

Research to Reality

Funding Program

A Campaign to Accelerate Treatments and Reverse Rett Syndrome

The IRSF Research to Reality Campaign

- Seeking an incremental \$5million in research to create near term breakthroughs
- Chaired by country music sensation, Clint Black – who lost his niece to Rett syndrome

The Research to Reality Campaign

- Working with the NIH and SAB, IRSF has established short and medium term strategic goals and funding priorities for the next three to five years
- Facing an unprecedented demand to fund high quality research initiatives
- IRSF is launching Research to Reality, an aggressive campaign designed to accelerate the research progress

IRSF is launching the campaign with a lead gift of \$1 million – a matching gift challenge from the Pioneer Fund*

Cure Ahead – Where will dollars go?

IRSF is committed to increasing annual support for research to intensify the speed of scientific discovery and convert new findings into real progress towards a treatment and an eventual cure!

- Translational research initiatives
- Drug discovery and development
 - Assay development, cell based screening, animal testing
- Disease modifying therapies like read through compounds, nerve growth treatments, and treatments targeting Rett symptoms
- Development of outcome measures to prepare for clinical trial testing

Grant Funding Mechanisms

- **“HeART”** (Help Accelerate Rett Therapeutics). Small, 1-year seed grants for cell based assay development (a critical bottleneck) for in vitro screens (cell based) and for follow on in vivo screens of candidate therapeutics.
- **“ANGEL”** award mechanism (Advanced Neuro-therapeutic Grants of ExcellLence) to provide targeted funding of specific/solicited programs with focus on pre-clinical/clinical testing and drug development – using revised/renamed G.E.A.R. grant.

How does the match work with the Pioneer Fund? What income is eligible?

- All net income from new events held after 10/23/09
- All increases in net income from events held after 10/23/09 that exceeds the average of the last two years, for example:
 - Example 1: Your event in Oct 2008 raised net \$10,000. Your event in Oct 2009 raised net \$15,000. The average of the 2 events is net \$12,500. So every net dollar raised over \$12,500 in Oct 2010 will be eligible for the match. If you raise net \$20,000 in Oct 2010, then \$7,500 is eligible for the match ($\$20k - \$12.5k = \$7.5k$), so you will actually have helped raise a total of \$27,500 for Rett syndrome in 2010, and \$52,500 overall!
 - Example 2: You held an event in 2007 and 2008, but not in 2009. You will calculate your 2-year net average in the same way as Example 1 using the figures from 2007 and 2008.
 - Example 3: You held your first-ever event for IRSF in 2009. The terms of the Pioneer Fund require a 2-year giving history; a one year history is ineligible.
 - Example 4: You held your first-ever event in 2008, but did not host the same event in 2009. The terms of the Pioneer Fund require a 2-year giving history; a one year history is ineligible.
- All new donations (out right gifts-non event revenue) received after 10/23/09
- All increases in donations that exceed the average of the last two years

I have a Care+Cure page for my child on the IRSF website. Will these donations count towards the matching gift campaign?

If they meet the criteria for the match, yes.

I used to donate but haven't lately, will my gift be considered new?

- If you haven't given before or if you haven't given a gift in the last two years it will be eligible for the match
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Is the match good for up to 1 million dollars?

- Yes! The first \$500,000 of the match will be used for current research uses, the next \$500,000 will be used to create an endowment fund to insure we have "extra" money for breakthrough cutting edge or "must fund research".

Will this new money raised be used for research in addition to what we fund already?

Yes, all net new money will be used for research and will support our goal to *double* our current research funding over the next 3-5 years; the goal this year is to fund over 3 million dollars, that is almost a million more than last year.

What else will we be doing to increase research money?

IRSF has started a new public policy program in Washington DC. We intend to mobilize the Rett community to:

- lobby the NIH for increased funding of Rett research
- lobby the FDA to fast track any new medicines and to approve new clinical trials
- work with the CDC on new programs of professional education, standards of care and support for families and patients.

How will this affect IRSF's commitment to support families?

IRSF is committed to family support programs; our stated mission is research, family support, advocacy and awareness. The Research to Reality Campaign is specifically an effort to grow critical research dollars, which will be greatly jump-started by the generous Pioneer Fund matching gift program. The foundation will not divert committed resources from other programs or services. It is expected this campaign will attract new interest to Rett syndrome, which will directly and indirectly allow us to grow and strengthen all of our programs and services.

What happens when the match is met?

- IRSF intends to use the campaign to build our fundraising capacity. We expect our increased funding of research will directly influence the growth of NIH Funding to Rett syndrome research as well.

How can IRSF help me raise money? What help do you have if we haven't done this before?

- IRSF has implemented new online tools for fundraising such as letter writing, acknowledgements and campaign organization all utilized online. These are no cost tools at the disposal of everyone who wants to do our traditional fundraisers like Strollathons and new fundraising like recruiting friends and neighbors to solicit online gifts. IRSF staff and volunteers are ready and available to help anyone needing fundraising advice or support.

How will we know how we are doing?

- Look for regular updates on rettsyndrome.org and for reports and updates in our newsletter.
- Since October 28th 2009, the start of the match, IRSF has received \$311,000 in matchable donations!!

We are already 1/3 of the way to \$1million – we can meet this challenge with your help!

*The Pioneer Fund, a private family foundation created by the late Helen M. McLoraine