

IRSFlash: 2.8.2011

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IRSF Welcomes New Board Member: Eric Diamond

Eric Diamond, an active volunteer in the Rett syndrome community, has been elected to the IRSF board. Eric lives in New Jersey with his wife Robin and two daughters, one of whom has Rett syndrome. "We are very pleased and thrilled to have such a committed and active volunteer join our board" said chair of the board, Kathryn Kissam, "and all of us look forward to working with Eric in creating a world where Rett syndrome is a memory." Eric works in New York City as a trader at Goldman Sachs. Please look at the IRSF website for a complete bio on Eric Diamond.

Investigator Spotlight: Rajiv R. Ratan, MD, PhD of Winifred Masterson Burke Medical Research Institute, Weill Medical College of Cornell

IRSF's HeART grant Award recipient, Dr. Rajiv Ratan of Winifred Masterson Burke Medical Research Institute, Weill Medical College of Cornell utilizes a screening strategy that aims to identify drugs that modulate MeCP2 stability or synthesis in human cells. The project behind his grant titled "Role of MeCP2 in the maturation of neocortical GABA interneurons and critical period of plasticity" involves a method operating on the same principal as a dimmer light switch.

[Learn more about Dr. Ratan and his research](#)

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Featured Angel: Leev Novel

Dear all, my name is Leev which means "life" and "protection." I am three years old. It is true that I am full of life, often happy, other times more observant and sometimes angry. But every day I prove to fight Rett syndrome.

I attend the local nursery where I made friends and even have a boyfriend who is sweet, but sometimes surprises me by giving me a big cuddle.

I love babies and I ask about them, so sometimes my caregiver brings me to the babies' room so that I can look after them. At the nursery I use a walking device that enables me to move around independently.

[Learn more about Leev and her family](#)

Register Today!

"Cheers to Research to Reality"

May 27-30, 2011*

The Boston Park Plaza Hotel

Boston, MA

The IRSF annual education conference is the only one of its kind where parents, caregivers, extended family, educators, therapists, physicians, case managers – indeed every advocate for someone with Rett syndrome – come together from all over the world, under one roof, to learn the most current recommended care and advocacy strategies for every stage of life and hear first-hand the latest in research and clinical trials.

This is an investment in YOU!

Join us in Observing Rare Disease Day February 28th

To raise awareness of rare diseases and the need for safe, effective treatments, people around the world will join together to observe Rare Disease Day on February 28, 2011. NORD is coordinating this project in the U.S., and is inviting all patient organizations, caregivers, researchers and companies developing orphan products to join in this observance. The purpose is to focus attention on rare diseases, the challenges encountered by those affected and the importance of research to develop diagnostics and treatments. Read more about how you can participate: www.rarediseaseday.org

MECP2 Duplication Syndrome Family Conference

Texas Children's Hospital and Baylor College of Medicine released the MECP2 Duplication Syndrome Family Conference brochure. Parents of boys with MECP2 gene duplication may want to consider attending. The Conference will be held in Houston, TX, May 25-27, 2011. If you would like to receive a PDF copy of the conference brochure, please contact Dick Sobsey at dick.sobsey@ualberta.ca

Missouri Legislature Debates to include Rett Syndrome in Autism Insurance Bill

Joyce Opinsky, IRSF Regional Representative for Missouri, was instrumental in getting this legislation passed. We asked Joyce to comment on her involvement: "As the Missouri legislature debated an autism insurance bill for the second year in a row, we wanted to make sure that Rett syndrome would be included. The bill used the current DSM definition to define autism spectrum disorders (ASD), which we know will soon be changed to exclude Rett syndrome. Also, a local neurologist involved in the process had recommended that Rett syndrome be specifically excluded from the bill. So we worked with friends in the autism community and presented testimony to legislators to include Rett syndrome by name to the definition of ASD used in the bill. So even when the DSM is changed, Rett syndrome will still be included in the legislation. Effective Jan. 1, this new law should help provide additional coverage for girls and women in Missouri with Rett syndrome."

Be Bold. Get Active. Give Hope.

Take a BOLD action this year and help us fight for a cure for Rett syndrome! Set your 2011 resolution NOW to get involved and make a difference. Our Rett angels take on each day with a brave face as they patiently wait for us to find treatments and a cure. IRSF has hit the ground running this year – make this the year you get ACTIVE and give HOPE to thousands. Take part in a local IRSF Strollathon, host your own IRSF Signature Event or create an online fundraising page! IRSF makes it easy to get involved. Your help is our hope; your help is their hope.

Are you holding an event in 2011? Fill out this form and send back to Jenni Grammer at jgrammer@rettsyndrome.org

Henhouse Coffee Supports Rett Syndrome & You Can HELP!

IRSF is excited to announce a new fundraising partnership with Henhouse Coffee. Henhouse Coffee is a Colorado based specialty coffee roasting company. You can now buy your premium coffee AND contribute to finding a cure for Rett syndrome without ever leaving your home!

To place your order for Henhouse Coffee and to lend support to IRSF, go to www.Henhousecoffee.com. From there, you can browse the website to learn more about Henhouse, the art of coffee roasting and discover which brew is right for you. When you've decided, click "Buy Online" and make your selection. BE SURE to click on IRSF as the recipient of your coffee order under "Support a Partner Organization". The coffee will be shipped directly to your door and IRSF will receive a donation of \$3.50 per 12 oz. bag.

The Spirit of Giving!

Try out our NEW IRSF App, a safe, free and revolutionary approach to online giving.

Every purchase and search you make online can generate money for IRSF. Please download The IRSF APP. We can now raise money from big online stores such as Amazon, Skype, EBay and thousands of others at no cost to you. Simply download the IRSF App using Firefox, Internet Explorer or Chrome and continue searching and shopping as usual. You can choose to install the app as a toolbar or as a small icon . It only takes a minute to download. If you do not like the app, it takes one click to uninstall.

Help us spread the word among your family and friends. We need you now more than ever!

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Upcoming Events

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Educate Yourself

[Annual Family Conference](#)

[Memorial Day Weekend, May 27-30, 2011*](#)

[The Boston Park Plaza Hotel](#)

[Boston, MA](#)

[12th Annual Rett Syndrome Research Symposium](#)

[June 26 – 28, 2011](#)

[The Lansdowne Resort and Spa, Leesburg, Virginia.](#)

Pharmacological Treatment of Rett Syndrome with IGF-1

After Phase 1 determines the safety of IGF-1 therapy for girls with Rett syndrome, phase two will conduct a 20 weeks long treatment program in which the girls are seen monthly.

Rett Syndrome Research Moves Even Closer to Reality

IRSF approved additional Translational Research grant awards in December, bringing 2010 to a close with a record \$2.7 million in funded research grants out of a total direct research spend of \$3 million.

Rett Syndrome Natural History Study

We have several enrollment openings for the Chicago spring data collection April 9-10, 2011.

Basic and Translational Research Programs Grants Available for 2011

Basic Research Program

(Regular Research Grants & Post-doctoral Fellowship Awards)

Translational Research Program

(HeART and ANGEL Grant Awards)

NIMH's Top 10 Research Advances of 2010

In a recent post by the Director of the National Institute of Mental Health (NIMH) 10 research breakthroughs made in 2010 are changing the way we approach the development of treatments for nervous system disorders like Rett syndrome.

Educators Network

Attention All Parents! Get your daughter's Rett-related educators registered to become part of this Network! Simply download, personalize and share this letter with anyone you feel would benefit from IRSF's new Educators Network.

Join the Educators Network

[Click here to download our Educator Invitation Letter \(for parents & Caregivers\)!](#)

Silent Angels

By Ayme Sanchez

Download the new single, Silent Angels, by Rett supporter and singer/songwriter Ayme Sanchez. Ayme co-wrote the song Silent Angels in honor of our Rett angels.

Download the song now from the IRSF iFan store on Facebook.

The Combined Federal Campaign

CFC Code Number: 11046

The 2011 CFC campaign continues through November. If you have a fair happening near you, contact the office at 1-800-818-7388 for materials.

United Way

While we don't have a UW code, many will accept donor directed donations. Write our EIN – 31-1682518, name & address on the donor designation line.

Donations

Please send to P.O. Box 706143 Cincinnati, OH 45270-6143.

Matching Gift Program

Check if your company has a matching gift program. Send forms to cleighton or by fax at 513-874-2520

Mail

Please send to 4600 Devitt Drive Cincinnati, OH 45246.

"It is surprising how much you can accomplish if you don't care who gets the credit."
~ Abraham Lincoln

