



**Matthew Siravo Epilepsy Resource Center**  
**“Matty Matters”**  
*Helping Others with Epilepsy*  
[www.MattyFund.org](http://www.MattyFund.org)

April, 2010

According to the Center on Philanthropy at the University of Indiana, “changes in giving are linked to changes in the overall economy. During good economic times, giving tends to grow robustly. When the economy grows at a moderate or slow rate, philanthropy continues, although at a slower rate of growth.” While the economy has impacted non-profit organizations nationally, these are particularly challenging times in Rhode Island where families, funding organizations and non-profits have endured one of the country’s highest unemployment rates at 12.7%, growing budget deficits and most recently, historic flooding, has wreaked havoc on an already fragile economy. *We are so grateful to our funding organizations, corporate and individual donors, for your continued generosity during these challenging times. With so many competing priorities you continue to support the important work of the Matty Fund. Because of you, this spring and summer, UCB Pharma in partnership with The Matty Fund will sponsor an Epilepsy Parent Conference at the Children’s Neurodevelopment Center at Hasbro Children’s Hospital, and a CVS grant will sponsor children with epilepsy to participate in Camp Matty!*

*Thank you! -Richard and Debra Siravo*

**TOPIC: A Good “IDEA” – Reproduced from the Epilepsy Advocate** ([www.EpilepsyAdvocate.com](http://www.EpilepsyAdvocate.com))

**Epilepsy Parent Conference**  
**“Transitions”**

*A conference for parents and caregivers of children who are patients at the Children’s Neurodevelopment Center – there is no cost for participants*  
*Saturday, May 15, 2010 • 8 a.m. – Noon*

Workshops will focus on important issues that parents and caregivers face as children living with epilepsy “transition” from childhood to adulthood including:

- **School Issues** - Individual Education Plans (IEP) and 504 Plans
- **Parent and Family Support** - managing anxiety, depression, and social isolation
- **Transition to Adult Independence** – managing health and medical regime management, preparation for college and work and adulthood
- **Twenty-one and Still dependent** – planning for post school-age years, including legal issues, social security income, financial planning, trusts and insurance
- **Treatment Options** – Future for treatment, research, new medicines, surgery, ketogenic diet and alternative therapies
- **En Espanol** – Review of all workshops for Spanish speaking parents & caregivers

**Take the Lead: Three Steps to Help Your Child – A Good “IDEA”**

Students between the ages of 3 and 21, who have trouble keeping up in school may be eligible for special assistance to help them succeed under the federal **Individuals with Disabilities Education Act (IDEA)**. According to Martina Bebin, a pediatric neurologist at the University of Alabama, “students may be too tired to concentrate on their work or do their best on an exam the day after a seizure. Medication side effects can cause problems that may be less obvious to teachers than seizures. If you look at children with epilepsy as a group, they are at increased risk for academic underachievement.”

**STEP 1: Request an Evaluation:** Let the Director of Special Education or Principal know your child needs educational assistance

**STEP 2: Provide the Proof:** Review child’s medical history

**STEP 3: Develop a Plan:** Once eligible for IDEA benefits, an Individual Education Program (IEP) is created; goals are updated annually and can be revised if parents feel their child is not making enough progress



**UCB Pharma**

A UCB Pharma grant will sponsor in part an Epilepsy Parent Conference on 5/15/10!

**CVS Caremark**

A CVS Community Grant will sponsor in part children with epilepsy to participate in Camp Matty!

**Washington Trust**  
**McDonald’s**

**Heatherwood Nursing**  
**ABC 6**

**Rock n Jock Charities**  
**Belmont Market**  
**Brickley’s Ice Cream**  
**Vespa of Newport**

Sponsors for the 8<sup>th</sup> annual Matthew Siravo Memorial 5K Run/Walk for Epilepsy:

**June 12, 2010**

8:00 Registration

9:00 Mighty Dash

10:00 5K Run/Walk

