

IRSFflash: 8.25.2011

August

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A Message from IRSF Executive Director, Stephen Bajardi

What Can YOU Do To Get Involved Today?

Dear Rett syndrome community,

I hope all of you are having a good summer. The staff and volunteers of IRSF have been working over the summer months to prepare a full calendar of events and activities for this fall event season in order to raise awareness and funds for Rett syndrome.

The Clint Black Public Service Campaign, IRSF's major public awareness initiative, is on track. We expect to distribute 15, 30 and 60 second TV and radio PSA's to over 210 viewing areas in the United States. Virtually every community will be contacted. The launch has been planned so that the ads are played during October Rett Syndrome Awareness Month. This is a great opportunity for the community to increase awareness of Rett syndrome as well as help IRSF connect with new families and supporters. It is a community wide project and everyone can participate by using the online tools we will provide to contact local stations. Please make yourself available to your local radio and TV stations for interviews. We will kick off October Rett Syndrome Awareness Month in the northeast with the 2nd Rally for Rett- THE TODAY SHOW on September 30th.

There is a full menu of activities this fall in advocacy and fundraising. The Family Advisory Board is contacting the governor's office in each state to secure a proclamation establishing October as Rett Syndrome Awareness Month. This successful project has resulted in close to 30 proclamations in years past and we look forward to seeing many more this fall.

Events season is in full swing; there is a jam-packed calendar of Rett syndrome Strollathons planned throughout the country; the Ohio/Kentucky/Indiana Strollathon is one of the oldest and largest strolls. It will be held on September 17th. Also, Clint Black will perform a live concert in Houston as part of the Spending Time Ending Rett Texas stroll-fishing-golf event on October 20th. Boston will hold its 11th annual Festival of Food and Wine event on October 20th. There are special events planned such as HER Night, HER Knight, The Phantom Tea and The Care and Cure Cafe all of which focus on October Rett Syndrome Awareness Month. There are special "how-to" tools online for fundraising events of all sizes available. Check the IRSF calendar on the website and speak to your regional representatives for events happening in your area.

Rett syndrome fundraisers aren't the only thing growing. Scientists working on Rett syndrome never stop their work; the Research Review Committee will convene this fall at the Kennedy Krieger Institute to review a second round of research grants to be awarded by IRSF. Also, IRSF will co-sponsor a scientific workshop with the National Institute of Neurological Disorders and Stroke this September. The workshop will look at symptoms of Rett syndrome in mice that are found in people. The goal is to standardize pre-clinical animal studies so that all RTT investigators approach the problem the same way using a standard method of measurements to monitor change and improvements in symptoms. This kind of work is vital to moving clinical trials forward in Rett syndrome. The Natural History Study also has a full calendar of traveling clinics this fall. This project has been essential to providing uniform standards of care to the girls as well as gathering essential data on Rett syndrome.

The backdrop to all of these events and activities is the feeling, based on facts and expectations, that we are going to have an exciting year in research. We expect to see major advances toward a new round of clinical trials to reverse symptoms as well as significant advances in scientific information to understand Rett syndrome.

We look forward to working together this fall and winter on fundraising, family support and advocacy. We will take positive steps forward together to make life better for families and children with Rett syndrome.

Stephen Bajardi

Executive Director

IRSF

Research

The SMART Library Now Available for Research

Researchers who study Rett syndrome are increasingly identifying new underlying biological pathways that contribute to the cause of and to the symptoms of the disease. The researchers believe that a chemical or biological compound that influences such a biological pathway (or disease mechanism) that they are studying may have an important effect on Rett syndrome. Thus, understanding these disease mechanisms is a starting point for drug discovery.

[Read More...](#)

Exciting IRSF Studies in Motion: Investigators pursue potential HDAC6 inhibitor Rett therapy

We are happy to report that IRSF funded investigator Dr. Alan Kozikowski from the Department of Medicinal Chemistry at the University of Illinois-Chicago has recently published work in Nature Medicine that a compound in the SMART library demonstrates curative effects in a mouse model of the peripheral neuropathy disorder called the Charcot-Marie-Tooth (CMT). CMT is a disorder of the peripheral nervous system and is characterized by a slowly progressive degeneration of the muscles of the limbs and extremities. Although the complete spectrum of symptoms associated with CMT differs from those of Rett syndrome (RTT), these two disorders do share some commonalities at the cellular level, where the neurons are not functioning normally. Within the neurons associated with CMT or RTT, there is evidence that the transport of essential cellular components is inefficient, and this results in impaired neuronal cell communication.

[Read More...](#)

HDAC6 inhibitors reverse axonal loss in a mouse model of mutant HSPB1–induced Charcot-Marie-Tooth disease

Constantin d'Ydewalle, Jyothsna Krishnan, Driss M Chiheb, Philip Van Damme, Joy Irobi, Alan P Kozikowski, Pieter Vanden Berghe, Vincent Timmerman, Wim Robberecht, & Ludo Van Den Bosch

[Link to Abstract](#)

[Link to Article](#)

Happenings

VOTING ENDS SATURDAY!

Voting Ends

August 27th

Sign up for DAILY EMAIL REMINDERS

Want to Know More...

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.

Advocacy Resource Websites for U.S. Families, from IRSF BOD member Karen Nussle

U.S. families often ask us about how they can find reliable and credible information about what's going on in Washington. We know you are interested and powerful advocates and we want to help you keep informed. When you don't live in DC and you don't regularly follow all the activity on Capitol Hill, it's hard to keep track of what might be happening with things like Medicaid funding, Education Reform, NIH funding and the wide variety of issues we care about, and want to be sure we are vocal about on behalf of our girls. In an attempt to help answer this question we did a little research and wanted to pass on what we found. Unfortunately there are no perfect sites. But for general information, we recommend that you check out and track the following sites:

www.ucp.org/public-policy

www.researchamerica.org/advocacy

www.thearc.org

All of these organizations (above) are well funded national organizations. So they have staff dedicated to tracking and updating legislative issues and they will be up to speed on the big issues. Now each of them has their own agenda, so we all need to be smart consumers – the agendas of these organizations may not exactly align with Rett syndrome and our families' needs. But in general all of these sites have good solid information.

I also found the site below. While the site looks primitive, they have compiled some very good resources. I haven't had a chance to check out all of the links they recommend, and clearly they have a California focus. But I was impressed by the fact that they are trying to do here exactly what we are trying to do -- create a clearing house of information for families.

www.supportforfamilies.org/legislative/alerts.html

www.supportforfamilies.org/legislative/links.html

We hope you find this is helpful. Let us know if you have questions about anything you find on these sites or if we can provide additional information. We'll keep looking for the best resources and pass them on when we find them.

Alabama Advocacy Success Story

Dana Sutton, Southeastern Rett Syndrome Association (SRSA) Board member, reports that as a result of their efforts, the State of Alabama Governor's Office on Disabilities has now listed IRSF, SRSA, and RettConnect as resource links at

good.alabama.gov/resourcelinks.htm. New families that have a child diagnosed with Rett syndrome, or who move to Alabama, now have access to information for all levels of support at their fingertips. She says IRSF benefits families by providing information on Rett syndrome, names of their state regional representative, information on the latest research, and also fundraising efforts to further research. SRSA directs families in how they can become involved in these fundraising efforts and provide connections to local support, and Alabama Rett Connect directs families to local institutional supports, with all roads pointing back to IRSF. This is a win-win situation for the families in Alabama. Their hope is that this effort provides a crucial step towards building up support networks in the state, and continues building fundraising efforts for research.

Mrs. Sutton says that most states have these Resource pages mandated by law, though some are better than others as far as listings and directing consumers to links. She emailed, and personally called the contact person for Alabama's site and asked for a listing of the International Rett Syndrome Foundation, the Southeastern Rett Syndrome Alliance, and Alabama Rett Connect, and they were more than happy to list these organizations.

They also asked their state Developmental Council for a listing of IRSF on their web site, but they responded that the board would have to vote on this. All states have a DD Council website for listings.

IRSF congratulates these women for taking the time to simply investigate their state's website, and request the addition of resource links to IRSF. We encourage you to pursue this in your own state, so that no family is left alone on their journey with Rett syndrome

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.

[Click here to download the flyer](#)

Featured Angel: Jillian Endres

Hi! My name is Jillian Endres but almost everyone calls me Jilly. I am 8 ½ years old and I was diagnosed with Rett syndrome at 17 months. I attend an amazing school where I am integrated into regular classes such as gym, art, music and library—and this year I will be in second grade! My main classroom is a therapy-based classroom so even when I am doing something fun, my teachers and therapists turn it into some form of therapy. I feel very blessed to “have it all” at school and I know my parents feel this way too!

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

Start the School Year off Right

By Jennifer Endres, Family Resource Manager, IRSF

Another summer has passed and some of us are already back in school while others are eagerly awaiting the first day. The beginning of a new year is exciting but can also be stressful for parents and caregivers of children with Rett syndrome while they prepare for a smooth and successful transition. As the mother of a daughter with Rett syndrome and also a former special education and regular education teacher, I wanted to use my experiences to help you get your child's school year started off on the right track.

- Educate Peers
- Educate Educators
- Check Equipment
- Important Tips

[Read More...](#)

[Fundraising and Hope Raising...](#)

Take a bold action this year and help us fight for our girls and women fighting Rett syndrome! Set your 2011 resolution NOW to get involved and take part. Every day our Rett angels face the world 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! Click here for an A-Z list of easy fundraising ideas to get your office, kid's school or your community on board with fundraising for your Rett angel! IRSF makes it easy to get involved.

Your help is our hope. Your help is their hope.

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!

Casino Night

Do you have friends and family that play poker or like to go to casinos? Then why not host a "Casino Night for Rett"! A Casino Night fundraiser offers several ways for donations including silent and live auctions, raffles, poker tournaments, sponsorship opportunities, ticket sales, and even a cash bar. Include a certain amount of gambling tokens or play money with each ticket to get your guests playing. Be prepared to sell a lot more during the event. If you have great prizes, your guests will keep gambling! Click here for a how to sheet to help you plan your Casino Night for Rett! Give yourself at least a few months to plan an event like this. Check out this flier that IRSF created for a Casino Night that was held this winter in Virginia!

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 - Idaho

Running For RETT: Jogging For Jorga

7th Annual Roanoke Strollathon

3rd Annual Charlotte Troy Golf

2nd Annual Kansas Strollathon

8th Annual OH/KY/IN Strollathon

5th Annual Wrightsville Beach Strollathon

Natural History Research Study - Oakland

6th Annual Portland Strollathon

Recent scientific articles related to Rett Syndrome

Recent Publications

Transgenic complementation of MeCP2 deficiency: phenotypic rescue of Mecp2-null mice by isoform-specific transgenes.

Kerr B, Soto C J, Saez M, Abrams A, Walz K, Young JI.

[Abstract](#)

[Article](#)

Rett syndrome: exploring the autism link.

Percy AK.

Abstract

Article

Neuronal maturation defect in induced pluripotent stem cells from patients with Rett syndrome.

Kim KY, Hysolli E, Park IH.

Abstract

Article

Ghrelin levels are reduced in Rett syndrome patients with eating difficulties.

Hara M, Nishi Y, Yamashita Y, Yoh J, Takahashi S, Nagamitsu SI, Kakuma T, Hosoda H, Kangawa K, Kojima M, Matsuishi T.

Abstract

Article

Epilepsy in Rett syndrome: Association between phenotype and genotype, and implications for practice.

Cardoza B, Clarke A, Wilcox J, Gibbon F, Smith PE, Archer H, Hryniewiecka-Jaworska A, Kerr M.

Abstract

Article

A novel transcript of cyclin-dependent kinase-like 5 (CDKL5) has an alternative C-terminus and is the

predominant transcript in brain.

Williamson SL, Giudici L, Kilstrup-Nielsen C, Gold W, Pelka GJ, Tam PP, Grimm A, Prodi D, Landsberger N, Christodoulou J.

[Abstract](#)

[Article](#)

The Role of MeCP2 in the Brain

Guy J, Cheval H, Selfridge J, Bird A.

[Abstract](#)

[Article](#)

A role for glia in the progression of Rett's syndrome.

Lioy DT, Garg SK, Monaghan CE, Raber J, Foust KD, Kaspar BK, Hirrlinger PG, Kirchhoff F, Bissonnette JM, Ballas N, Mandel G.

[Abstract](#)

[Article](#)

Complexities of Rett syndrome and MeCP2.

Samaco RC, Neul JL.

[Abstract](#)

[Article](#)

Synaptic microcircuit dysfunction in genetic models of neurodevelopmental disorders: focus on Mecp2 and Met.

Shepherd GM, Katz DM.

[Abstract](#)

[Article](#)

MeCP2 Rett mutations affect large scale chromatin organization.

Agarwal N, Becker A, Jost KL, Haase S, Thakur BK, Brero A, Hardt T, Kudo S, Leonhardt H, Cardoso MC.

[Abstract](#)

[Article](#)

Extrasynaptic NMDA receptor stimulation induces CDKL5 cytoplasmic translocation and proteasomal degradation.

Rusconi L, Kilstrup-Nielsen C, Landsberger N.

[Abstract](#)

[Article](#)

Clonal Rett Syndrome cell lines to test compounds for activation of wild-type MeCP2 expression.

Yu D, Sakurai F, Corey DR.

[Abstract](#)

[Article](#)

15q11.2-13.3 chromatin analysis reveals epigenetic regulation of CHRNA7 with deficiencies in Rett and autism brain.

Yasui DH, Scoles HA, Horike SI, Meguro-Horike M, Dunaway KW, Schroeder DI, Lasalle JM.

[Abstract](#)

[Article](#)

[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!

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, 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 or by fax at 513-874-2520

Mail

Please send to 4600 Devitt Drive Cincinnati, OH 45246.

Rett Quote

"The future belongs to those who believe in the beauty of their dreams."

~ Eleanor Roosevelt

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

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