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Dealing With Epilepsy Head On

October 05, 2011 - Elyse Glickman, Jewish Exponent Feature

Shortly after the birth of her second son, Matthew, Abbey Shuster was reassured by well-intentioned friends and family that any abnormality she observed in his behavior -- such as erratic body movement -- was a passing thing.

Abbey's maternal intuition got the better of her, however; those instincts, combined with determination, led Abbey and husband, Stephen, to get a definitive diagnosis of pachygyria when Matthew was 10 months old, via tests at Children's Hospital of Philadelphia.

This rare form of epilepsy -- the disease itself is a disruption of the way the brain works -- occurs when the right frontal part of a baby's brain does not develop fully during pregnancy, resulting in a rare migrational brain disorder that inhibits movement and muscle activity on one side of the child's body.

"Matthew's situation, 'electrical status epilepsy of sleep,' is a rare form with daytime seizures as well as a marked increase in seizure activity" as registered on an electroencephalogram at night while asleep, explains Dr. Brenda Porter, who currently oversees Matthew's medications.

"Matthew looks to be asleep, but his EEG has continuous abnormalities which disrupt sleep and result in issues as varied as complete loss of the ability to understand speech to behavioral and memory and learning issues."



Matthew Shuster, 7, at play with some help from his friends

No parents are prepared for a life-altering medical diagnosis for their child; however, what Abbey and Stephen were prepared for was jumping into action to build a team of the best doctors, therapists and experts who could put their son on a path to a healthier life, and the rest of their family -- including first-born Benjamin, 13 -- into a mode where they could at once support Matthew's healing and be supportive in those efforts.

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Says Abbey: "I made a promise to Matthew that I was going to be his biggest advocate and work as hard as I could for him to have the best care and the top doctors on his case."

The Cheltenham couple fulfilled that promise: "With our commitment, he was sitting up independently at 12 months and walking with orthotics at 20 months. I threw us into all kinds of activities, such as gym class, music class and play group to exercise his motor skills."

The Shusters did suffer their share of setbacks. Having good professionals lined up (including Dr. Joyce Sapin and Dr. Gihan Tennekoon of CHOP; occupational therapists Allan Glanzman and Deb Humpf; and, more recently, Porter), nevertheless, ensured Matthew could quickly get back on track.

Besides taking care of his nutritional needs, Abbey provides nourishment for her son's soul via positive encouragement. This, in turn, has provided Matthew with a willingness to work hard with his teachers and therapists, such as occupational therapist Lisa Baum.

Matthew's disposition, and Abbey's resolve, however, was tested earlier this year when she concluded that the public school Matthew attended fell short. Through his career as a reading teacher, Stephen heard about Abington's The Center School, known for shifting the special-needs education paradigm from "learning disabilities" to "learning differences."

Especially helpful, says Abbey, was enrolling him at Ramah Day Camp this summer.

"Matthew just finished lunch and was dancing and singing to Jewish music when he suddenly fell to the ground and went into a seizure," says Abbey. "His counselor quickly got to another counselor, who then got one of the directors, Mark Levy, who, in turn, reached out to Anne, the camp nurse, who was keeping Matthew calm until medical help arrived."

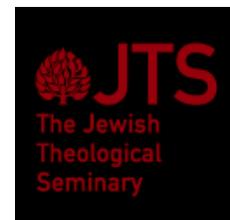
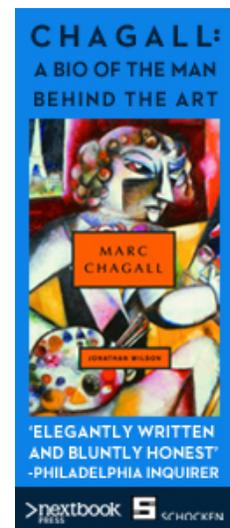
But not all institutions may be as adept at handling children with epilepsy, says Porter. "Opening up to programs that discuss epilepsy such as those put on by the Epilepsy Foundation or organizing health classes with experts to discuss epilepsy" as Ramah Day Camp does, is beneficial.

Beaming with pride, Abbey points out that Matthew, now 7, has a genuine sensitivity toward others -- as well as a marked sense of humor.

For example, when Matthew experienced the East Coast earthquake in August, he told her nonchalantly that it felt like a seizure.

For more information, visit: The Children's Hospital of Philadelphia (www.chop.edu); and the National Institute of Health's epilepsy research source (www.ninds.nih.gov/research/epilepsyweb).

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