

IRSFlash: 7.21.2011

July

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A Message from IRSF Executive Director, Stephen Bajardi

IRSF Scientific Symposium, June 26-28, 2011

The International Rett Syndrome Foundation hosted an exceptional 12th Annual Rett Syndrome Symposium from June 26th through June 28th, 2011 at the Lansdowne Resort in Leesburg, Virginia. The goal of the symposium was for researchers to share results of their latest research projects among peers and widen the knowledge base of Rett syndrome science. As a lay person, I was fortunate to hear very compelling Rett syndrome research presentations among which there were many. The quality of the participants was outstanding; every session, from morning till late into the evening was at full attendance. There are very dedicated, committed people working on Rett syndrome and I wish every member of the community could have seen this. There are young, new scientists being nurtured and mentored in the field by some of the most accomplished Rett syndrome scientists. Their protégés are smart; eager and full of energy and ambition to succeed in reversing Rett syndrome. Our thanks and gratitude goes out to this year's symposium co chairs: Dr. Yi Eve Sun, PhD, UCLA, and Dr. James H. Eubanks, PhD, Toronto Western Research Institute. They did a superb job organizing the program and selecting the presenters. Dr. Alan Percy, MD, UAB, a highly recognized authority on Rett syndrome known to many of you and Dr. Thomas Südhof, Stanford University, whose research interests focus on understanding the molecular mechanisms contributing to neurological disorders, gave the Keynote addresses at the symposium. A record-breaking 135 members of the scientific and medical community from the US, Germany, UK, Canada, Israel, Australia, Italy, Japan, Singapore, and Ireland participated to discuss the latest advancements in Rett syndrome and MECP2 gene research and therapeutic strategies.

IRSF takes great pride in reporting that this year's event was attended by a long list of distinguished guests from NIH and the field of Autism Spectrum Disorders. These experts engaged in highly stimulating discussions on the regulation and function of the MeCP2 protein, the neurobiology and pathophysiology of Rett syndrome, the status of animal and human models of Rett syndrome, as well as therapeutic strategies and treatment of RTT. The remarkably talented individuals presenting at this year's symposium, many of who embarked on their research careers with IRSF grants and fellowships, reported significant progress in their work. A wide array of research was presented at this year's symposium, and all of the conference talks and poster sessions were attended at full capacity from early morning until late evening.

The notable and novel topics discussed at this year's symposium were:

- Use of stem cells to study Rett syndrome mechanisms and treatments (Qing Chang, Wisconsin; Jim Ellis, Toronto; Alysson Muotri, UCSD; Alesa Renieri, Siena; Yi Sun, UCLA)
- Use of histone deacetylase (HDAC) inhibitors as potential therapeutic agents for treating Rett syndrome (John Christodoulou, Westmead; James Eubanks, Toronto; Alan Kozikowski, Illinois; Yi Sun, UCLA)
- Genetic components that contribute to the pathogenesis of multiple Autism Spectrum Disorders (ASDs) other than Rett syndrome (Maja Bucan, Pennsylvania; Mark Daly, Harvard; James Sutcliffe, Vanderbilt)
- Role of glia (neuronal support cells) in the progression of Rett syndrome (Daniel Lioy, OHSU)
- Role of MeCP2 protein needed in adult neuron function (Helene Cheval, Edinburgh; Christopher McGraw, Baylor)
- IGF-1 clinical trials in Italy (Daniela Tropea, Trinity)
- Identification of genes that can modify Rett syndrome symptoms (Monica Justice, Baylor)

The meeting was underwritten for IRSF mainly through the Pepsi Refresh Project which was won in October 1st, 2010 through the sheer community voting power of families, friends, and researchers interested in reversing the symptoms of Rett syndrome. We also wanted to thank partial sponsors such as Optronics, Pfizer, PsychoGenics and the International Foundation for CDKL5 Research.

We left the symposium invigorated, encouraged and reassured; Rett syndrome research is moving ahead. We look forward with anticipation to the high-quality Letters of Intent being received now through August 15th for IRSF's next round of Basic and Translational Research grant applications and review.

Stephen Bajardi

Executive Director

IRSF

## Happenings

### Help IRSF Earn Up To \$2,500 from Vivint

Vivint.givesback PROJECT generously offers special matching period Thursday and Friday, July 21-22 only to give IRSF a guarantee to earn extra funds no matter what. Donate up to \$50 per person to IRSF through our voting webpage and Vivint will match that donation dollar for dollar up to \$2,500. This means that with your donations, IRSF can earn up to \$5,000.

### Vivint Voting Awareness Cards Sheet

### Vivint Voting Half Page Flyer

## How to Donate

Simple. Click on the donate button on IRSF's Gives Back Project web page. Once you have clicked on the button, you'll be taken to a page where you can enter the amount you want to donate, and your credit card billing and address information. And don't worry—it's a completely secure process. This will allow you to donate directly to IRSF and have your donations matched by Vivint. It has never been easier to earn money for the charity closest to your heart.

## How to Vote

The International Rett Syndrome Foundation is competing in the vivint.givesback PROJECT. Cast your DAILY Facebook vote for IRSF EVERY DAY from June 14th through AUGUST 27th. You can vote for ONE CHARITY PER DAY! The charity that earns the most overall votes will then be awarded \$250,000. The remaining charities that earn the most from each of the regions will each receive a \$100,000 donation! Vote and share EVERYDAY!

## Sign up for DAILY EMAIL REMINDERS

[Click here to learn more about the project](#)

Can I vote if I am not a U.S. citizen?

Yes. Everyone with a Facebook log in can participate in the voting process.

Can I vote if I'm not on Facebook?

Unfortunately, this voting competition is run solely on Facebook. We are aware that not everyone utilizes Facebook, but hope that you might still support us by spreading the word via email, phone, etc. to all of your friends and family who do use Facebook and ask them to vote daily. You can still be an key part of this competition just by vote-raising for IRSF.

Clinics!

Please learn more and become a Location Site Chair to join and support Dr. Sasha Djukic, Director, Tri-State Rett Center at Montefiore Rett Center in New York, in her efforts to create a ground-breaking, unified Rett syndrome awareness event around the world on October 15, 2011.

Featured Angel: Ashley Fry

Hello. My Name is Ashley Fry. I am 31 years old and have Rett syndrome. My family thinks I am here to teach a different kind of love. To me, it's just love. After developing normally until 18 months, I started regressing. None of the doctors in Houston knew what was wrong with me. So, Mom and Dad took me to see Susie and Bears Kaufman at The Option Institute and integrated a program at home of one-on-one positive play which encouraged me, made me feel good about myself, and gave me lots of attention.

[Learn more about Ashley and her family...](#)

## Fundraising and Hope Raising...

Over the years, IRSF volunteers, parents, caregivers and advocates have used fundraising to do more than raise crucial research funding – it has helped instill hope in the community, and has helped those with loved ones suffering from Rett syndrome to heal. As a volunteer-driven Foundation, IRSF prides itself in supplying their dedicated volunteers with the skills, materials and support they need to make their fundraising successful.

Over the last 10 years the momentum being built in the community is unmatched. The evolution of the IRSF fundraising program is proof that hope does drive many and getting involved is contagious. **THIS IS THE YEAR TO TAKE ACTION!** Many of you already have planned fundraising events – are they listed on the IRSF calendar? If not, please fill out this form and email to Jenni Grammer at [jgrammer@rettsyndrome.org](mailto:jgrammer@rettsyndrome.org). Also check the website calendar for events in your neck of the woods! IRSF events are growing and growing. Do you have an idea for an event and need help getting started? That's what the IRSF Staff is here for! Reach out to us, let us help you. Contact the IRSF office at 1800-818-7388 (RETT) to ask questions, get information and answers or if you just need help brainstorming.

Your help is our hope. Get involved!

Each Month IRSF will Provide you with a Fundraising Idea!

These ideas can be used throughout the year to keep the fundraising going and keep your community involved! Many of the Fundraisers we are going to share can be put together fairly quickly and are easy to do!

Cool off this summer with a Lemonade Stand for Rett! Many families across the country have turned this long time summer tradition into a fundraiser for IRSF. Our partners at DotGain Solutions, Inc. created the artwork for the cups, signs and fliers so everything you need to advertise and get your stand up and running is ready to go! All you need is the lemonade, cups, donation jars and a good salesgirl/boy! Enjoy this fun and refreshing idea with the kids on a hot summer day – get the whole neighborhood involved! Click here to download the one page “how to” and the “Stand For Rett” logos and artwork! Check out the McMahan family's lemonade stand last summer! They set up shop right in their front yard and raised over \$2,000!

A Glance @ Rett

Join a Support Network

Find your Regional Rep

Shop

Friend us on Facebook



Follow us on Twitter

Past Issues

Tell a Friend

Upcoming Events

Casting 4 A Cure Fly-Steamboat, CO

Annual OH/KY/IN Family Picnic

8th Annual IRSF Charity Golf Classic

2nd Annual NJ Golf Outing

8th Annual Spike Rett

An Evening With Angels: Night At The Oscars

5th Annual SRSA Conference

2nd Annual Dani's Drive For A Cure

Natural History Research Study - NJ X

Recent scientific articles related to Rett Syndrome

Recent Publications

iPS cells to model CDKL5-related disorders

MeCP2 Is Critical within HoxB1-Derived Tissues of Mice for Normal Lifespan

Support Rett Syndrome

NEW: State Facebook Pages!

Some of your Regional Representatives have created state Facebook pages! The mission of these pages is to connect the families of each state impacted by Rett syndrome in a place where many of you already are – FACEBOOK! Utilize your state's page to chat about Rett syndrome issues, share in the excitement of IRSF events and connect with

individuals near YOU. This page will be primarily run by you, so feel free to post and comment as you'd like. IRSF will moderate as needed; however YOU decide how to best use this page for your state! Search for your state's page by "(State) IRSF Rett Syndrome Families." You may have to request to join the page before you can start posting!

Find out if your state has a page! Here are a few:

[Alaska IRSF Rett Syndrome Families](#)

[California IRSF Rett Syndrome Families](#)

[Connecticut IRSF Rett Syndrome Families](#)

[Florida IRSF Rett Syndrome Families](#)

[Iowa IRSF Rett Syndrome Families](#)

[Nevada IRSF Rett Syndrome Families](#)

[New York IRSF Rett Syndrome Families](#)

[North Carolina IRSF Rett Syndrome Families](#)

[Pennsylvania IRSF Rett Syndrome Families](#)

[Rhode Island IRSF Rett Syndrome Families](#)

[Virginia/DC IRSF Rett Syndrome Families](#)

[Washington IRSF Rett Syndrome Families](#)

[The Rett Gazette](#)

[Don't receive the Rett Gazette?](#)

[Check it out online!](#)

[Sign up to receive the Rett Gazette](#)

[We NEED YOUR Reviews](#)

If you love helping us fight for a cure for Rett syndrome then tell the world! You have an exciting opportunity to help us make an even bigger impact in our community. Charity Navigator has partnered with GreatNonprofits to enable people to share their stories about nonprofits that have touched their lives!

Please help us raise visibility and support by posting a review. All reviews will be visible to potential donors and volunteers.

[It only takes a few minutes! Go now!](#)

## Henhouse Coffee Partners with Rett Syndrome!

You can now buy your premium coffee AND contribute to finding a cure for Rett syndrome without ever leaving your home!

Visit [www.Henhousecoffee.com](http://www.Henhousecoffee.com), browse the website to learn more about Henhouse, the art of coffee roasting and discover which brew is right for you, choose your blend, click "Buy Online" and make your selection. BE SURE to select IRSF 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!

Use our 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.

## The Foundation

## 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 "EIN - 31-1682518, IRSF, 4600 Devitt Dr, Cincinnati, OH 45246" 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 [lhayden@rettsyndrome.org](mailto:lhayden@rettsyndrome.org) or by fax at 513-874-2520

## Mail

Please send to 4600 Devitt Drive Cincinnati, OH 45246.

## Rett Quote

"What lies behind us and what lies before us are but small matters compared to what lies within us."

~ Ralph Waldo Emerson

IRSF is the world's leading private funder of basic, translational and clinical Rett syndrome research, funding over \$24M in high-quality, peer-reviewed research grants and programs to date. Annually, IRSF hosts the world's largest gathering of global Rett researchers and clinicians to establish research direction and priorities while exchanging ideas and the most recent information. IRSF is the most comprehensive non-profit organization dedicated to providing thorough and accurate information about Rett syndrome, offering informational and emotional family support and stimulating research aimed at accelerating treatments and a cure for Rett syndrome and related disorders. IRSF has earned Charity Navigator's most prestigious 4-star rating. To learn more about IRSF and Rett syndrome, visit [www.rett syndrome.org](http://www.rett syndrome.org) or call IRSF at 1-800-818-7388 (RETT).



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