



THE Matty Fund®
Epilepsy Resource Center
For children and families



December 2012

As the New Year approaches, I reflect on all that I have to be thankful for in the past year. I will take this opportunity to thank all of you for connecting with The Matty Fund, as it reminds me each day how support for families with children diagnosed with epilepsy and seizure disorders is needed. We look forward to being here to continue to provide services and programs to your family. **Wishing you a joyous holiday season and a happy & healthy 2013 -Deb Siravo**

Read the entire story in the
December issue of ...

FamilyCircle

Helping Families Affected by Epilepsy by *Andrea E. McHugh*

When Matty Siravo was diagnosed with epilepsy at 11 months old, Debbie and her husband, Richard, were frantic to learn everything they could about the condition. "Initially, I didn't even know what it was," recalls Debbie. When Matty was 5, Debbie and Richard took him to Boston for a two-part surgery that was supposed to alleviate his debilitating seizures. While recovering from the first operation, Matty suffered a severe seizure and passed away soon after, on May 11, 2003—Mother's Day. The outpouring of support reminded Debbie that Matty's passing affected more than just herself, her husband and their boys, Joe, now 23; Steve, 21; and Chris, 19. She decided to establish The Matthew Siravo Memorial Foundation, an organization that provides resources and opportunities for children and families living with epilepsy. By July, she and Richard had registered the nonprofit, written a mission statement and created a board of directors. Richard then set up a workspace in the basement, which became the newly nicknamed Matty Fund's headquarters, and together they identified their first goal: to build a special-needs playground at Matty's school. On the one-year anniversary of their son's passing, the Siravos led a ribbon-cutting ceremony to open Matty's Place, which features padded flooring and specially made swings as well as a wheelchair-accessible playhouse. Spurred on by their success, the Siravos started planning the Snow Angel Ball, named after Matty's love of making snow angels. On a cold winter night in January, hundreds of supporters dined and danced the night away while collecting \$50,000. Raising awareness about epilepsy and keeping Matty's memory alive became more than a passion for the Siravos. Debbie's next goal was to bring families together at a central location for emotional comfort and to share resources. In 2007 they moved the foundation to an office space where they offer free programs like Discovering My Epilepsy, an ongoing support group for children, teens and their families. Looking to help kids with epilepsy bond in a lighthearted environment, in 2009 Debbie organized Camp Matty, an annual, free, four-day summer therapeutic horseback riding camp for children with epilepsy. Volunteer medical staff are on hand to ease fears, answer questions and treat seizures. "It's good for the kids to be involved in something where they can have fun and parents don't have to worry," says Debbie. What started as a trio of fundraising events nearly a decade ago has blossomed into the only epileptic resource center of its kind, with four paid positions plus countless unpaid interns and volunteers. But Debbie's ultimate goal is to establish resource centers across the country. "We know how important it is to have that support. Without that it is so hard to navigate the medical and educational systems," Debbie says. "But this is also how we honor Matty, by assisting other families who are going through the same thing we did. And all the smiles I see on the faces of the children we help is Matty's smile coming through to us."



**Discovering My
Epilepsy®
Family Support**
Upcoming meetings:

Tue. 12/18 in Warwick

**Wed. 1/2 in Lincoln*
(with Music Therapy)**

Tue. 1/15 in Warwick

Please RSVP to
401-789-7330 or
Jessie@mattyfund.org

Snow Angel Ball



Saturday, Jan. 26th
Crowne Plaza, Warwick
*To support
The Matty Fund's
Epilepsy Resource Ctr.*

Thanks to the generosity of an event sponsor, a limited number of tickets will be made available at no charge to Matty Fund Families. Please Contact the Matty Fund if you are interested in space at this sponsored table!
401-789-7330
www.MattyFund.org

MATTY HATTY.....Raising Epilepsy Awareness in Schools!

The Matty Hatty Dance-A-Thon is a statewide epilepsy awareness program created by the Matty Fund for elementary and preschools. This program teaches seizure protocols and encourages a welcoming, safe and productive school experience for children with epilepsy. **Please encourage your child's school participate in this program!**

Contact The Matty Fund for more details • (401) 789-7330