



The Matty Fund®
Epilepsy Resource Center
Helping Others with Epilepsy
www.MattyFund.org



May, 2012



**MATTHEW SIRAVO
MEMORIAL 5K**
RUN/WALK FOR EPILEPSY
June 9, 2012

Saturday, June 9, 2012 is Matty's 5K Run/Walk for Epilepsy & "Matty's Mighty Dash" Help spread awareness and support the Matty Fund's programs and services for children diagnosed with epilepsy by creating a FirstGiving page, getting the word out and participating in this year's 10th annual race in honor of Matthew Siravo. Visit www.firstgiving.com/mattyfund to create your page/team and to register. Prizes for top finishers in 7 age categories, tee shirts for the first 300 registrants, free BBQ & free raffle for all registrants, tee shirts and medals for all Mighty Dashers. **We hope to see you there!**

Excerpts from an interesting Wall Street Journal article on April 23rd

Tobias Loddenkemper, a pediatric neurologist, works with some of the hardest epilepsy cases—the children whose seizures have been little helped by medication or surgery.

Nearly a third of epilepsy patients don't get sufficient relief from conventional drug treatments. But where advanced techniques don't help, Dr. Loddenkemper hopes a simple solution might: timing patients' medication to better coincide with their seizures.

Dr. Loddenkemper's approach seems basic. He asked his patients, or their parents, to keep seizure diaries, a standard practice. From those diaries, he noticed many patients had seizures around the same time every day, but often took the same dose of medication throughout the day. He changed their medication schedule so they took a higher dose when they most frequently had seizures. "Why give the medication in the morning if the patient isn't having seizures then?" he says. "If they are having more seizures at night, give it to them at night." Although targeted dosing isn't new, "it's slowly growing" as a common treatment, he says.

In a small study published last year in the journal *Epilepsy & Behavior*, Dr. Loddenkemper and several colleagues at Children's Hospital looked at 17 children who had seizures at night or in the early morning. The researchers varied the patients' doses to administer more of their anti-seizure medication when episodes were more likely to occur, while leaving the total dosage unchanged. After five months, 15 of the patients saw their seizures reduced by more than half, and 11 had become seizure-free. Part of the challenge in creating an individualized medication routine is determining when seizures typically occur, and patients' seizure journals aren't always accurate. Dr. Loddenkemper is working with Rosalind Picard, director of the Affective Computing Research Group at the Massachusetts Institute of Technology, to develop better ways of tracking seizures using wristband sensors that detect changes in the body's autonomic nervous system.

The sensors detect seizures about 94% of the time, says Dr. Picard. "Ideally, we'd like to use them to predict seizures, but we're not there yet," she says.

Dr. Loddenkemper also is studying other biomarkers that may be able to detect seizures, including levels of melatonin or cortisol. With children, "if you can make an impact early then they have a lifetime of freedom ahead of them," he says.

Matty's Mother's Day Drawing Contest

See attached for details!

*We are in the midst of our
Mother's Day giving
appeal. Donations to The
Matty Fund help us to
provide epilepsy
awareness, education, and
family programs to better
the lives of children
diagnosed epilepsy.*



Camp Matty July 9-12

Therapeutic horseback riding summer day camp for children diagnosed with epilepsy sponsored by the Matty Fund contact us if you would like to receive an application packet! Visit our website to learn more or to read what other families have said about their experience at camp!

The Matty Fund Epilepsy Resource Center for Children and Families
10 High Street – Suite F, Wakefield, RI

Mailing address: P.O. Box 5300 Wakefield, RI 02880

Phone: 401-789-7330 • Fax: 789-7364 • Web: MattyFund.org • Email: MattyFund@cox.net



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