



# "Matty Matters"

Matthew Siravo Epilepsy Resource Center

Helping Others with Epilepsy

[www.MattyFund.org](http://www.MattyFund.org)

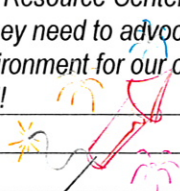
June, 2010

According to the Epilepsy Foundation, "the number of people living with epilepsy in the U.S. is almost equal to the number living with Parkinson's disease, cerebral palsy and multiple sclerosis combined, yet epilepsy remains one of the world's most misunderstood conditions." *We established the Epilepsy Resource Center to provide support and resources to families living with epilepsy to ensure parents have all the information they need to advocate for their child; to increase awareness about the realities of epilepsy to ensure a welcoming, safe and happy environment for our children at school, home and play.*

*We hope you find this information helpful!*

*--Richard and Debra Siravo*

**TOPIC: "Independent Day"**



## Camp Matty July 12-July 15

Turning Pointe  
Therapeutic  
Horseback Riding  
Facility

Applications  
789-7330



## Rock'N'Jock Charity Concert 8-8-10

Crowne Plaza,  
Warwick

Doors Open: 6:00 PM

Concert: 7:00 PM

Bring your friends!

## Matty's Golf for Epilepsy 9/18/10

Richmond Country  
Club

Registration form  
available on-line  
Print and mail-in with  
check

The beginning of summer is a good time to start working with your teen to prepare them for later transitions to college, work and ultimately independence. The joys and temptations of youth are challenging for most parents and children, but for parents of children living with epilepsy there are unique concerns as "our" children think about driving, college, work, relationships, and yes, even leaving home! Then there are the worries associated with making good choices when peer pressure impacts teen decision making – substance abuse, staying out late, remembering to take medications just to name a few – this is enough to think about!

The recent Matty Fund Epilepsy Transitions Workshop in May, 2010 at the Children's Neurodevelopment Center at Hasbro Children's Hospital included workshops to provide parents with tools and resources to help prepare teens to make good choices, take responsibility for their health and become happy independent adults. As with everything, planning, preparation and communication are critical to successful transitions. Resources included checklists to encourage and guide communications relating to self-advocacy, social & recreational issues, independent living skills, school and work.

Here is one tool that some Matty Fund parents have already started to use to help teens start to take responsibility for their medications. This idea was generated from the "Transition to Adulthood Independence" workshop facilitated by Dr's. Julie Roth and Susan McLaughlin .

Try "Independent Day"- pick a day in the week that your teen takes responsibility for those tasks that you normally handle for them. For example, on "Independent Thursday" your teen is responsible for their medications, after you have trained them of course! They learn to become responsible for everything from calling in the prescription and picking it up to taking the correct dosage. Family neurologists often get calls from a college student who is away from home, and has run out of medication for several days – not a good scenario. "Independent Thursday" is an important first step to ensure your teen becomes a young adult responsible for their own health. It was also suggested that students away from home get hooked up with a neurologist local to the college or school to manage medications from afar.

### "Teen Tips"

- Know the medications you are taking, their names, when to take them, how to call them in
- Make sure you know your health insurance and how to get a referral
- Talk to your doctor about an appropriate age to transition to an adult doctor
- Be your own best advocate!

