

## Dystonia Medical Research Foundation

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### *Living with Dystonia: Emily Blum*

As a child, Emily Blum—now age 32—grew up in the suburbs of Chicago and was active, playful, and outgoing. She ran, jumped, and skipped with no difficulties. She enjoyed playing tennis and took ballet and jazz lessons at a local dance studio. When she turned 9 years old, however, her dance teacher noticed that her left foot was slightly inverted and she was walking on the outside of her foot.

Initially doctors didn't think there was any cause for alarm, but by a year later, both feet were inverted and walking proved difficult. Thus began a seemingly endless journey to doctors, specialists and therapists but no one—including pediatricians, orthopedists, neurologists, chiropractors, and even an acupuncturist—could determine why her feet and legs were turning into such awkward positions.

By the age of 13, in addition to her inward turning legs, Emily's left leg began to kick up awkwardly and then her right leg followed soon thereafter. Walking became even more difficult and physically exhausting, and she could barely walk a mere two blocks without exerting tremendous energy.

One doctor incorrectly diagnosed her as having a muscular degenerative disorder and performed two surgeries that proved to be of no help. Frustrated himself, this doctor suggested that the problem may be psychiatric.

“To think that at age 13 I was making up these problems to get attention was inconceivable to me. I remember feeling so shocked, angry, and sad,” Emily said.

Fortunately, her parents refused to stop looking for answers and found new doctors willing to consider her case.

Finally, at age 15, six years after noticing any symptoms, Emily was correctly diagnosed at Rush Medical Center as having dystonia, a neurological movement disorder.

Relieved that her disorder finally had a name, there was little her doctors could do to relieve her discomfort. She took medications to reduce the muscle spasms, but high doses left her even more exhausted and concentrating in school was difficult.

Doctors continued to monitor Emily's progress and Emily continued on with her life as best she could. Her legs continued to turn inward and awkwardly kick up in the back. Because of these awkward positions, Emily's balance was compromised and she eventually relied on a cane to help keep herself upright.

While Emily's walking was limited, she found ways around her disability. She attended Kenyon College, a small liberal arts school in Ohio, and was able to ride her bicycle to classes, and did so even in rainy and wintry conditions. Later when she lived in Washington DC and worked at a political consulting firm, Emily relied heavily on taxi cabs and DC's extensive public transportation system.

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Emily volunteered with the Dystonia Medical Research Foundation which funds medical research and provides support for those affected by dystonia. She authored publications for children and young adults with dystonia and offered support and advice to those facing similar challenges.

“I knew I walked funny, and at times it felt like the whole world was staring at me, but I couldn’t let that stop me from living my life, going to college, working, and living independently. When I was a kid, I really held my breath for that magic pill that would take away my dystonia, but I started giving up hope and really came to terms with my disability.” Emily remembered.

That’s not to say, however, that her life was easy. Forced into a forward-bending position and putting considerable strain on her knees and ankles, Emily suffered from chronic back pain and other sore joints. She also learned to endure endless unsolicited comments from strangers about her walking, and on one harrowing evening was followed and harassed by a group of men while walking home from dinner with friends.

Emily eventually moved back to Chicago to be closer to her family and took a job at a public interest communications firm. She continued to rely on her cane, cabs, and Chicago’s elevated train to get around. The back pain, stares, and comments remained pervasive.

Shortly before Emily’s 31<sup>st</sup> birthday, her neurologist at Rush Medical Center suggested she consider undergoing a new invasive brain surgery called deep brain stimulation (DBS). DBS involves inserting electrodes into the brain that are wired to a battery pack implanted in the chest or abdomen. Electrical pulses from the electrodes enter the brain and, for some dystonia patients, helps alleviate symptoms.

Emily went home that day, spent some time researching the surgery and immediately knew this was what she wanted to do.

“I knew if there was a chance I could walk normally again, I’d take it. Brain surgery sounded drastic and scary, but I’d do anything to reclaim control of my body and have the freedom to move,” Emily said.

After the system was implanted and turned on, Emily saw dramatic improvement within 2 weeks. Within 4 weeks, she no longer needed her cane and could easily walk for miles, an activity she once thought was never possible.

For Emily, DBS has been life-changing to say the least. These days she rises each morning at 5:30 am and happily strides out into the Chicago weather—rain, snow, or shine. “Honestly, it doesn’t matter if it’s 105 degrees out or 105 below zero—I do it,” she says. “My mom always says to me, ‘You’re crazy! It’s too cold outside—why are you doing this?’ I always tell her, ‘Because I can.’”