



We have some very exciting news regarding research that was funded, in part, by the Matthew Siravo Undergraduate Awards in Epilepsy Research in 2010. The research proposal of two Brown University undergraduates, Hannah Johnson and James Belarde, was selected by the Matty Fund Medical Advisory Board and Board of Directors to study the role of the molecule "putrescine" in the brains of tadpoles subsequent to a seizure. This research is of particular importance because tadpoles share similar brain chemistry to humans, and the findings could be significant in developing drugs to treat young children with epilepsy. The findings of their research were highlighted in an article distributed nationally on March 6, 2011 titled, "New role for an old molecule: protecting the brain from epileptic seizures." The article has been posted to several national education and epilepsy websites. The Matty Fund is very proud to have funded research that has such future potential in the understanding and treatment of epilepsy in children.

-Richard and Debra Siravo

TOPIC: Understanding and Preparation Matter!

The Caregiver -The Child -The Doctor

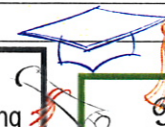
The relationship between parents/caregivers, children and doctors is very important in living with and treating epilepsy. This relationship impacts quality of life issues for the child and caregiver as well as effective treatment of this chronic condition. Like any relationship, each comes to it with their own perspective, concerns and desired outcomes. One study on the quality of life in childhood epilepsy suggests there may not always be agreement between parent and child on quality of life issues. Parents tend to underestimate their child's quality of life viewing it more negatively than their child does. This may be due to a number of variables; for example, children and youth with active epilepsy tend to keep their feelings private, and parents base their opinions on what they observe because the child tends to display the negative and keep the positive more to themselves. Parents, because of their life experiences and cognitive abilities, think and worry more about the future for their child and how they will cope through life with a chronic health condition, while the child focuses more on their daily quest for "normality". (Epilepsy & Behavior 14 (2009) 407-410)

In a survey of 257 patients and 5 clinicians, 4 physicians and a nurse practitioner who treated those patients in Ohio's outpatient epilepsy clinic between March, 2009 and February, 2010, "patients as a group were far more concerned with memory loss than were practitioners, and practitioners were more concerned about unexpected seizures than patients." (Medical News Today, March 9, 2011)

Make the most of your visits with your Neurologist

Preparation is the most effective tool to get the most out your visits with your child's Neurologist or Pediatrician. Knowing that your concerns and desired outcomes may be different than that of your child and doctor can help you prepare to ensure that your Neurologist is well informed about your child and you get all your questions answered. As a parent/caregiver, you are in the best position to track your child's physical and emotional health. Your doctor will appreciate your preparation too! Just some tips:

- Keep a seizure journal
- Note changes in your child's behavior and mood
- Document side effects and effectiveness of medications
- Note feedback from teachers and school concerns
- If appropriate, ask your child if they have any questions or concerns before the appointment to include on your list
- Compile a list of questions and concerns and bring them with you
- During the visit, write down your doctor's answers & recommendations



Matty's Scholarship

April 1st application deadline!

If you know a Rhode Island high school senior living with epilepsy planning to go to college connect them to the website!

Matty's Easter Egg Hunt!



When: April 16, 2011

Time: 11:00-1:00 PM

Matty's Place Playground
Hazard School

Matty's 5K Run/Walk

June 11, 2011



MATTHEW SIRAVO
MEMORIAL 5K
RUN/WALK FOR EPILEPSY
JUNE 11, 2011

www.MattyFund.org for all event and program details!

Gifts to the Matty Fund allow us to expand programs to help more families

To make a donation visit www.MattyFund.org or mail your donation to P.O. Box 5300, Wakefield, RI 02880