



August 15, 2009

Dear Joe,

**On October 22, 2009, the 9<sup>th</sup> annual Festival of Food & Wine to benefit the International Rett Syndrome Foundation will be held at the State Room in Boston.** Thanks to the generous support of family, friends, and the local and national business community, this event has raised more than \$3 million for research since its inception. Tremendous scientific progress has been made in a short time.

With funds raised last year, IRSF was able to fund a promising clinical trial currently being initiated by the Rett Syndrome Clinic at Children's Hospital Boston. The trial, developed in conjunction with researchers and scientists at MIT, promises to improve – and even possibly reverse – the progressive course of Rett Syndrome. Slated to begin this fall, this clinical trial offers hope where there hasn't been any and could provide the answers – and treatment – we've all been seeking for far too long. We were thrilled to be able to support this exciting initiative.

In addition, there are many other promising research proposals on the horizon that still need funding. Since Dr. Adrian Bird's 2007 landmark announcement that **Rett Syndrome is reversible**, scientific minds have been turning with new fervor. So it is with great hope and enthusiasm that we ask you to **make a donation to this year's live or silent auction**.

The relief of our girls' suffering is our primary concern. It's what motivates us as parents, doctors and researchers. Girls and women with Rett Syndrome are victims of one of the cruelest biological accidents imaginable, but we can see light at the end of the tunnel. You can be a part of the momentous time in the lives of those suffering with Rett Syndrome. Your help will be appreciated more than you can imagine.

I have enclosed an Auction Donation form for your use. If you have any questions, please contact me at 781-740-6221 or jane.joyce@comcast.net.

Thank you for your continued support.

Sincerely,

Jane Joyce, Auction Chair

*Rett syndrome is the number one cause of severe neurologic impairment in girls. It is genetic, but it is not hereditary, meaning it can strike any family regardless of race or ethnicity. There are nearly 5,000 known cases of Rett syndrome in the United States, and it is considered in research circles to be the Rosetta Stone disorder to unraveling the mysteries of more widespread neurologic disorders such as autism, mental retardation and schizophrenia. Rett symptoms begin to manifest between the first six to eighteen months of life and eventually incapacitates the affected child so she cannot survive without constant assistance. The disorder robs her of speech and hand function, and can also cause seizures, respiratory, orthopedic, gastrointestinal and sleep complications. Despite these challenges, she is most often emotionally and socially vibrant, enjoying relationships and being a part of her community. There is no cure or real treatments – yet.*