

IRSFlash: 5.17.2011

MAY

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HELP IRSF WIN \$500,000 FROM CHASE!

IRSF has the chance to win \$500,000 from the Chase Community Giving Competition AND WE NEED YOUR HELP! Thanks to you, IRSF won \$25K in Round 1! As a finalist in the top 100 charities in Round 1, IRSF has advanced to Round 2 (the final round) for a chance to win up to \$500,000 – that's in addition to the \$25K awarded in Round 1!

CAST YOUR ONE TIME VOTE FOR IRSF ON FACEBOOK BETWEEN MAY 19-25th!

*Please note that you will have to “like” the Chase Community Giving Page and “allow” the app to access your profile in order to vote.

Chase Community Giving is a program that allows users to vote for local charities that matter most to them. By participating, users will help Chase direct corporate philanthropy dollars to eligible organizations. Round 2 voting will last

one week, beginning on May 19, 2011 and ending at 11:59 PM EST on May 25, 2011. Each person has 5 votes to cast for the Top 100 winners from Round 1. You can see how many votes you have remaining at the top of each page. Also, the Advisory Board will be granting an additional \$500,000 to select charities in the Top 100 (see below).

HOW CAN I HELP VOTE RAISE FOR THIS COMPETITION?

- Add this to your Email signature!

- Help IRSF Win up to \$500,000!

Cast your one-time Facebook vote

between May 19th—25th, 2011.

Vote & Share TODAY!

- Repost or "share" IRSF's daily reminder Facebook posts to your own FB and Twitter pages.

- Email your contacts:

- Help IRSF Win up to \$500,000 from Chase!

Cast your one-time Facebook vote for IRSF between May 19th-25th!

Vote & Share TODAY!

HELP IRSF WIN \$500,000 FROM CHASE! IRSF has the chance to win \$500,000 from the Chase Community Giving Competition AND WE NEED YOUR HELP! Thanks to you, IRSF won \$25K in Round 1! As a finalist of Round 1, IRSF has advanced to Round 2 (the final round) for a chance to win up to \$500,000 for Rett syndrome!

The Chase Community Giving program allows users to vote for charities. Voters will help Chase direct corporate philanthropy dollars to eligible organizations. Round 2 voting will last one week, beginning May 19 & ending at 11:59 PM EST on May 25, 2011.

Cast your 1-time vote for IRSF Today!

Please Note: This voting competition is hosted solely on Facebook. In order to vote, you must have a Facebook Profile,

must “like” Chase Community Giving and allow the “app” to access your profile.

Thank you for your support!

Call 1-800-818-7388 for questions

- Pass out flyers and/or awareness cards (attached). at: school; your workplace; at social, recreational, sporting events; stores and local places of business and more!

- Download flyers

Download pass around awareness cards

- Carry your iPad or wireless laptop the week of May 19-25 and encourage people to vote and share on Facebook in real-time. EVERY VOTE COUNTS!!

CAN I VOTE IF I AM NOT A U.S. CITIZEN OR UNDER 18 YRS OF AGE?

Yes, voting is open to all those who have Liked Chase Community Giving and who follow the Official Rules Spring 2011.

Want to Know More...

IRSF Boston Conference: 1 Week Away

There's still plenty of time, it's not too late to register and make travel plans for IRSF's annual education and awareness conference in Boston May 27-30, 2011. Don't miss out on this unique opportunity to attend almost 40 unique sessions on specific Rett-related care, treatments, and research. With expert speakers, exhibitors and attendees from all over the world, you can't afford to miss this one-of-a-kind event. Learn more at www.rettsyndrome.org/conference.

Can't attend in person? Sign up for the Saturday webcast sessions!

Your webcast registration offers you real-time virtual attendance to the Saturday sessions, plus continuous on-demand replay for 90 days after the event, all for only \$125 USD. Sign up here!

One webcast attendee made an event out of it last year, and you can too! Organize your event for Saturday May 27th, or if the time zone doesn't work for you, host your gathering a week or so after the conference on your own time schedule. Here's what one parent said of last year's webcast:

"The response was great! We got together at my church, I provided lunch, dinner, and childcare. Parents, a school PT, a teacher, an aide, a behavioral specialist and the children. People were educated, relationships developed and girls and their families have a roadmap!" - Kara D

This year's webcast program is as follows:

Saturday Webcast Broadcast during EASTERN TIME,
MAY 28, 2011

SESSION

SPEAKER

7:30am

Understanding RTT and other MECP2 Disorders

Alan Percy, MD, Director UAB Rett Center at the University of Alabama Civitan International Research Center

8:30am

Parents' Experiences with Genetic Testing for Rett syndrome

Christine Delaney, MS, Genetics Counselor

8:45am

IRSF Welcome Address

Kathryn Kissam, IRSF Board Chairman, and Steve Bajardi, IRSF Executive Director

9:15am

Current State of Translational Research

Tony Horton, PhD, Chief Science Officer, IRSF, Jeffrey Neul, MD, PhD, Baylor College of Medicine, and Omar Khwaja, MD, PhD, Director Rett Syndrome Program, Children's Hospital Boston

10:00am

Keynote Motivational Address: "YES YOU CAN"

Dick Hoyt of famed Team Hoyt

10:30am

Refreshment Break – webcast paused

10:45am

What Goes Right with Her Brain

Aleksandra Djukic, MD, PhD, Director, Rett Syndrome Center, Albert Einstein College of Medicine at Montefiore

11:30am

Communication at All Ages

Susan Norwell, MS Ed

12:15pm

Lunch break – webcasting paused

1:45pm

Sibling Panel

Brian Skotko, MD, MPP, Clinical fellow in genetics, Boston Children's Hospital

2:30pm

Neurology: Epilepsy

Ann Marie Bergin, MB MD, BCH, BAO, Epilepsy Specialist, Rett Center, Children's Hospital Boston

3:00pm

The Importance of Therapies

Donna L. Nimec, MD, Pediatric Physical Medicine & Rehabilitation Specialist, Children's Hospital Boston

3:30pm

Refreshment Break – webcasting paused

3:45pm

Endocrinology

Ingrid A. Holm, MD, MPH, Director, Phenotyping Core, Program in Genomics, Divisions of Genetics and Endocrinology,

Children's Hospital Boston

4:20pm

Gastroenterology

Kathleen Motil, MD, PhD Pediatrician and Gastroenterologist, Blue Bird Rett Center BCM, TCH

5:00pm

Well Child and Adult Care Overview

Jane Lane, BSN, RN, University of Alabama and IRSF

Research

Investigator Spotlight: Dr. Monica Justice, Baylor College of Medicine

Dr. Justice from Baylor College of Medicine received IRSF's second ANGEL Grant Award last year for her project titled "Developing new therapeutic targets for amelioration of Rett Syndrome from the identification of genetic suppressors in mice." This project is backed by strong scientific evidence that suggests that Dr. Justice's discoveries will have applications for identifying therapeutic targets. This year Dr. Justice will Co-Chair a Session at IRSF's 12th Annual Rett Syndrome Symposium in Leesburg, VA.

Learn more about Dr. Justice and her research.

A \$1.4M Award Shines a New Light on Rett Syndrome

IRSF funded researcher, Dr. Yi Eve Sun was recently awarded \$1.4M for a study focusing on Rett Syndrome in stem cells.

Dr. Sun, a UCLA based Rett researcher who will co-chair IRSF's 12th Annual Rett Syndrome Symposium was awarded the \$1.4M grant as part of a program designed to help move stem cell research from the laboratory bench into the clinic. Dr. Sun's new project will develop new ways to monitor the connectivity and function of neurons by engineering two types of neurons from normal stem cells, and a stem cell model of Rett syndrome. Her team is currently developing a novel cellular model of Rett that can be controlled by a light-dependent switch. They aim to study the fate of these cells by transplanting them into mice to better understand neural communication – comparing normal and diseased human neurons. This model will provide another tool for researchers to find ways to correct neural dysfunction with new treatments.

Dr. Sun is Associate professor of psychiatry and biobehavioral sciences at the Semel Institute for Neuroscience and Human Behavior at UCLA, and of molecular and medical pharmacology at the David Geffen School of Medicine at UCLA.

For more on this story click [here](#).

IRSF's 12th Annual Rett Syndrome Symposium to take place Sunday, June 26th – Tuesday, June 28th 2011 in Leesburg, Virginia is at full capacity!

We're excited to report that we have experienced a record interest in attending this year's meeting--especially from the international community.

Next year IRSF will host the 7th World Congress on Rett Syndrome to take place June 24th - June 28th, 2012 in New Orleans, Louisiana. This very important, global meeting will bring together speakers and luminaries in the field of Rett syndrome together with families, IRSF staff and a host of other colleagues and professionals. Please lookout for further communication on this meeting as the details become available.

[Read more...](#)

Happenings

Featured Angel: Victoria Calabrese

Hello, my name is Victoria Francesca Calabrese. I was born November 11, 2004. My friends call me Tori and my Mom calls me her angel.

When I was 7 months old, doctors were concerned with my low gross motor skills and referred me to the Infants and Toddlers program. Physical Therapy was started and by 9 months old I still was not making significant progress with my gross motor milestones, so I was referred for further treatment and testing.

Learn more about Tori 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. 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!

Autism Speaks Announces New Science Funding

Autism Speaks is pleased to announce its first research grants of 2011 totaling more than \$1.4 million. One of the projects, the result of a Suzanne and Bob Wright Trailblazer Award, is a cutting edge study on gastrointestinal issues, which affect many children and adolescents with autism. Read more about the other funded studies [here](#).

-e-Speaks, April 15, 2011

Morgan's Wonderland

By: Clifford Fry, Chairman, Family Advisory Board

The hands! They are so similar in spirit to the hands that are such a part of Rett syndrome. They are not clasped, for they are reaching to the sky for a nearby butterfly -- hands of hope and beauty. This is what one sees when entering Morgan's Wonderland, which is the first amusement park in the USA, and I suppose the world, designed for the handicapped.

[Read More...](#)

The Rett Gazette

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Past Issues

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Upcoming Events

Samantha Corpus Golf Tournament

2nd Annual Raisin' The Roof For Rett

2nd Annual Ella Foard Golf Tournament

Ella Foard Charity Golf Classic

8th Annual Golf Outing - Boston

Annual Family Conference

Memorial Day Weekend, May 27-30, 2011*

The Boston Park Plaza Hotel

Boston, MA

Recent scientific articles related to Rett Syndrome

Habituation without NMDA receptor-dependent desensitization of Hering–Breuer apnea reflex in a *Mecp2*^{+/-} mutant mouse model of Rett syndrome

In the News

[Treatment of Rett Syndrome - How to Treat Symptoms](#)

[Role of MeCP2 in Regulating Synapse Function and Behavior](#)

[Role of MeCP2 \(Methyl CpG-Binding Protein\) during replication](#)

[Atlantic Health Hospitals - Treating Rett Syndrome](#)

[Rett Syndrome - Nursing Link](#)

[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

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, 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 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 lhayden@rettsyndrome.org or by fax at 513-874-2520

Mail

Please send to 4600 Devitt Drive Cincinnati, OH 45246.

Rett Quote

"Only he who can see the invisible can do the impossible."

~ Frank Gaines

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.rettssyndrome.org or call IRSF at 1-800-818-7388 (RETT).

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