and physical therapy, but as my symptoms changed and progressed, Dr. O'Suilleabhain mentioned that brain surgery might help me. Specifically, he recommended a surgery called deep brain stimulation (DBS).

## The lowdown on DBS

"Deep brain stimulation is brain surgery, with all the attendant risks and complications," says UTSW neurologist and movement disorders specialist Pdraig O'Suilleabhain, M.D. "It's also technically challenging to steer the tip of the stimulator implant to within a millimeter or so of the sweet spot. For these reasons, it's advisable to undergo this procedure with a surgeon and hospital with training, experience, and a proven track record.

"At UT Southwestern, multiple health care disciplines meet at least monthly to discuss cases, including the neurosurgeon and neurologist, along with the cognitive psychologist, speech pathologist, physical therapist, and our coordinator. The DBS technology has been with us only approximately two decades and is a learning field. New hardware, software, techniques, and evidence challenge us to constantly work to bring the best processes and equipment to our patients. Each one, like Rogers, deserves the best individualized, patient-centered, evidence-based care. We are so proud of how she has jumped back into her life."

The surgery he was describing would involve very precisely mapping my brain and then surgically implanting a battery-operated medical device called a neurostimulator that would deliver electrical stimulation to block the abnormal nerve signals that were causing my symptoms. The device works sort of the way a pacemaker works for the heart, except for the brain. Essentially, we were talking about rewiring my brain.

The thought of having brain surgery was possibly one of the biggest fears in my life, and initially I balked at the idea. But as my real No. 1 fear persisted—suffering daily and without ceasing—I eventually came to the conclusion that Dr. O'Suilleabhain was right.

Every patient has to qualify for a DBS procedure. During that rather grueling but necessary process, I experienced a sea change of emotions, moving from fear and dread of the impending procedure to what I'd describe now, in retrospect, as giddiness. I had my stupendous neurophysiologist, Dr. Manjit Sanghera, to thank for walking me through how all of it would work. Under the most difficult of circumstances, we forged a friendship that I know will last a lifetime.

## My lucky day

By the time my qualification for the procedure was successful, I was actually excited. I believed in my crack team, led by Dr. O'Suilleabhain and neurosurgeon Dr. Tony Whitworth, Dr. Sanghera, Dr. Mae Orlino, and a host of other specialists. After hearing their plan of action that was specifically tailored to me, I didn't want a second opinion. I just wanted it done. And I wanted it done at UT Southwestern.

I chose the first available date: St. Patrick's Day, March 17, 2015.

In a way, it's hard to believe that was already more than a year ago. My team told me it would take time to know how successful the DBS was, but it did not take me long to know it had changed my life. After not too long, there were no more wheelchairs or walkers. Soon enough, I was safely driving and able to see the world again.

Once I was on my feet, I remember going into a drugstore and just being overwhelmed by all the options available. It felt like I'd been in a time capsule and had missed even that measure of freedom. It was one of many times I realized that my UT Southwestern team had really given me back my life.

**For more information about Ms. Hartmann's foundation, The Beat Dystonia Fund, visit [cftexas.org/beatdystonia](http://cftexas.org/beatdystonia).**



One year to the day after her deep brain stimulation surgery at UT Southwestern, Rogers (left) visits with her sister, Kate Hartmann, and newest niece, Harris, who was born in January at UTSW's William P. Clements Jr. University Hospital.