



Richard and Debbie Siravo keep the memory of their son alive while helping others.



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. A neurological disorder that causes a wide spectrum of seizures, epilepsy can develop at any age (nearly three million Americans are living with the disease) but appears most often in children and teens. 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 Siravos’ close-knit Wakefield, Rhode Island, community helped by running errands and preparing meals. 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. Joe, an avid runner, organized a fun run with friends a month after Matty’s passing to honor his brother. As Debbie watched 250 parents and kids participate, 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. Not long after, they formed a medical advisory board.

Richard then set up a workspace in the basement, which became the newly

In Remembrance

Debbie Siravo created The Matty Fund to help families affected by epilepsy—and to honor her late son’s life.



The Matthew Siravo Memorial 5K Run/Walk for Epilepsy averages 400 participants annually and raises approximately \$20,000 every year.

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. A community collaboration, the playground was built with the help of local volunteers from the family's church and students from Richard and Debbie's alma mater, the University of Rhode Island.

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 took a leave of absence from her job as a middle and high school Spanish teacher, and eventually she resigned to become a full-time volunteer. Soon after, Richard, who had been an independent insurance adjuster, became the executive director.

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, and workshops in which parents learn how to manage health care costs and work with their kid's school to develop an Individualized Education Program.

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 3- to 21-year-olds. 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. Last year 20 kids attended, and returning teens are granted leadership positions as junior camp counselors.

In spring 2010, The Matty Fund hosted a free Epilepsy Transitions Workshop, a one-day seminar for nearly 80 families and caretakers at the Children's Neurodevelopment Center at Hasbro Children's Hospital in Providence, Rhode Island, where 15 volunteer experts addressed everything from new medications and treatments to issues facing epileptic teens as they transition to adulthood, such as getting a driver's license. Based on the positive feedback, Debbie aims to create a similar workshop in webinar format for families beyond the New England area.

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."

➔ Learn more at mattyfund.org.