



Living with Dystonia: ELISSE LORENC

North Barrington resident Elisse Lorenc, 17, was 10 years old when she first noticed something was wrong. Her right foot pointed awkwardly inward and became tight and stiff. Then the same thing began happening to her right arm; it became stiff and twisted in awkward positions.

Elisse was frustrated with the changes to her body, but at first she did not tell her parents, hoping it would go away. However, they gradually noticed her symptoms as well and soon took her to Rush University Medical Center. Elisse was diagnosed with general idiopathic dystonia in 2000. Elisse and her parents were no strangers to dystonia. Her older brother Kevin was diagnosed with it at age 14, but her family never knew the disorder was genetic.

As the months went by, Elisse learned to cope with her disability. She continued to attend North Barrington Elementary School and then Prairie Middle School. Elisse admits going to school was “weird” at times, “I would get strange looks and questions from classmates. But I just tried to carry on with my life.”

Hoping to find some support and answers, Elisse’s family attended the Dystonia Medical Research Foundation’s 1st Children and Family Symposium in 2001.

“The symposium was the best thing that has happened to my family,” says mom, Dianne. “The Foundation really provides a support system by telling these families ‘you are not awkward or strange. We are all in this together.’”

Unfortunately, Elisse’s condition worsened each year. It hurt Elisse to swim; her muscles would ache. Walking became a challenge; she had difficulty climbing stairs. By 14, her right hand and arm were completely nonfunctional; she couldn’t write or hold a pencil. Doctors prescribed heavy medication to alleviate the pain to no real avail.

The family, especially Elisse’s brother Kevin, researched and tried many treatment options. In 2003, Kevin underwent 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. Kevin had the surgery performed at Rush with Dr. Leo Verhagen and Dr. Roy Bakay. A year later, Kevin convinced his younger sister to follow in his footsteps.

“He encouraged me to take back control of my body,” recalls Elisse.

In 2004, right after her last day of school in 8th grade, Elisse went in for the operation. Soon after, the results were immediate and dramatic: Elisse’s body straightened out. Under the care of Dr. Vergahen, it took about 6-9 months to get the settings right. A year after her surgery, Elisse took up running and joined her high school’s cross country team.

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Today, Elisse looks forward to her senior year at Barrington High School. But she still has reminders of her dystonia. Her handwriting is not perfect and she has some trouble with fast note taking; but she is grateful to be able to walk and move freely.

Elisse's future plans are to attend a university at a Big 10 school and continue to hang out with her close friends. She has dreams of becoming a nutritionist and marketing healthy lifestyles to counties in Asia and abroad.

Elisse was excited about attending the 2007 Children and Family Symposium. "I feel relieved when I see lots of people just like me," she says. "It feels good to see and talk to others who have gone what I've gone through. I know I'm not alone."