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IRSF INTERNATIONAL RETT SYNDROME FOUNDATION

RETT Gazette

THE YEAR AHEAD

Research to Reality: Funding Progress

Your work is paying off... all of the events... Strollathons, galas, golf tournaments, bikes, bakes and requests for funds are producing results; Research to Reality is happening because of you. The Rett community is a true success story - a group of families working on a rare disease that is ready to reach the tipping point, a place where events and circumstances all converge to change everything.

The Research to Reality Campaign is our new effort to re-energize our commitment to research. Chaired by Clint Black, supported by his brother Kevin and an army of volunteers, IRSF wants to change the research agenda again by putting basic science to work and bringing it to the bedside, putting smart research advances to work for people touched by Rett syndrome sooner than we could have ever hoped.

The cornerstone of this effort is the Pioneer Fund's $1 million challenge grant. The intent of the gift is to encourage new giving and increase gift giving from an already strong base of support.

Sponsorship Levels

Pioneer	$100,000 and above
Patron	$50,000 - $99,000
Benefactor	$25,000 - $49,999
Sponsor	$10,000 - $24,999
Partner	$5,000 - $9,999
Friend	$100 - $4,999

This lead gift was secured by IRSF chair Kathryn Kissam. Even if our search for a cure leads to a treatment, our job won't be done until there is a cure for everyone to realize for their children. The criteria for Pioneer Fund matching dollars are straight forward; all net money from new events held after October 23, 2009 can be matched; all events with a documented two year history will have all new net money greater than the two year average matched. New donors, who make outright gifts and lapsed donors, those who haven't given in the past two years and resume outright gifts, will be matched dollar for dollar.

The match for current program expenditures primarily research, is exhausted after the first $500,000 raised. The remaining $500,000 match is for endowed funds; the income from it is for "must do, or high payoff but risky" research. Our hope and expectation is that the endowment will meet the special needs of donors who can take advantage of endowed gifts. It is important we recognize the matching gift is just the beginning of our effort to double the amount of research we fund every year from now on, and we achieve that goal over the next three to five years.

New tools are available to volunteers on the IRSF web site for strollathons; organizing teams, making donations and organizing campaigns can all be secured on line; making it easier and less costly to hold an event and fundraise. The Phantom Tea and Care and Cure Cafe can be accessed online and will require very little, if any, paper; donations can be made on line as well. IRSF will be actively seeking corporate support to augment our fundraising efforts as well as special foundation support for our programs. In addition, with the help of IRSF board members, we will be aggressively pursuing social marketing on the Web to locate more Rett families, secure more funds and pursue our public policy efforts to build larger and more partnerships with the government and private sector interests to support the Rett movement.

Our small yet dedicated semi-virtual staff will continue their efforts to provide support to the families that reach out to us; to support your fundraising efforts and to help everyone whenever we can to make this coming year the most successful yet in our mission to provide care while searching for a cure. IRSF has continued to maintain its stellar 4-star Charity Navigator rating, with over 90 cents of every dollar going to programs; and these are solid numbers.

We will go all out in 2010 to build the base and make the Research to Reality campaign a huge success. At the December board meeting the directors committed to a fundraising goal of $6M for this year. We expect to see exciting research results, the start of clinical trials, and more new research to be funded than in any previous year, all to continue our momentum towards treatments and a cure.

We hope many of you will attend the exciting **26th annual family conference** planned for May in Colorado Springs, CO. Volunteers and staff have been hard at work to make the 2010 "Ain't No Mountain High Enough" family conference the best and most highly attended in IRSF history.

Remember: You are part of a great success story. This year we will build on our success by putting more of the essential building blocks in place that will bring us closer to arresting and reversing Rett syndrome. Your work has been at the heart of all of this, all of it very much needed and greatly appreciated. It is an honor to be part of your team. The IRSF staff stands ready to help you in any way we can as you develop your local fundraising strategies.

On behalf of the board and staff of IRSF please know we will work vigorously to exceed your expectations toward our common goals and aspirations... your support fuels our hope... thank you.

Stephen Bajardi
Executive Director