

Dystonia Medical Research Foundation

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Living with Dystonia: MICHAEL SHARP

18-year-old Michael Sharp once enjoyed a healthy and active life. As a young child, he played hockey and was on the swim team; he liked to run and play. But when Michael was 11, his right hand started acting funny. His fingers would curl, his wrist would twist, and writing became a challenge.

His mom, Victoria, decided to take him to a neurologist at Miami Children's Hospital where doctors performed an MRI. But shortly after that, Michael's symptoms became much worse. His whole arm, starting at the shoulder, was in pain and would twist awkwardly. In 2000, Michael was diagnosed with dystonia.

Over the next several months, Michael's arm became "stuck" in an awkward position. Then other parts of his body started developing symptoms of dystonia. When Michael was 13, he started developing severe pain in his left hip. His legs also began to hurt. It was as if his body didn't listen to him.

The last three months of his 8th grade year, he could barely move or function. He couldn't sit down in a chair, let alone a wheelchair. All Michael could do is lay down in bed or on the floor. Michael continued to attend school, but could only manage it on a part time basis. His teachers would give him school lessons orally while he lay on the floor of an empty classroom. By June 2002, dystonia had taken over Michael's entire body.

"As each part of his body started developing dystonia, it would hurt him extensively and then just twist into an uncomfortable position," recalls Victoria. "It hurt me so much to see him in so much pain."

Frustrated, confused, and in need of answers, Victoria took Michael to countries all over the world to find help for her son. He visited doctors in Europe, underwent a special physical training in Slovakia, and even went to see a spiritual healer in Brazil. Each time, Michael would see some minor, temporary improvements, but no real change.

Like many dystonia-affected individuals, Michael was prescribed heavy medication to help ease his pain. Michael also tried botulinum injections, which hurt and didn't really help. The high amounts of medicine left him drained and "in a daze." Michael doesn't have clear memories of this time, "I feel like it was all a dream, just one big blur."

In 2004, Michael's family attended the Dystonia Medical Research Foundation's 3rd Children and Family Symposium. Victoria found it to be the best experience for her family. "I gained more information over the course of those two days than I had ever learned in all these years researching and reading over the internet."

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Living with Dystonia: Michael Sharp/page 2

It was at the Symposium where they learned more 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. Victoria and Michael liked the results from the team of Dr. Michele Tagliati and Dr. Ron Alterman of Mount Sinai Medical Center and flew to New York to meet with them. In 2005, Michael had the DBS procedure; he was 15 years old.

The results were miraculous. In one month, Michael was practically straight. After continued fine-tuning of his settings, Michael regained control of his body. In 11th grade, he returned to a traditional classroom setting, joining friends and classmates who had supported and stood by him through the years.

In the spring of this year, Michael graduated valedictorian from his high school with a 4.3 GPA. This fall, Michael will start freshman year at Nova Southeastern University in Fort Lauderdale, studying finance and business. He is proud to say that he will be walking to campus.

Michael and his family are grateful for this “second chance” and Michael sees this as a new life for him. “When I saw a video of how I looked before DBS, I couldn’t believe that was me,” recalls Michael. “I never really noticed how severe my body was. I had always just thought ‘oh I have bad posture.’ I am very lucky to be where I am today.”

Michael spoke to other dystonia-affected youth at the 2007 Children and Family Dystonia Symposium. He encourages those with dystonia to pick up some sort of hobby to help get through hard times. His family wants the general public to not see people with dystonia as having some sort of “mental retardation” and pass judgments solely on appearance. “We are real people,” says Victoria.

Michael’s future plans include donating “a lot of money” towards the Dystonia Medical Research Foundation to help find a cure.