



June 15, 2008

Dear Friend,

The 4<sup>th</sup> Annual Cape Cod Strollathon is quickly approaching! The Strollathon will be held on September 20, 2008. The event promises to be fun filled and family oriented... it truly will be enjoyed by all! There is something for everyone at the Strollathon! Come enjoy costumed characters, a moonbounce, face painting, food, live entertainment and more! Not only will you enjoy yourself, but you will be supporting a very worthwhile cause!

***Will you consider becoming a Captain at our Strollathon? Are you willing to commit to forming a team of friends, family members and acquaintances and encourage them to take part in our Strollathon? If so, please mail the enclosed form so we can plan accordingly! We are thrilled to have your consideration!***

You will find helpful information below:

**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?**

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.

*When we planned our first Strollathon in 2004 we did not know what was in store...the event has raised over \$400,000, each year over 1,000 people participate, over 30 Rett families have become involved, research has moved along in the right direction and hope has been given to all those affected by Rett syndrome! We look forward to continuing this amazing event...but we need your help!!!*

### **Questions?**

Contact Jennifer Endres at: [capecodstrollathon@yahoo.com](mailto:capecodstrollathon@yahoo.com) or 508.394.3011

**Please mail the enclosed form no later than July 18, 2008**

**All Captain Packets will be mailed to you by July 31<sup>st</sup>.**

Most sincerely and with many thanks,

Jennifer and Justin Endres  
Chairs of the Cape Cod Strollathon



**IRSF**  
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