

## Dystonia Medical Research Foundation

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### *Living with Dystonia: MORGAN GREENWALD*

18 year old Morgan Greenwald loved to dance as a kid. From ballet and jazz to acrobatics and hip hop—Morgan enjoyed moving her body freely to music. But when she was 9 years old, Morgan noticed something wrong with her left foot—it wouldn't stay flat.

As months went by, Morgan's leg progressively got worse: her ankle was sore and walking was painful. Her parents, Lori and David, figured it was Morgan's dancing that was causing the strain. Although her father, David, was diagnosed with dystonia in his youth as well, initially the family did not think it had passed on to Morgan. But during a leisurely stroll at a shopping mall, Morgan's parents were stunned at her awkward walking.

"They thought I was making fun of someone with a disability," recalls Morgan. "But I told them, 'this is how I walk now, I can't help it.'"

Morgan was taken to Emory University Hospital in Atlanta and diagnosed with dystonia in 1999.

The thought of having a disease was "upsetting and scary" to Morgan, but despite the changes to her body, she would not let that change her spirit. However, Morgan's life quickly began to change as the dystonia progressed. Doctors prescribed heavy oral medication and in 5<sup>th</sup> grade she began treatments with botulinum toxin injections. The treatments did provide some relief but there were side effects. With a petite frame, Morgan became easily tired and thirsty. Concentrating in school became challenging and Morgan, a straight-A student, noticed her grades began to slip.

Socially, Morgan had to deal with the curiosity and sometimes taunts of her classmates. She had a supportive group of her best girl friends from her youth, but the boys in her class would at times tease and call attention to her differences: Why did Morgan need to take the elevator? Why did she carry a water bottle? Why was she always so tired?

In 2001, Morgan and her family attended the Dystonia Medical Research Foundation's 1<sup>st</sup> Children and Family Symposium. There, Morgan met many dystonia-affected youth. "It was really great to meet others that were going through the same thing I was going through," says Morgan. "I've kept in touch over the years with some individuals and definitely remember some personalities."

Despite Morgan's positive spirits, her dystonia worsened each year. Walking became an extreme challenge; her left foot would drag and twist. Then Morgan noticed her hand was acting funny. Her handwriting, usually beautiful and neat, became sloppy. By 8<sup>th</sup> grade, the botulinum toxin injections stopped working completely. When Morgan reached high school, her dystonia was at its worst: she could barely walk.

"I've always taken so much pride in being a healthy person," says Morgan. "It was really hard to have the dystonia take over the way it did."

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In 2003, Morgan traveled to Pittsburgh for a special surgical procedure. A pump the size of a hockey puck was inserted into her abdomen. The computer-controlled pump dispensed medicine, called baclofen, directly to her spinal canal via a catheter. The result would be to help control her dystonic movements. Sadly the procedure did not work. Morgan and her family were heartbroken. More than 5 weeks of school were missed for the surgery, and the family was losing hope for any real solutions.

Determined, Morgan's parents continued to research treatment options. They learned about an invasive brain operation 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.

The thought of brain surgery was scary to Morgan, but she met with a doctor in Atlanta to discuss the procedure. However, Morgan still wasn't 100 percent comfortable with the idea. In December 2003, Morgan and her parents flew to New York to meet with Dr. Michele Tagliati and Dr. Ron Alterman of Mount Sinai Medical Center. Morgan felt at ease with the medical team and decided to proceed with the surgery. Morgan had the DBS procedure on February 12, 2004; she was a freshman in high school.

Two months later, Morgan was walking normally again.

Today, Morgan is enjoying life as a teenager. She works at a trendy department store, wears stylish high heels, and drives her own car. In the fall of 2007, Morgan became a freshman at Northwestern University, majoring in Radio/Television/Film and possibly seeking a business or law degree as well.

In August 2007, Morgan shared her story with young attendees at the 4<sup>th</sup> Children and Family Symposium. She encouraged dystonia-affected teens to not be afraid and pursue experiences such as higher education.

"Being able to walk again is such an accomplishment, and I am glad I have always maintained a positive attitude," says Morgan happily. "Never once did I think my dystonia would keep me from going to college or fulfilling my goals."