

Annual Appeal

Dear Friends,

This year has certainly been an exciting one for the International Rett Syndrome Foundation community: over \$2 million was spent on research grants, the 25th Annual Family Conference had record attendance, more phone calls were answered and more literature was distributed than ever before. For the very first time, clinical trials start early next year and a new Research to Reality Campaign was launched, the cornerstone of which is a \$1 million challenge grant from the Pioneer Fund of Denver, CO. All of this has become possible - because of you and your past support - that is why we are reaching out to you again and asking you to support our annual appeal and help us continue our mission to find treatments and a cure for this cruel disorder that is Rett syndrome.

The following story, written by the mother of a daughter with Rett syndrome, validates why you do what you do...

October 23, 2009 marked the third anniversary of diagnosis day for my five-year old daughter, Grace Reddington. Overnight, Grace transformed from a very active and happy child to a tortured little girl showing signs of regression and waking at night screaming for hours.

We have four other children who need us, yet Grace began to require almost 100% of our time. Still having no answers, I decided to search for one on my own; I instantly recognized something eerily familiar about the description of this obscure disorder called Rett syndrome.

The relief of "what it is" was replaced with shock at the breadth of "what it was". The wind was instantly knocked out of me; I was numb! I remember hearing the words pouring from my mouth as if I was also hearing them again for the first time... Rett syndrome, no treatment, no cure, devastating, loss of everything, no wedding, no first kiss, no more healthy little girl. It was one gigantic, tragic piece of news to have to give your husband; the urgency, to do something now was overwhelming.

We had to tell our parents, our family, our friends... over and over again, explaining something I couldn't grasp myself. I remember lying in bed hearing my husband sobbing and putting my hand on his back, only triggering him to apologize to me for crying. We tried to act normal for the sake of our other children. I remember hiding in the bathroom, just to allow myself a few minutes to cry. We asked our children to hope for Grace.

We turned our worst fears into our greatest strength. Rett syndrome wasn't going to conquer or cripple us. It mobilized our family, our friends, and our community. We became involved with IRSF, a supportive community of people who help our girls and offered hope for the future. Hope is turning into a realistic possibility for our girls and that is why I am writing this today. Our family has become warriors for the girls who suffer from Rett syndrome. Being a warrior means fighting hard for our girls whenever and where ever we can. For our family this includes raising awareness and the desperately needed funds for research.

The Race for Grace Strollathon for IRSF was born the night Dr. Adrian Bird's reversal study was released in February 2007. It became more than a fundraiser; it is a faith-raiser and a way of living. We live our lives as fully as we can to spread awareness about Grace and all the girls and women suffering from Rett syndrome. They are silent, but we hear them. They are immobile, but move mountains with their faith. They are destined to suffer but they are not alone. We suffer with them. We share their pains, their joys, their losses and their hopes for a cure. - Tara Reddington, mom

Through the work of IRSF volunteers, the organization is launching a new Research to Reality Campaign. The

cornerstone of this campaign is a million dollar challenge grant. This grant builds on all of the fundraising we currently do and rewards us by matching all of the new money we are raising up to \$1 million. IRSF is using the new money to double the amount we spend on research over the next three to five years. The knowledge we have gained over the last ten years is ready to move into the next phase; and that is why your support today is so critical...

All of your previous support has brought us to where we are today. We thank you and appreciate the sacrifices you've made. Your work, your time and your financial support are having a greater impact than you can possibly imagine. At IRSF, over 90 cents of every dollar is spent on programs. IRSF's four-star Charity Navigator rating speaks to our high standards of ethics and excellence in peer reviewed research projects and practices and our family support programs. IRSF has the same solid focus as Tara and that of every other parent, family member, or friend of a child with Rett syndrome: a Cure; and until that day, providing Care and Treatment. That is what drives every project and endeavor that we do.

We need our work to succeed and we need your support to continue. Please see your way to giving \$100, \$250, \$500 or more. Every gift matters no matter how large or small and any first-time gift or gift higher than the average over the last two years will be matched by the Pioneer Fund. If you've never given before 2009 is the best year to start!

Please continue your support for the search for a cure while we care for those touched by Rett syndrome. Our families are counting on us. Your help is our hope.

Sincerely,

Stephen E. Bajardi

Executive Director