



**DYSTONIA
MEDICAL
RESEARCH
FOUNDATION**

serving all dystonia-affected persons

Brain Surgery Allows 15-year-old Girl to Run in LA Marathon Despite Disabling Movement Disorder

Santa Clarita, CA – March 1, 2013: Three years ago, parents Marci and Steve Goldstein’s wish for their daughter Emily was that an eight-hour brain surgery would give her the ability to simply stand up from her wheelchair and possibly use her hands. The surgery was far more successful than anyone imagined: Emily is now training for the Los Angeles Marathon, without any indication that she ever suffered from dystonia, a disabling neurological disorder.

“I love running. I get so stressed out with school, if I didn’t run I would just explode,” Emily explains with a laugh. “I like to get out and explore when I run.”

Emily was a healthy, able-bodied child until age nine when her beautiful cursive handwriting began to inexplicably deteriorate and her foot started to turn inward. She soon lost control of her hands, required a wheelchair full-time, and her speech began to slur. It took two years for Emily to be properly diagnosed. Marci and Steve were beside themselves. Steve explains, “I found myself worrying, *Will she ever be independent? Will she have a boyfriend?* You want your kids to experience love and fun, and I was worried about her survival.”

Dystonia is the third most common movement disorder after essential tremor and Parkinson’s disease. Chaotic signals in the nervous system cause the skeletal muscles to contract or spasm involuntarily, causing twisting, repetitive movements as well as sustained, abnormal postures. Although dystonia is generally not life-threatening, it is a chronic disorder that causes varying degrees of disability and pain from mild to severe. There are many types of dystonia that can impact people of all ages and backgrounds.

Treatment may include oral medications, therapeutic botulinum neurotoxin injections (e.g. “Botox”), and deep brain stimulation (DBS), which is the procedure Emily underwent at age 12. Doctors drilled through her skull to implant two electrodes deep into the brain. Wires from the electrodes were snaked under the skin to pacemaker-like battery packs in her chest. The hardware is activated and settings adjusted by remote control. Impulses from the electrodes suppress the abnormal brain signals that cause the involuntary muscle spasms and postures.

The benefits of DBS are neither guaranteed nor immediate. Emily began to see subtle improvements about a month out of surgery. Within two months her wheelchair was collecting dust, and after four

months she was taking dance classes. Her symptoms are now 90% gone.

The Goldsteins are hoping Emily's participation in the LA Marathon on Sunday, March 17 will help improve awareness of dystonia, so that those who are affected have prompt access to diagnosis and proper treatment. They also wish to provide hope to other dystonia-affected families.

Marci explains, "We went two years without a diagnosis for Emily. We have to make dystonia more well-known. Especially because in some cases the earlier you do DBS the better the results. The clock is ticking. We need awareness."

The Dystonia Medical Research Foundation (DMRF) is dedicated to advancing research for improved dystonia treatments and ultimately a cure, promoting awareness, and supporting the well-being of affected individuals and families.

The DMRF can be reached at 800-377-3978 or www.dystonia-foundation.org.

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