



July 20, 2008

Dear Friends,

The 4th Annual Cape Cod Strollathon is coming up! We are in the process of securing items for our Silent Auction. **We are wondering if you would be willing to donate one item to help us raise as much money as possible for the International Rett Syndrome Foundation with the hopes of finding a cure for Rett syndrome.**

Event:

The Cape Cod Strollathon, set for Saturday, September 20, 2008, is a fun filled, family event, held in South Yarmouth, MA. It includes entertainment, food, silent auction, and a beautiful 3-mile stroll along the water. The event, chaired by Jennifer and Justin Endres, (parents of a five year old daughter, Jillian, diagnosed with Rett syndrome) has raised over \$400,000 for research in the first three years! Each year approximately 600-800 participants attend, including approximately 30 Massachusetts girls and their families affected by Rett syndrome.

What is Rett syndrome?

Rett syndrome is a genetic neurological disorder that occurs almost exclusively in females. Rett syndrome becomes apparent after 6-18 months of early normal development. It results in a regression that leads to lifelong impairments. It is often misdiagnosed as autism or cerebral palsy and has no cure. Those inflicted with this disorder have no purposeful hand use due to their repetitive hand movements, hand wringing and mouthing. Speech is lost, seizures develop and scoliosis occurs. Irregular breathing patterns, hyperventilation and breath holding take place. More than half of the girls and women lose their ability to walk. Those diagnosed with Rett syndrome require maximum assistance with even the most basic daily activities. **A girl is born every five hours with Rett syndrome.**

What is the International Rett Syndrome Foundation (IRSF)?

IRSF is the largest and most comprehensive non-profit organization for families and friends, scientists, professionals and others concerned with Rett syndrome. The mission of IRSF is to fund research for treatments and a cure for Rett syndrome while enhancing the overall quality of life for those living with Rett syndrome by providing information, programs and services. IRSF was formed in July of 2007 through the merger of the Rett Syndrome Research Foundation (RSRF) and the International Rett Syndrome Association (IRSA).

[Why help now?](#)

Since the discovery of the gene that causes Rett syndrome (1999) and recent research that proves the theory of reversibility in mice (2007), we now have an unprecedented and historic opportunity to fund crucial new research. Rett syndrome is the only autism-spectrum disorder with a known genetic cause. It is often characterized as a "Rosetta Stone", a key that will help unlock treatments and cures for other disorders including autism, schizophrenia, Parkinson's, anxiety and autonomic nervous system disorders.

[Who is Jillian Endres?](#)

Jillian, or Jilly as we call her, is a five year old little girl who lives in South Yarmouth. She was diagnosed with Rett syndrome at the age of 17 months. Despite the fact she cannot walk, talk, or use her hands, she is full of life and personality. Her laugh is infectious and her smile brightens up the darkest of days. She has taught her family and friends about courage, bravery, compassion, strength, and love more in her short 5 years of life, than most people do in a lifetime. Jilly has brought the community, family, and friends closer together. We all share a common goal. We want to find a cure for Rett syndrome for Jilly, as well as for the thousands of girls and women affected by this devastating disorder world-wide.

<p><i>Please fill out the enclosed form and mail in the enclosed envelope by September 1, 2008.</i></p>

We sincerely appreciate your consideration!

With gratitude,
Jennifer and Justin Endres