

IRSF Partnership Program

Become a partner in advancing the International Rett Syndrome Foundation's (IRSF's) mission to fund research for treatments and a cure for Rett syndrome. As the leading international organization working for the individuals, families and friends affected by Rett syndrome, your partnership will help the Foundation achieve its core mission of enhancing the overall quality of life for those living with Rett syndrome by providing information, programs and services.

PLEASE PRINT OR TYPE:

Name _____
Street _____
City _____
State _____ Zip _____
Phone (Home) _____
Please list Name, Address & Telephone No.
of Diagnosing Physician _____

Occupation(s) _____
Child's Name _____
Date of Birth _____ Age _____
☐ New Partner ☐ Renewal
Phone (Work) _____
E-mail _____
Please Check All Applicable Categories
☐ Parent ☐ Relative ☐ Friend ☐ Teacher
☐ Physician ☐ Researcher ☐ Physical Therapist
☐ Music Therapist ☐ Occupational Therapist
☐ Other _____

Please check below if you give permission for your name and address to be released to:

☐ Other parents for correspondence ☐ Researchers for study ☐ Use of child's photo (please include photo)

Has the diagnosis of Rett syndrome been confirmed by genetic testing? ☐ Yes ☐ No Mutation # _____

- ☐ Corresponding Partner (Free) (1 person)
☐ \$30 Active Partner (1 person)
☐ \$40 International Partner (includes Canada; 1 person)
☐ \$125 Organization/Group Partner (*5 people)
☐ \$500 Lifetime Partner (*2 people)
☐ If you are a PARENT and cannot afford full dues,
please check here. We welcome your partnership.

* ALL PARTNERSHIPS MUST BE PAID IN U.S. CURRENCY

Please make check/money order payable to:
INTERNATIONAL RETT SYNDROME FOUNDATION
and mail with this form to:
4600 Devitt Drive, Cincinnati, Ohio 45246 USA

You can join online at www.rettsyndrome.org

IRSF would like to thank all of our generous supporters.

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RETT
Gazette



Volume 1, Issue 2

INSIDE THIS ISSUE

9th Annual RTT
Symposium
Page 1, 4, 5

24th Annual
Conference
Page 1, 12, 13

Family Advisory Board
Page 2

RTT Cases
State-By-State
Page 3

Research Updates
Page 3, 4, 5

Family Support
Page 6, 7, 8

Connecting
Grandparents
Page 9

Sibling Stories
Page 10

Regional
Representative
Program
Page 14

Events and Fundraising
Page 15, 16, 17

Awareness
Page 18

In Honor of Angels
Page 19

9TH ANNUAL RTT SYMPOSIUM

On June 23 – 25th IRSF hosted the 9th annual Rett Syndrome symposium at the Eaglewood Resort and Spa, Itasca, IL. The symposium was attended by around 100 participants and featured 21 guest speakers covering a range of topics from new micro-array and gene expression studies to neuronal systems physiology and potential therapeutic strategies. The talks were also accompanied by detailed discussions and a scientific poster session where attendees were able to review the latest research findings and converse directly with presenters in an informal setting.

There were several talks at the symposium focusing on specific regions of the brain where MeCP2 may play a vital functional role by controlling downstream gene expression. Investigating MeCP2 function in separate regions can provide vital clues as to which



Dr. Rick Altschuler welcomes the 9th Annual Symposium attendees

areas of the brain or which specific neuronal populations are most susceptible in RTT. Some of the research presented in the speaker sessions is highlighted below.

A talk by Dr. Jeff Neul of the Baylor College of Medicine, focused on newly developed animal models where *Mecp2* function was removed in specific populations of neurons in three segregated regions within the cortex and cerebellum. Dr. Neul's work used a technique called Cre/Lox that allows specific genes to be controlled and effectively "switched off" in certain brain regions.

The results of this work suggested that when MeCP2 is switched off in certain regions of the brain, such as the hypothalamus (a region of the brain known to play a role in controlling basic drives such as hunger) mice became obese and were continuously feeding. *Mecp2* was also switched off in other neurons resulted in a loss of certain motor functions. In cerebellar Purkinje cells however, the loss of *Mecp2* did not appear to produce any serious effects although subtle effects on neuronal function cannot be ruled out.



In the same session, Dr. Lucas Pozzo-Miller of UAB, discussed his research findings on *Mecp2* in the hippocampus, a brain area which is known to play a vital role in learning and memory. Dr. Pozzo-Miller has devised a brain slice culture system allowing direct visualization of synapses, the structures in neurons that allow cell to cell communication. Using this system, it is possible to perturb specific genes such as *Mecp2* in order to study their functional consequences. Dr. Pozzo-Miller described the effects of these changes, either removing or introducing specific RTT mutations in *Mecp2* which resulting in changes in the shape, structure and electro-chemical properties of dendritic spines within neurons – the parts which contain the synapses. This work also focused on brain-derived neurotrophic factor (BDNF), a signaling molecule and known target of *Mecp2* that was previously shown to increase the density of dendritic spines.

continued on page 4

Rett Syndrome
Association of Illinois
rettillinois.org



IRSF 24TH ANNUAL CONFERENCE

Our 24th annual conference over Memorial Day weekend in downtown Chicago kicked off in style with a Friday night reception at the Fairmont Hotel's Crystal Room, graciously sponsored by the Rett Syndrome Association of Illinois. Our theme "Together We Are Better" was evidenced everywhere: parent-to-parent; professional-to-professional; parent-to-professional. Over 250 attendees from all over

continued on page 12



Paige Nues welcomed attendees

The Rett Gazette is published periodically by The International Rett Syndrome Foundation (IRSF), a non-profit 501(c)3 organization. IRSF's mission is to find treatments and a cure for Rett syndrome (RTT) while improving the day-to-day lives of those living with RTT.

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About Rett Syndrome (RTT)

Rett syndrome (RTT) is a devastating neurological developmental disorder that occurs almost exclusively in females. It is usually caused by a mutation of the MECP2 gene on the X chromosome. Rett syndrome is found in all racial and ethnic groups throughout the world, and in every socioeconomic class. RTT affects 1 in 10,000-15,000 live female births. Early developmental milestones appear normal, but between 6-18 months of age, there is a delay or regression in development, particularly affecting speech, hand skills, and coordination. A hallmark of Rett syndrome is repetitive hand movements that may become almost constant while awake. Other features may include seizures, irregular breathing, swallowing difficulties, deceleration of head circumference with age, and curvature of the spine. Many individuals with Rett syndrome live well into adulthood. There is currently no cure.

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All submissions and correspondence regarding the newsletter, information and partnerships should be directed to:

IRSF
4600 Devitt Drive, Cincinnati, OH 45246
1.800.818.RETT or 513.874.3020

Policy Statement

In an effort to improve the quality of life for those with Rett syndrome we welcome ideas from our readers on various techniques of management and care, general and educational suggestions that individuals have investigated and/or found beneficial. This exchange of ideas is welcome. Parents and others have the opportunity to decide if they want to follow through with the suggestions. As a foundation, we do not support or endorse any particular treatment, therapy or medication. We encourage parents to support one another with suggestions and to contact their child's physician for final approval.

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Family Advisory Board

INTRODUCING THE FAMILY ADVISORY BOARD!

The International Rett Syndrome Foundation Family Advisory Board (FAB) is now fully operating, and working hard and hand-in-hand with parents, caregivers, IRSF staff and its board of directors to serve you.

Led by its chairman Dan Brinkhaus, the FAB is comprised of 14 members, serving revolving terms of three years. Each member serves on one or more committees that focus on Support Programs & Services, Advocacy & Awareness, Fund Development, and Information & Communication.

The FAB is strong, diverse and rich with seasoned "Rett parents" who excel in both their personal and professional lives. Its members are wholly committed and tremendously motivated to bettering the lives of all those living with Rett Syndrome.

Support Programs & Services

The FAB realizes that IRSF's support programs and services are a lifeline to many families living with Rett Syndrome and remain crucial to fulfilling IRSF mission. So the FAB will help IRSF stay focused and on track administratively, providing the support programs and services that are most needed.

The FAB Support Programs & Services committee's primary objective is to keep the pulse of the Rett syndrome community—to know its needs, to advise IRSF on and develop appropriate new support programs and services, and to determine the effectiveness and performances of existing support programs and services.

The Support Programs & Services committee is currently evaluating existing support programs and services. Its members are anxious and looking forward to reviewing the data that will result on the soon-to-be-launched IRSF family survey so that it can more wisely and adequately advise the IRSF.

The Support Programs & Services

Committee is led by Jeff Huisingsh, father to Shelby (RTT) age 6. Jeff welcomes your questions and feedback. Feel free to contact Jeff at lhuisingsh@mac.com

Advocacy & Awareness

The objective of the Advocacy & Awareness committee is to advise IRSF, to help disseminate Rett syndrome knowledge so that RTT is promoted and made relevant to a broader population.

The FAB Advocacy and Awareness Committee will help shape the IRSF's long term strategic plan, to help establish a grass roots framework to accomplish advocacy and awareness objectives, and encourage participation at the local, state, national and international levels.

The Advocacy & Awareness Committee is led by Vera Munn, mother to Lilia (RTT) age 3. You may email Vera at veramunn@SBCGLOBAL.NET

Fund Development

The primary objective of the Fund Development Committee is to encourage families to plan or participate in fundraising for the IRSF, and to provide the tools and support necessary to make events successful, fun, and as easy as possible to carry-out.

Currently, the committee is forming a mentor program, and detailed documentation on how to plan and succeed at various fundraising events. The committee plans to offer organizers ideas of different events that have been successful in the past, then to draw on the experiences of others and match them with an appropriate mentor. Anyone interested in organizing an event, has questions or ideas to share are encouraged to contact this committee.

Additionally, the Fund Development committee is committed to helping establish and build lasting relationships with major donors in exchange for national exposure. Families who may know of potential sponsors or major donors but are apprehensive to make the "ask" are encouraged to contact this committee for guidance.

The Fund Development Committee is led by Leslie Greenfield, mother to Heather (RTT) age 29. Feel free to contact Leslie at leslieg@optonline.net

continued on page 6

Research Updates

MEET TONY HORTON, P.H.D.

I am greatly honored to take up the position as your new Chief Scientific Officer with IRSF. I had the chance to meet many of you reading this and some of your daughters with Rett syndrome at this year's family conference. For those of you whom I have not yet had the pleasure of meeting, I would first like to introduce myself and some of the direction I will be setting as I settle into my new position at IRSF.

As a scientist, I have a relevant background suited for the position; my own research encompassed two disciplines related to RTT research. These were the areas of developmental neurobiology, specifically on peripheral and autonomic nervous system development at St. Andrews University in the UK and development and neurodegeneration in the central nervous system at Rockefeller University in New York. I first learned about Rett syndrome during this time after hearing about the then recent cloning of the *MECP2* gene in a talk given by Dr. Huda Zoghbi at the Society for Neuroscience's annual meeting in 1999.

Prior to joining IRSF, I also gained several years experience in research program development at two non-profit funding organizations; the Juvenile Diabetes Research Foundation (JDRF) and the Alzheimer's Drug Discovery Foundation (ADDF). Working with the scientific and lay communities at JDRF to develop a research portfolio focused on developing new treatments for the serious complications of diabetes. In addition, I worked with both academic and industry groups to provide seed funding for the discovery and development of new drugs specifically targeted at Alzheimer's disease.

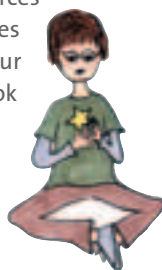
As your new Chief Scientific Officer, I am now committed to bringing this experience to bear on Rett syndrome, and to help facilitate in translating the many important recent discoveries in the field, into the discovery and development of new therapies to prevent, treat or reverse Rett syndrome and its associated complications. I aim to continue the strong legacy and high standards set by my predecessors at

IRSA and RSRF; ensuring that the best quality and highest impact research is carefully reviewed and funded.

In the coming months, I aim to work with an advisory panel of leading scientists from within the Rett syndrome field accompanied by researchers experienced in drug discovery and translational research program development. With this expert advice, our goal will be to develop a strategic plan focused specifically on the generation of novel therapeutics for Rett syndrome. In parallel we will continue to work towards providing support for the important clinical research that will enable us to properly assess and advance new therapies forward to improve the lives of those living with this disease.

I can best achieve these goals in partnership with you, the families touched by Rett syndrome; it is through your efforts that we will attract the vital resources needed to unlock the mysteries of Rett syndrome and make our shared mission a success. I look forward to working with and for you.

Thank you,
Antony Horton Ph.D.
Chief Scientific Officer.



FROM KNOWLEDGE WILL COME A CURE

The passing of a loved one, especially a loved one who has lived with a diagnosis of Rett syndrome, can be a very difficult time. You may find solace knowing that in death she can give the gift of hope to finding treatments and a cure for those living with RTT today, and for future generations to come. The best time to consider this option is before it becomes necessary.

Organ donation is critical to the dedicated researchers working tirelessly to unravel the mysteries of RTT. We urge you to please consider this selfless and courageous gift to the Rett syndrome research community.

If your family decides to support RTT research, contact the <http://www.brainbank.mclean.org/> Harvard Brain Bank or IRSF as soon as possible after or near the time of death. The process must begin within hours of passing, and before any preparations. It is important to know that this will not interfere with any funeral arrangements, including viewing. The kind and respectful staff at the Harvard Brain Bank will handle all arrangements directly with the hospital, hospice nurse, coroner, or pathologist.

For more information, contact the Harvard Brain Bank directly at 1.800.BRAIN BANK, or the IRSF office at 1.800.818.RETT or Paige Nues at pnues@rettsyndrome.org

RETT CASES BY STATE

Total number of cases in the USA: 4412



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Research Updates

continued from page 1

This work may lead to a better understanding of *Mecp2* mediated BDNF function, further suggesting that BDNF might present a target for therapy.

Several talks in the symposium were centered on gene expression changes seen as a result of *Mecp2* loss or mutation. Some of this work challenged the prevailing view of *Mecp2* as a transcriptional silencer.



Dr. Percy and Dr. Kaufmann

Maria Chahrour an investigator from the Zoghbi lab at Baylor, discussed her recently published work where she has conducted a detailed microarray analysis of gene expression following changes in *Mecp2* levels. In this work, *Mecp2* null mice or *MECP2* transgenic overexpressing mice were used for expression profiling. *Mecp2* has long been thought to act as a transcriptional repressor. The results of Dr. Chahrour's study however, suggest that transcription of certain genes might be activated by *Mecp2* as opposed to repressed. The study also suggested that *Mecp2* binds to a known activator of gene transcription called CREB1 at the site of activated target genes. Dr. Chahrour's work also highlights certain genes that are known to function in diseases associated with mental retardation and which could therefore present possible new drug targets.

In a separate study conducted by Dr. Dag Yasui of UC Davis, the large-scale mapping of *Mecp2* DNA-binding sites was carried out. In this study, Dr. Yasui's work used sensitive techniques called ChIP-on-chip (chromatin immunoprecipitation on a microarray chip) and MeDIP-on-chip (methylated DNA immunoprecipitation on a microarray chip) analysis to determine methylated sequences of DNA – areas where *Mecp2* might bind at sites across the entire genome. Dr. Yasui's work suggests that the

Mecp2 binds the promoters of numerous genes that are highly expressed and many do not contain methylation sites, thus signifying that *Mecp2* may function as a modulator of gene expression not as a silencer. This view suggests that *Mecp2* functions more as a “dimmer-switch” turning up or down the expression of particular genes rather than as a straight on/off switch.

Dr. Yi Sun of UCLA presented her research findings which also used very sophisticated ChIP-on-chip and MeDIP-on-chip microarray techniques to conduct a *Mecp2* genome-wide expression analysis to analyze *Mecp2* binding. Dr. Yi's work relies upon the use of differentiated mouse embryonic stem cells – cells that have been converted from a stem cell into neurons. These stem cells can be taken from mice where *Mecp2* has been knocked-out. When these stem cells are differentiated (converted) into neurons the expression of genes can be compared in populations of cells that possess or lack *Mecp2*. Dr. Sun's work ultimately suggested that *Mecp2* binding was closely correlated with patterns of methylation in specific areas called CpG islands (areas of DNA known to possess methylation sequences).



IRSF Scientific Symposium

In discussions on this area, it was cautioned that further detailed analysis is warranted especially to directly demonstrate that transcriptional activation of target genes is associated with *Mecp2*.

Several presentations were made that concentrated on neuronal pathways and specifically those that are perturbed in RTT. Targeting specific neuronal circuits might provide a means of reducing some of the serious complications of Rett syndrome.

Jeffrey Macklis of Harvard University gave an overview of neuronal circuitry in the central nervous system (CNS) with a specific focus on the control of developmental

organization. His talk centered partly on specific cortical circuitry that connects the two hemispheres of the brain called callosal projection neurons. Dr. Macklis' talk stressed that a greater understanding of how different molecules influence the developing CNS can lead us towards improved efforts at repairing damaged circuitry caused by different disease states. His talk was also complemented by a separate presentation from his collaborator, Noriyuki Kishi. Dr. Kishi has analyzed *Mecp2* target genes in these callosal projection neurons. Dr. Kishi has now identified a specific target gene called *Mtg-2* in these neurons. *Mtg-2* may play a role in neuronal maturation and is implicated as a target in Rett syndrome.

Dr. David Katz of Case Western Reserve University gave a presentation primarily focused on the role of the autonomic nervous system (ANS) in Rett syndrome. Dr. Katz discussed the role of signaling systems. Levels of BDNF and the neurotransmitters norepinephrine and GABA – signaling molecules used by neurons to communicate – are reduced in mice that lack the *Mecp2* gene. This reduction is prominent in specific populations of neurons in the brain stem in an area called the locus ceruleus (LC). These LC neurons form extensive circuits throughout the cortex and control critical functions such as breathing. Changes in LC circuits may underlie the respiratory and cognitive defects seen in RTT.

Dr. John Bissonette of Oregon Health and Science University, also discussed respiratory disorders in RTT in the context of the neurotransmitter GABA. Since GABA levels are known to be reduced, augmenting GABA by use of reuptake inhibitors, may be a potential therapeutic avenue to pursue. Dr. Bissonette's work suggested that by use of specific GABA inhibitors, it may be possible to correct the respiratory disorders seen in mouse models of Rett syndrome.

Two talks were given that focused on the potential to correct the underlying defects in Rett Syndrome, using gene therapy approaches.



continued on page 5

Research Updates

continued from page 4

In a talk by Dr. Steven Gray, of UNC Chapel Hill North Carolina, the potential for use of a specific means for ferrying corrective genes into cells was discussed. Gene transfer using a harmless virus called “adeno-associated virus” (AAV) was the focus of Dr. Gray’s talk. Since there are difficulties in getting the viral particles into the brain, Dr. Gray’s approach is to use “directed evolution” to re-engineer the outer coat of the virus particle. This technique has been successful in producing viral particles that can penetrate within the CNS to various regions. Additional technical hurdles still exist however, and this approach while promising still faces a number of challenges.

In a similar approach, Dr. James Ellis of the Hospital for Sick Children in Toronto used a different type of virus called a lentivirus to be used in gene therapy. Dr. Ellis used the lentivirus as a means to test whether different forms of MECP2 can be delivered into isolated cortical nerve cells in culture.



Jill walking to the podium

His work demonstrates in principle the potential utility of these vectors as a means to restore *MECP2* by gene therapy.

IRSF STRATEGIC PLAN AND ROADMAP DEVELOPMENT

In the next six months, IRSF will conduct a strategic planning exercise and conduct a review of funding for Rett syndrome and to set short and medium term strategic goals and funding priorities for the next three to five years.

Firstly, a “Rett Syndrome Landscape Analysis” will be carried out to provide a comprehensive review of the past ten years of research funding for the RTT field. This will assess how funding has been spent and what it has accomplished in real terms. This analysis will ultimately provide a detailed assessment of where the RTT research field is today along the path towards finding therapeutics and treatments for Rett syndrome and associated complications.

The Rett Syndrome Landscape Analysis will analyze the funding of both IRSA and RSRF and compare this with spending from other sources such as Government funding provided by the US National Institutes of Health (NIH) and UK Medical Research Council and other relevant funders using publicly available information. The underlying purpose of this will be to identify areas of critical unmet need that can be specifically targeted by the foundation. This will allow strategic targeting of funds that both complements and supports funding from NIH and other sources in order to accelerate progress towards the development of therapies for Rett syndrome.

Towards the end of the process, a blue ribbon panel will be convened to discuss potential funding mechanisms, identify specific translational research programs and to set research goals and direction. This strategic advisory panel will consist of advisors from the Rett syndrome field, NIH and other individuals with experience in drug discovery and program development. The Rett Syndrome Landscape Analysis and roadmap will be made publicly available on completion of this strategic planning and goal setting process.

CLINICAL RESEARCH MINI-SYMPOSIUM

Dr. Walter Kaufman and Dr. Alan Percy co-chaired a mini-symposium in conjunction with the 9th Annual Rett Syndrome Symposium. This mini-symposium, titled “Clinical Trials in Rett Syndrome” was a follow-up to a conference held in San Francisco in May 2006 that addressed major issues regarding collaboration on treatment research and led to the formation of the consortium of Rett clinical researchers, RettSearch, and revisited topics of relevance to multi-center clinical trial initiatives.

The second mini-symposium was enriched by the participation of representatives of new Rett clinical centers and potential industry partners. The mini-symposium’s scheduling, immediately before the IRSF’s annual research meeting, allowed Rett clinical researchers to get acquainted with the latest developments in basic and experimental research on Rett syndrome and MeCP2. This fundamental knowledge will certainly enhance the efforts of the working groups established at the mini-symposium, which will be reporting at a teleconference to be held at the end of 2008.

Walter E. Kaufmann M.D.

IRSF GRANTS UPDATE

This year IRSF received 61 letters of intent for the current grant review cycle in February 2008. From these, a total of 36 full proposals were solicited and 33 were finally submitted. There were a total of 21 research grant applications and 12 post-doctoral fellowship applications submitted. The grant review process is scheduled to take place during the months of July-August. Applicants will be notified of their funding status in September.

Family Support

continued from page 2

Information & Communication

The FAB recognizes that accurate and timely information, which can be easily accessed and understood, is the key to support. Making sure this information is available is the primary objective of the FAB Information & Communication committee.

The Information & Communication Committee wants to help the IRSF give both families and caregivers the information they need, when they need it. This information may be about the latest in new therapy technologies, educational strategies, progress in research—and be available through the RettNet or the IRSF forum.

To date, the Information & Communication committee has worked on the soon-to-be-launched family survey. Its members have looked at the IRSF web site and made suggestions to the IRSF on how the site can be improved.

The committee is also developing new ways for the IRSF to communicate with the Rett syndrome community and to ensure that the RettNet remains a warm and resourceful place for on-line support.

The committee draws on the varied experiences of all of the FAB's members, and is led by Jane George, a journalist, whose daughter Aniko died in 2005 at age 29. Jane welcomes your questions and feedback.

Feel free to contact Jane at jgeorge@globetrotter.net.

Together, we ARE better!

The IRSF and its Family Advisory Board believes that **together, we ARE better**, and wholeheartedly welcomes your participation.

The IRSF is seeking 4 new Family Advisory Board members to serve 3-year terms to begin on January 1st, 2009. Applications are being accepted starting on September 1st, 2008 and through October 31st 2008.

Please visit www.rettysyndrome.org for more information or contact Paige Nues at pnues@rettysyndrome.org

For more information or have questions about the Family Advisory Board, please contact Dan Brinkhaus at danbrinkhaus@yahoo.com

MEET LISA HAYDEN

My name is Lisa Hayden and I am IRSF's new Family Support Coordinator. I began working with the foundation in June 2008, after graduating from the University of Miami, in Oxford, Ohio, with a Bachelor of Arts degree in Strategic Communications.

My first experience after joining the IRSF team was to go to Chicago for the 9th annual Scientific Symposium. I met a lot of wonderful people who really care about this foundation and what it strives to accomplish. It is truly inspiring to see so many caring and compassionate people focused on a common objective.

Though I have no personal tie to an individual with Rett syndrome I have had to help care for many people in my family with obscure illnesses that doctors could not properly diagnose or treat. I know what it is like to want to find a cure so badly to help someone you love. I can't wait to know you and your daughters better because I too want a better today and a cure for each and every one of them.

I am very excited to join the foundation, and to support the Family Support activities with Paige Nues and Jennifer Endres. I will strive to help the organization with the everyday things that keep our goal for "care and a cure" alive. I look forward to hearing from you.

Lisa Hayden

Family Support Coordinator, International Rett Syndrome Foundation



Lisa Hayden



HOW TO ADAPT A TOY FOR \$1

By Eric Diamond, Father of Abby

If your daughter is like mine, then she loves those walking, talking, singing, dancing, tickling, robotic plush toys. We probably have ten of them scattered around our house. And yes, they drive us crazy, but what annoys us more is that our daughter cannot activate the toys because she cannot squeeze the appropriate hand, ear, foot, etc... Well I found a way around that and it only costs a dollar.

Go to your local Dollar Store and look for those battery operated stick on lights; (they look like big buttons) some even have designs like smiley faces on them.

If you open them up you will see a push button switch on one side with two wires attached to it.

Cut those wires, leading to the bulb. Leave yourself at least one inch of wire to splice and attach speaker wire, or any other type of wire, to each side of the switch. Secure the wire and screw

the light back together. You do not need batteries for the light; you are only using it as a switch.

Now you have to do a little surgery on the toy. Slice the hand or ear carefully to get to the "squeeze switch" that is embedded in the toy. Pull it out carefully and you will see the wires that it is attached to. (Be sure to remove the batteries!)

Cut off the switch and securely attach the other end of the speaker wire to the exposed wires in the toy.

The adaptive 'switch' you created should complete the circuit when pressed and the toy will turn on.

After you test that it works, carefully glue or sew the limb back together and you are done. Leave plenty of wire so you can place the button where your daughter can reach it.

Do you have any great money saving ideas? Please share your experiences with us so we can be sure to pass along the helpful information to all families! Contact Jennifer Endres. jendres@rettysyndrome.org

Family Support

GRIEF TO GROWTH by Diane Ross, MS, LCPC

Part One: The Grief

D-Day. I remember it like it was yesterday. Not the intricate details of the day, like my husband Mick remembers, but the overriding, profound agony I felt. That pain would alter my life forever. It was not a World War II explosion, but an emotional eruption at the very core of my heart and soul. You see, in our family D-day has a different meaning than for most of the general population. For us, it is Diagnosis Day: September 5, 1989, the day Lindsey was diagnosed with Rett syndrome. Thus began our grief. Our perception of who or what Lindsey would be was no longer congruent with the harsh reality we now faced.

Our story is like thousands of others. Immediately shock set in. I was in such a daze that I had to set two goals for myself during the first week after D-day: One, to make sure that everyone was dressed in the morning, thus preventing anyone from leaving the house naked. Two, that there would be some semblance of dinner on the table every night. That was all that I could handle at the time. We had one older child, as well as a new born. I remember after a few days, that I sat down at the kitchen table with Kristi, our oldest, and asked how she was feeling about Lindsey and Rett syndrome. She responded with a very appropriate response to grief - "I'm angry!!" she shouted at me. When I asked what she was most angry about she responded with a typical five year old's view of things: "I'm not getting any attention around here any more!!" At that moment I knew that I would never be able to predict how others would respond to Lindsey and Rett syndrome.

When a child is diagnosed with a disability or an illness there is a deep sense of loss experienced by the child and others. Letting go of the 'normal child' and accepting the child with a disability or illness is a process. Perhaps you are aware that there is an actual cycle of grief or stages that people go through in any grieving process. However, this process differs for individuals depending on their relationship with the child, their life experiences, who they are, their emotional make-up and how their day to day life is altered by the diagnosis.

Dr. Elisabeth Kubler-Ross identifies five stages of grief people go through when they experience any loss.

1. Denial - at first we tend to deny that the loss exists. People tend to withdraw from others and their usual social contacts. This stage can last anywhere from a few moments to many, many months.
2. Anger - often times we become angry at others or at the world for having done this to us. We can also become angry at ourselves, even though we know that realistically we could not have done anything at all to prevent the loss.
3. Bargaining - we may try to make a bargain with God, asking that if we do 'this' will you take away our loss.
4. Depression - we feel numb, with overriding sadness.
5. Acceptance - the anger, sadness and mourning taper off and we accept the loss and all that it encompasses.

It is normal and natural to feel these emotions. The stages are spontaneous and may or may not follow the described order. In addition to the identified stages people often experience extreme sadness, stress, confusion, disappointment, a sense of powerlessness and rejection for one's self as well as the child. It is not unusual for one to feel that they have reached acceptance, when a person, place or event triggers the grieving process into action once again.

Many people grieve for the child diagnosed with a disability. The child themselves grieves over the loss that they must deal with for their entire life. Those with Rett syndrome, I believe, mourn the loss of skills they once had. Parents, siblings, grandparents and many other family members grieve for the child. I believe that grandparents struggle with a double dose of grief - the grief for their grandchild as well as grief for their own child's pain. In addition to family, friends, neighbors and others may also share in your grief. My experiences have demonstrated to me that many others including the professionals that work with the child grieve also. This includes those in the medical profession, in the educational

arena, therapists and many others who have a connection with your child.

How does one deal with all these feelings? How does one learn to grow from their grief and pain? Watch for answers to these questions and more in the next issue of this newsletter.

Diane and Mick live in Schaumburg, IL. They have four children; Kristi, 23, Lindsey 21, Andy, 19 and Corey, 13. Diane is a Licensed Clinical Professional Counselor in private practice. She has served as a source of support for hundreds of families of children with disabilities.



Save the Date!

25TH ANNUAL EDUCATION & AWARENESS CONFERENCE

Memorial Day Weekend
May 22-24, 2009

10 Years Since the MECP2 Discovery

Celebrating our Past, Bettering our
Today, and Advancing our Future

Details to be Announced! See You There!

HAS YOUR ADDRESS, PHONE OR EMAIL CHANGED?



Please visit www.rettsyndrome.org to update your information online or call 1-800-818-RETT.

We want to hear from you!

Family Support

MY DAUGHTER NEEDS A PIECE OF ADAPTIVE EQUIPMENT—NOW WHAT? “IT DEPENDS!”

by Jennifer McLaughlin Maly, PT, DPT

As a pediatric physical therapist, I usually hear this question after months of frustration from the parents attempting to figure out the procedure of getting an item for their child. Unfortunately, there is not a specific answer except for “it depends,” which can be just as frustrating as the question at hand. I hope by the end of this article the procedure will be clearer and the process will be less intimidating.

Typically a piece of adaptive equipment is utilized to increase the child's function. Examples of adaptive equipment or assistive technology may be wheelchairs, lifts, standing frames, gait trainers, augmentative communication devices, bath chairs, and recreational items such as swings or tricycles. The process of obtaining the equipment is defined primarily by the funding source. The funding source may be through your child's health insurance, it may be through the child's school system, or it could be through private funding.

Coverage for adaptive equipment through your child's health insurance varies between coverage types and insurance companies. State funded insurance requires that the item being requested be medically necessary – meaning that the use of the item will assist your child with their medical condition. Certain private insurance companies will base their funding on a yearly allowed amount of money, commonly referred to as a DME (durable medical equipment) cap. This is typically used up quickly near the start of that funding year. The best way to understand your child's coverage is to connect with a representative at the insurance company to review your family's policy. The company

that supplies the equipment (vendor) must be able to work with all of your insurances. For most items, the vendor will request a letter of medical necessity and a prescription from your child's providers (physician, physical therapist, occupational therapist, or speech therapist). You may also want a sales representative to come to your home or go to a clinic to trial the piece of equipment, as most insurance companies encourage this.

Equipment provided through the school system is an item that will assist your child in succeeding within their academic curriculum. The piece of equipment is identified by the school staff and/or the parents, and then written as part of your child's Individual Educational Plan (IEP). This equipment is to be used during the school day and may meet other children's needs when not in use by your child. The school district may insist that the piece of equipment stays at school at all times, while other districts may allow the equipment to travel home on vacations.

Private funding for equipment is common when insurance or school cannot assist. Most insurance companies will not cover recreational items, therefore it is left to the child's family to purchase this piece of adaptive equipment. If possible, trial the equipment prior to ordering to ensure size and your child's prospective ability to use it. When purchasing a piece of equipment privately, the research is done by the family. At the end of this article are helpful websites for reviewing a variety of equipment.

HELPFUL TIPS:

Communication: Stay in contact with all involved parties (vendors, therapists, doctors, and the insurance company).

Documentation: Keep a file for each piece of equipment with all of the paperwork that goes with it—letters from doctors and/or therapists, prescription, order forms, names and phone numbers of sales people, instruction manual, and warranty information.

Resources: Know your funding resources.

Time: Remember it may take some time, especially if it is a customized item, so try to plan ahead.

Trial: Borrow a friend's equipment or have a vendor bring out the item before ordering, if possible. When the item arrives, trial it

again to make sure it is the right size and has the correct option (any bathing/toileting items must be fit with your child's clothes on, in case it needs to be returned).

Ease into use: Some equipment may take time for your child to get used to it. Consult with the recommending specialist for instruction.

WEBSITES:

Here are some websites that have adaptive equipment available. I am not endorsing any of these websites or their products; the list is to be used as informational.

Abilitations: www.abilitations.com

Ablenet, Inc.: www.ablenetinc.com

Adaptive Mall: www.adaptivemall.com

Answers4Families:
<http://nnccf.unl.edu/common/toys.html>

Assistive Technology, Inc.:
www.assistivetech.com

Invacare: www.invacare.com

Leckey: www.leckey.com

Rifton: www.rifton.com

Sammons-Preston:
www.sammonspreston.com

Snugseat: www.snugseat.com

Sunrise Medical: www.sunrisemedical.com

Therapro, Inc.: www.theraproducts.com

Jennifer lives in Massachusetts and has worked with 5 year old Lily since she was diagnosed four years ago. She has not only helped Lily improve physically, but she has become a special part of Lily's family.

Are you a therapist who would like to become part of our Therapist Network? Does your daughter have a therapist you think would like to join?

Please contact Jennifer Endres at jendres@rettsyndrome.org for more information!



Connecting Grandparents

HEAR MY THOUGHTS

Sonora

By Anita Poulton

Our family received the diagnosis of Rett syndrome in 2002. Our beautiful granddaughter Sonora was 4 years old at the time. We knew she had developmental delays but we weren't ready to hear the words "Rett syndrome."

We knew very little about it but what we knew was very frightening. As grandparents our hearts were breaking for our granddaughter and our son and his spouse. We hardly had time to think of our own feelings at such a time. Like many of you we swallowed hard, tucked our feelings away and came to the aid and support of our children and granddaughter.

Today our son and daughter-in-law are not together. Sonora lives with her mother

about 5 hours from our home in Nashville, Tennessee. We remain in close contact with Sonora's mother. We continue to be very involved in her life. We bring her to our home every few months so our son may have parental visits but also to give her mom respite.

At age 10, Sonora is almost as big as me physically. At her last check-up I had 2 inches and 2 pounds on her. So she is definitely still growing. Grandpa ends up doing most of her physical care. He is the true picture of love. He has gone from a dad that couldn't change a diaper to a grandpa that loves making many trips to the potty and can change pull ups with the best of them. Sonora loves him and anything Grandpa does she wants to do too. They hike and go in the truck to the grocery store for a cookie everyday when she is with us.

Sonora loves the cartoon Sponge Bob Square Pants. She watches episodes repeatedly. She gets the jokes and smiles and laughs at appropriate times as any

child would. It is fun to watch her. She has her favorites and not-so-favorites. Plankton is the bad guy and she knows it. She doesn't like him. She knocks on the TV screen and complains so we can get rid of him in a hurry.

When we hit a bad spell and a total meltdown we can count on The Sponge Bob Christmas Special. We can put that episode on and she is immediately happy again and squealing with delight. As grandparents we are definitely more patient. Rather than going nuts with repetitive Sponge Bob episodes, we just laugh as we recite verbatim the Sponge Bob dialogue.

Being a grandparent to a child with Rett syndrome is certainly different than I expected. Dreams are different and the future is more uncertain. However, there is no difference when it comes to love. When I look into Sonora's eyes, they convey love. And those goodnight kisses just before she covers up her head in her Sponge Bob blankie...just can't be beat!

GRANDPARENT Q & A

Q: What has been most helpful to you in regards to coming to terms with your granddaughter's diagnosis of Rett syndrome?

A: It's been 3 years now since Madasyn was diagnosed with Rett syndrome and I remember how I felt as if it were yesterday. I had a pit in my stomach. I couldn't grasp why this was happening and I didn't understand what this meant. I was lost for words. This poor little girl didn't do anything wrong to deserve this. I was angry! You learn to cope with it in different ways. It's not easy. I cried a lot and then I settled down. Going back to church and praying everyday helps me. Never give up on your angel and hope for a cure. Knowing what Madasyn's diagnosis is helps me understand why she does and doesn't do things. It's important to express my love as with any grandchild. I hug and kiss her as much as possible and find new ways of playing with her. She especially likes rough

housing. She can really get a giggling! Seeing her smile and making sure she knows she is loved regardless is helpful in coping. Even though she can't do things that she could in the past, it makes it more of a miracle moment when she accomplishes new things! Just love her and be proud of your precious angel.

*Bob and Judy
Grandparents to Madasyn
Wilcox, PA*

A: My faith in Jesus Christ is what has helped me most through the grieving process. Through Him, I know that God is sovereign, He does all things well, and He never makes a mistake. Our Lauren is a precious gift from God, and He is teaching me things through her that I wouldn't learn any other way. His amazing grace continues to lift me up and give me hope for the future. The other thing that has helped me is working on our Strollathon to raise money for IRSF to fund research. This has provided a way to "do something" that will one day result in a cure. It is easy to feel alone on this journey with Rett syndrome, because few people are familiar with it.

I have been so encouraged by those who have come onboard to help us, and overwhelmed by the generosity of so many people.

*Suzanne McCarthy
Grandmother to Lauren
Wilmington, NC*

A: First of all, the news was so devastating that it would be almost impossible to cope without my faith in God. Even so, I was heartbroken for Rachel, her twin sister and my daughter and son in law. But through lots of prayer and support from so many of my friends, I finally came to realize that although it would be a tough road ahead for all of us, especially for our little Rachel, that she is truly a special gift from God and her life is to be celebrated in spite of her apparent limitations. For the first time in my life I know what the term "Special Child" means and whenever I look into Rachel's precious smiling face and beautiful blue eyes, I see pure unconditional love and a tiny glimpse of Heaven.

*Rose Giordano
Grandmother to Rachel
Williamstown, NJ*

continued on page 11

Sibling Stories

AN ANGEL ON EARTH by Katherine, age 12, California

On May 5, 1999 an angel was born. At three years old, my sister Danielle was diagnosed with Rett Syndrome. Her skills of talking and walking had not yet started. I was six years old when she was diagnosed with Rett Syndrome. Back then, I did not fully understand the meaning of my sister's disability.

I soon learned my sister's favorite things are music, swimming and going on her most favorite ride at Disneyland, "It's a Small World". My sister and I love to go to Disneyland. Since Danielle is handicapped and uses a wheelchair at Disneyland, we get to go to the head of the line so she doesn't need to wait as long.

I like to take care of my sister when my parents need me to, because I like to help and have fun. While I "sister-sit" Danielle, we listen to music, watch movies, play fun games, and make crafts. We even get to eat one of our favorite meals, macaroni and cheese with hot dogs. I recently took a "Safety Sitters" class and learned important safety rules for caring for children along with CPR training. I feel even more confident to care for my sister now.

Most people feel sorry for our family, but it's



Katherine and Danielle

fun having a little sister to play with and to help with. I like to think positive instead of negative with the things Danielle can do. When my little sister, "Sunshine," laughs and smiles it gives me and my family joy, a joy that a regular little sister could not give. My sister is very special to me and we have lots of fun together. Rett Syndrome is not a bad thing that just happens, in some ways you can find good things. There are some special things that only my sister, Danielle, can help me with because she has Rett Syndrome. I know she'll keep my secrets. I know that she will always comfort me to make me feel better, because that is what a family is for.



Cara with brother, Zack



Julia with brother, Jake



Isabella with brother, Cole



MY SISTER

Written by Jillian Diamond

My sister Abby is the best
She's a pretty blossom
I love her with lots of care
For she is so awesome



Jillian is 8 years old and is the older sister of Abby (RTT), age 5. She is pictured at left with Abby.



As a sibling, you play a very important role in your sister's life. You have so much to share and teach your sister! You are full of love and compassion. Many siblings, no matter what the age is, write the most beautiful poems or stories to share their thoughts and emotions about Rett syndrome and their sister. If you are a sibling of a special sister and would like to share something you have written, please contact Jennifer Endres at jendres@rettsyndrome.org.

Would you like to see yourself pictured here with your sister? If so, please send a picture to jendres@rettsyndrome.org. Close up shots work best! Be sure to identify who is in the picture!

IRSF looks forward to receiving photos and writings from all of the very special siblings out there!

“THROUGH DAWN’S EYES”

By Aunt Loretta Courtemanche

Even though I can’t speak
I have a lot to say
I have a loving family
And it shows in every way

You should see when I giggle
My mom has such a glow
So I try to do it often
She thinks I’m putting on a show

I even have my mother trained
When I’m bored or feeling sad
I just cry a little
Then she plays with me and
makes me feel glad

My walking is a little wobbly
It’s not my fault you see
I’ve got this really neat wheelchair
And it’s made just right for me

I go to school every day
I try to keep a little busy
We have games and music and things
Some days are good and some are
in a tizzy

I do have busy days a lot
Seeing doctors and such
The van picks me up at the house
Which means so very much

My therapy is going well
I go there once a week
My arms don’t extend like they should
And it’s hard to stand on my own two feet

Life is such a struggle
I try to learn new things
Like drinking through a straw
And pay attention to songs mom sings

So life for me as I see it
Takes up all my time
I just take it day to day
And thank God this family is mine



Sammi with sister, Ann and brother, Max



Jennifer and niece Addyson

HELPFUL TIP

Gas and electric bills getting you down?

Ask your utility company if they offer baseline discounts for those with qualifying medical conditions. Most of our girls and women have trouble regulating their body temperature because of the autonomic dysfunction seen in Rett syndrome, causing us to run the A/C or heater in our homes more than we would for ourselves. Usually a simple form provided by the utility company and completed by her physician will get you started in the program. Ask today!

continued from page 9

A: The only way it keeps us going day by day is believing there will be a cure. Keep believing; don’t lose hope.

*Pat and Stan
Grandparents to Jessie
Piermont, NY*

A: When asked how we “Came to terms” with our granddaughter’s diagnosis of Rett syndrome, we didn’t know quite how to answer.

Perhaps we’re more pragmatic than others but, after the initial shock, we quickly realized that our feelings of love, for Jillian,

were no different than before the diagnosis. Our concerns focused on how we could make her life as comfortable and fulfilling as possible. And, on how we could best assist our daughter and son-in-law (Colleen & Jeff Peterson) in her care and upbringing.

We’re extremely fortunate in that we live very close to Jillian and are able to spend many hours with her (and her siblings) each week. Her smiles and giggles are as rewarding, to us, as any achievement or success would be from a child with no disability.

*Chuck and Joan Carlson
Grandparents to Jillian
Livonia, MI*

Grandparents,

You have a wealth of knowledge to share with others! Do you have an idea for our next Q & A section? Would you like to share a story about your granddaughter? If so, please contact Jennifer Endres at jendres@rettsyndrome.org.



24th Annual Conference

continued from page 1

the globe spent the extended weekend listening, learning, digesting, and bonding. Friday's Welcome Address and Orientation were followed by Crackerbarrels, where attendees broke into open-discussion sessions by Child Age and had the chance to find camaraderie and support through sharing common experiences.

"From [the] beautiful facility, so nurturing for parents, to the support and wonderful information, this [was] a fabulous learning experience...uplifting"



Lt William Keegan opened the conference with his keynote address. Everyone was touched by the parallels he drew between the team work required to recover from the 9/11 attack in New York and the teamwork and togetherness required to rally around our children with Rett syndrome. Hardly a dry eye in the house, along with some chuckles; each one of us was elevated by his courageous tale of overcoming life's unplanned events.



Alan Percy, M.D., Rett Syndrome 101

Saturday offered us a look into health issues, including a series of talks by world-renowned physicians and clinicians, expert in some of the common complications seen in Rett syndrome. Without baseline good health, and strong flexible bodies, it's incredibly hard to work on the complex fun stuff – like communication!



Judy Lariviere, M.Ed., OTR/L Assistive Technology Specialist and OT

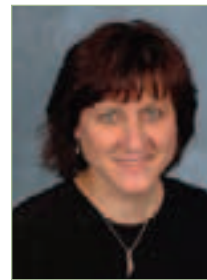
"Speaking" of communication...highest marks went to our exceptional communications speakers. Attendees "loved Susan Norwell and Judy Lariviere." Called "wonderful, exceptional advocates for Rett syndrome", these ladies really brought home the bacon in terms of the very real ways we can offer our "Silent Angels" a voice in this world. Parents of children young and old said these sessions were not to be missed. Our conference exhibitors Blink Twice! and My Tobii added depth to our conference by allowing parents plenty of hands-on demonstration time.



Communication with Susan Norwell, M.A. Spec. Ed.



On Sunday, we took a deep dive into the fascinating, sometimes hard to understand, world of Genetics and Research. Emerging data is helping us make sense of our children's mutation types, and is giving researchers direction and understanding of how the MECP2 gene affects development. Families had a chance to ask the experts questions, and have these tough concepts clarified.



Carolyn Schanen, M.D., Ph.D.



Genetics 101 with Dr. Carolyn Schanen

With over 30 unique sessions, there truly was something for everyone. This was definitely a fast-paced, listen-closely kind of conference. If you missed the opportunity to participate, you can catch up on the material by downloading many of the speaker handouts from our website, and purchasing the companion audio tapes of all sessions from Aurora Recording. Simply visit: www.AuroraRecording.com or call 1.800.972.8273

"Clinicians were engaging and spoke in a way parents could understand"



Fantastic Sibling Panelists with facilitator Diane Ross

24th Annual Conference

The exchange of ideas for everything from care techniques to managing services and raising important research dollars cannot happen in isolation. It takes this kind of face-to-face interaction, experiencing the spark, warmth, and humanity of our shared experience to shake us out of our learned habits and routines. The information learned in Chicago is best put into practice by carrying it home and putting into shared practice with our local physicians, educators, caregivers, policymakers and communities. Mark your calendars for Memorial Day weekend 2009 – Can't wait to see you there because Together We Are Better!

"The conference was well done. I learned many helpful things – ideas, tips, handling of local school system."



In the midst of learning, we took the time to honor some exceptional people that have advanced the mission of IRSF, and the field of Rett syndrome. We were honored to present 3 very special annual awards in Chicago.

ART OF CARING AWARD

Dr. Daniel Glaze, Medical Director, Blue Bird Circle Rett Center, Baylor College of Medicine, was recognized for his years of compassionate care to hundreds of families affected by Rett syndrome, and his outstanding contributions to improving the quality of life of his patients. Dr. Glaze is one of the world's leading experts in the neurophysiological manifestations of Rett syndrome, particularly for sleep and seizure problems.

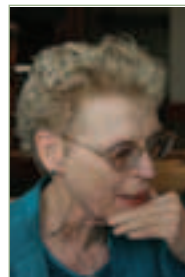


Daniel Glaze, M.D.



CIRCLE OF ANGELS RESEARCH AWARD

Dr. Helen Leonard, Clinical Associate Professor at the Telethon Institute for Child Health Research and Medical Coordinator of The Australian Research Study, received the 2008 "Circle of Angels Research Award". Dr. Leonard was honored for her substantial contributions which have increased the understanding of RTT at the most basic levels and helped define RTT phenotype and clinical outcomes. Her collaborative involvement with the InterRett Database is a critical resource for researchers, clinicians and families. Dr. Helen Leonard always keeps families at the heart of her research.



Dr. Helen Leonard

VOLUNTEER OF THE YEAR AWARD

Diane and Mick Ross of Chicago, Illinois, were awarded the IRSF 2008 Volunteer of the Year Award, for their long-standing fundraising activities, advocacy efforts, board service, and direct support and service to families affected by Rett syndrome within their own community and beyond.



Paige Nues, Mick and Diane Ross and Chuck Curley

6TH WORLD RETT SYNDROME CONGRESS

Beginning on October 10th and running through October 13th, 2008, the World Rett Syndrome Congress will be held in Paris, France.

IRSF is proud to support and attend the 6th World Rett Syndrome Congress. For program and conference schedule information, please visit www.rettssyndrome.org



Regional Representative Program

Our Regional Representatives have been busy this summer gathering families together and raising funds for IRSF's mission! Thank you to all of our Reps who give so generously to the families within their region! On behalf of all families, we sincerely appreciate all you do.

REGIONAL REP ACTIVITIES AROUND THE COUNTRY

Maggie Wurm, Bilingual Rep for the Eastern Time Zone, hosted a carwash which raised close to \$400! Korbin Wurm, older brother of Madasyn (RTT), worked hard selling lemonade to all participants! He was quite the salesman, urging folks to not only have their car washed, but also to buy a glass of lemonade! Way to go Wurm Family!



Korbin working hard!



Wurm family washing cars

Marla Black, Tennessee's Regional Rep, gathered 15 families together on June 28th for a picnic. Not only did the group enjoy the day getting to know one another, they also were able to hear three guest speakers from Rising Above Ministries, Neighborhood Networks and TN Microboard Association. Plans are already under way for the next gathering!



Getting to know each other at the Tennessee Family Picnic

Oregon's Regional Rep, Joey Razzano, was busy assisting the Northwest Rett Syndrome Foundation's dinner fundraiser where they drew approximately 75 attendees and raised close to \$7,000 for research! The guests were treated to an evening of traditional Bharatanatyan-Style Indian dancing performed by 6 Portland-area high school students. An Indian Cuisine was followed by an inspirational message by Dr. Patrick MacLeod on the interrelationship of art and science in decoding and solving the mysteries of Rett syndrome. What a fun way to raise money and awareness!



About 19 families enjoyed a family picnic hosted by Lisa Rushin in Alma, Michigan

Interested in becoming a Regional Representative?

If you are able to commit to providing information and emotional support to families, encouraging efforts to raise funds for treatments and a cure for RTT, and to increasing public awareness of RTT, please contact Jennifer Endres at jendres@rettsyndrome.org or by calling 508.394.3011. You may also apply online at www.rettsyndrome.org.

Our Southern California Regional Rep, Sherri Brady, has been busy as usual with a host of activities! One to make note of is that Sherri made a presentation on Rett syndrome at the Shea Center for Therapeutic Horseback Riding where she was able to inform the trainers, therapists and volunteers of Rett syndrome. Several girls diagnosed with Rett syndrome, including Sherri's daughter, Lauren, attend this center. Way to increase awareness and educate others!

Lisa Rushin, Regional Rep in Michigan, hosted a laid back family picnic in Alma, Michigan on July 26th. Lisa made the food, her sons grilled burgers and hot dogs, and friends donated fruit and pop. Lisa introduced herself, family and friends, talked a little about Ambucs.org (a program that finds donors for specially adapted bikes for those with special needs). Each family, about 19 total, introduced themselves and then everyone just mingled and had a great time. What a way to build friendships on a summer day!



Gala Events

PICTURE A CURE 2008 NYC

Held on June 26th, the 6th Annual Picture a Cure Benefit for IRSF was another great success! Event chairs, Maura and Steve Gallucci, IRSF Vice Chairman, were joined by close to 400 guests who gathered to lend their support. The evening's highlight, the live and silent auctions, raised over \$150,000 for IRSF! We would like to extend our thanks to the Gallucci's, the auction chairs and the journal chairs who all did an outstanding job. Steve Gallucci introduced Dr. Tony Horton, IRSF Chief Scientific Officer, who addressed the crowd and provided an overview of the research landscape and IRSF's future direction. The evening ended with a "Hero's Challenge" where attendees were asked to "bid" on straight donations to benefit the efforts of the Foundation. The energy in the room was extremely high as hero after hero raised their hands to pledge their support. This year's "Hero's



Challenge" raised \$48,000! Thank you to Maura and Steve and all who participated and supported the 6th Annual Picture a Cure Benefit - with donations still rolling in the event should top \$400,000!

THE NIGHT OF 1000 ANGELS

The Night of 1000 Angels was held on May 18, 2008 in College Park, Maryland. Marie Brayman chaired the event which raised \$10,300. The Night of 1000 Angels included dinner, music and a silent auction. The event was hosted by the American Legion and included auction donations from the local business community and friends. In attendance were figures from the local and state political arena. Senator Cardin sent a letter supporting funding for RS research, which was read by a representative from his office.



Sarah Chakwanda and daughter Libbie

FUND DEVELOPMENT

Fund development is central to IRSF's mission of Research, Family Support, and Advocacy and Awareness. Effective fundraising provides IRSF with the resources necessary to carry out our



*Chuck Curley,
IRSF Executive
Director*

mission and serve all those affected by Rett syndrome. Over the years a network of fundraising events has been established and we need to build upon that network in order to ensure we have the resources required to fulfill our mission.

From gala events to strollathons, golf tournaments, runs for Rett, bake sales, lemonade stands, fishing competitions, rides for Rett,...you name it, we have someone organizing it! We are extremely grateful for all who organize and/or

participate in an IRSF event. Your support is crucial to our success and our ability to meet the needs of the families and individuals living with Rett syndrome.

This fall we will launch our annual appeal in conjunction with October Rett syndrome awareness month. October will also play

host to the Phantom Tea, the newly created Cyber Café and numerous regional events. We need your active participation and involvement in order to achieve our mutual goal of finding a cure while also improving the lives of those living with Rett syndrome.

If you are interested in hosting an event please contact our office at 1-800-818-RETT (7388) and we will be glad to assist however possible. If there is an event in your local area please support those hosting it with your participation. It means a great deal to the host to see local families attending and supporting their hard work.

Thank you for trusting in our mission – together we will make a difference in the lives of those living with Rett syndrome.

*Best Wishes,
Chuck*



Supporting IRSF

STROLLATHONS

May 3, 2008 - St. Louis Strollathon - St. Louis MO

Chaired by: Joyce Opinsky
Amount raised: \$60,000

Summary: Over 400 people turned out for the first annual St. Louis Strollathon in Tilles Park. Despite a chilly morning, the Stroll was a huge success and raised approximately \$60,000. Fredbird, the St. Louis Cardinal mascot, led the 1-mile Stroll through the park. We also had a local radio personality, DJ, face painting and lots of family fun.



St. Louis Strollathon

May 17, 2008 - Emma and Friends Chicago Strollathon - Midlothian, IL

Chaired by: Marcia Adamski & Stephanie Bantsolas

Amount raised: \$13,000

Summary: The 1st Annual Emma and Friends Strollathon was a huge success. The



Chicago Strollathon

participants enjoyed a beautiful three mile stroll through nature followed by lunch and a performance of "Those Funny Little People". Music and fun were provided by our DJ and clowns. The weather was perfect and everyone had a great time while raising funds for research.

May 24, 2008 - 2nd Annual Race for Grace Strollathon - Narragansett, RI

Chaired by: Tara Reddington

Amount raised: Money is still coming in
Summary: Race for Grace uplifted many hearts and spirits as hundreds and hundreds of supporters came to walk, run stroll and roll for Rett. Not only did we raise a lot of money, but more importantly we raised tons of hope and faith in the community and beyond. The stories of how Grace has touched lives still reach us and continue to inspire us to work hard and help Grace continue her work in this world of spreading love wherever she goes.



Race for Grace Strollathon

June 1, 2008 - Greater Boston Strollathon, MA

Chaired by: Paula Curley, Maria McNernan and Irene Gladstone

Amount raised: \$20,000

Summary: Over 250 friends and family members gathered in support of the Greater Boston Strollathon. Our thanks to event organizers Paula Curley, Maria McNernan, Irene Gladstone and the many volunteers who made this event possible. Participants enjoyed the walk, a fantastic cookout courtesy of Chuck Horne of the Eaglebrook Saloon and our friends at Roche Brothers supermarkets, and were dazzled by the magic show. Everyone had a fantastic time.

RIDE FOR RETT

May 4, 2008 - Ride For Rett - Pipersville, PA

Chaired by: Mindy McCauley and Jenn Cwikla
Amount raised: over \$14,000

Summary: Ride for Rett was a fun-filled family



Ride for Rett - Pipersville

event that included pony rides, barbeque and bake sale, silent auction and basket raffle. The main event was a Ride-A-Thon on horseback. Each participant raised money to be able to ride. Our top fundraiser was Sarah Nedwick who raised over \$400.00. The weather was beautiful and turnout was fantastic.

June 1, 2008 - Lake Tahoe Ride For Rett - Lake Tahoe, NV

Chaired by: Bill Farnum

Amount raised: \$18,860

Summary: The weather was absolutely perfect, mid 60s and sunny, and you couldn't ask for a more picturesque backdrop than the crystal clear waters of Lake Tahoe. The ride started at the South end of the lake as we rode clockwise around it. First past the ching ching of the casinos in South shore, then up the epic climb at Emerald Bay, followed by a nice 40 mile cruise through Homewood, Tahoe City and King's Beach, past the multi-million dollar homes of Incline Village, and finishing with an 8 mile climb and 12 mile descent at Spooner Lake back to the finish line. It was truly incredible.

The greatest part was that thru generous pledges of friends, family, and co-workers, we were able to raise over \$18,000 for the IRSF for Rett Syndrome Research and Family Support. Thanks to everyone who helped make this a reality!!



Ella and Bill Farnum

GOLF!

May 10, 2008 - Par 4 the Cure Golf tournament - Rehoboth, MA

Chaired by: John and Ruth Slater, Cathie and Chuck Turner, and Gina Dulong

Amount raised: \$6,000

Summary: For the love of their granddaughter/daughter/niece, Sarah Elizabeth Turner, age 21, John and Ruth Slater (grandparents), Cathie and Chuck Turner (parents) and Gina Dulong (Auntie Gi) co-hosted the First Annual Sarah Turner Golf Tournament to benefit the IRSF. The tournament was held on May 10, 2008, at the Hillside Country Club in Rehoboth, Ma., and was by all accounts a huge success. We took out 70 golfers and had an additional 30+ for the dinner and raffles that followed.

May 20, 2008 - 3rd Annual Samantha Corpus Golf Tournament - Blackhawk, CA

Chaired by: John and Kathy Corpus

Amount raised: \$164,000

Summary: The 3rd Annual Samantha Corpus golf tournament sold out again this year! 144

Supporting IRSF's Mission

golfers and an additional 80 dinner guests came out to enjoy golf, silent and live auctions and dinner. In addition, over 45 companies supported the golf tournament with food, beverages and monetary corporate sponsorships. Over 60 individuals and families who could not attend this year's event donated to IRSF. Please visit www.samanthacorpus.org to check out pictures and all the stars that made it a spectacular event.



Samantha Corpus Golf Tournament

June 22, 2008 – 4th Annual Western MI Golf Tournament – Allendale, MI
Chaired by: Scott Novitsky
Amount raised: Money is still coming in!
Summary: The 4th annual West Michigan Rett Syndrome golf tournament had approximately 100 attendees. They were privileged to have two representatives from the Van Andel Research Institute (Bart Williams Ph.D. & James Resau Ph.D.) Dr. Williams also gave a brief description on Rett syndrome and the current work they are doing at the VARI. They also had five girls with Rett attend the event. As usual, it was a fantastic day and event!

FOR THE ANGELS

May 10, 2008 – Yard Sale for RTT – Shepherdsville, KY
Chaired by: Lauren Walls
Amount raised: \$925
Summary: This annual yard sale is held in honor of Michaela Walls by her family and friends. Volunteers bring all sorts of items to sell at this yard sale from jewelry to toys for children.

June 14, 2008 – 3rd Annual Race for Mace – Tustin, CA

Chaired by: Michelle Walker

Amount raised: \$15,000

Summary: On the morning of June 14th, 25 runners participated in the Camp Pendleton Mud Run with the team name "Race for Mace". One of the Race for Mace teams placed 3rd in the team event. After the run approximately 300 people celebrated at the Race for Mace party at the home of Ryan Woods.

HELPING HANDS

September 2, 2007 - With Your Helping Hands We Can Find a Way to Fight the Cause and Find a Cure! – Great River, NY

Chaired by: Anthony and Nancy Dattero

Amount raised: \$30,000

Summary: Thanks to all who attended and donated their time and resources to the first annual "With Your Helping Hands We Can Find a Way To Fight the Cause and Find a Cure!".



Anthony, Nancy and their daughter, Jayme

The evening was a tremendous success beyond anyone's expectations. What started out as a gathering to promote Rett syndrome awareness quickly turned into a gala event with over 200 people in attendance. Family, friends, community

members and local merchants combined efforts to raise over \$30,000 dollars in a spirit of fun and hope that one day a cure may be found.

A STAND FOR RETT

Thank you to all nationwide who participated in IRSF's A Stand for Rett summer lemonade fundraising activities!



Alison R's family

IRSF NEEDS YOUR HELP!

IRSF is currently leading an advocacy campaign designed to ask Congress for funding to support increased physician education about RTT. We are also asking Congress to encourage increased NIH funding of Rett syndrome research. Congressman Steny Hoyer (D-MD) and Senator Ted Kennedy (D-MA) have agreed to sponsor our request to the Labor, HHS and Education Subcommittee.

Specifically, the request is for funding to aid in education and awareness for patients, health professionals, and the public regarding Rett syndrome (RTT), as well as outreach, registry formation and database build-out to effectively organize and accurately inform families that are dealing with this debilitating disorder and the providers who serve them. This request will fund international conferences of parents, researchers and physicians, outreach materials and the continuation of a longitudinal study to chronicle and database the progression of clinical features, quality of life, and longevity of girls with RTT.

We need you! It is critical that we show widespread advocacy across the nation supporting this request. We are asking that you take the time to write a personal letter, make a call, and visit your local

Congressman's office. You can take action today! Please visit our newly expanded online advocacy website at www.rett syndrome.org. This turnkey site makes it easy for you to find your local congressmen and act quickly by providing you with sample letters and tips to make your visit successful. For more information, call 1-800-818-RETT.



IRSF Awareness

OCTOBER IS NATIONAL RETT SYNDROME AWARENESS MONTH!

It is not too late to make a difference this October by raising awareness of Rett syndrome and how it has impacted your life. IRSF hopes that you will consider some of the following activities when you are thinking about Rett Syndrome Awareness Month.

- Write a letter or call your local newspaper about what having a child with Rett syndrome means to you. Contact the local health reporter or tv station. We are happy to provide you with an IRSF media kit to assist your efforts.
- Take photos of your loved one and send them to IRSF for our promotional materials with a signed release form.
- Call and email your state and national legislators to ask them to support funding for RTT research and physician education. Send RTT materials and a personal note about how RTT has impacted your life.
- Order the Rett Syndrome Handbook for your school, doctor or local library.

- Offer to do a presentation on RTT at your local school, church or civic organization. Pass out flyers and literature. Wear a button of your loved one.
- Participate in the "Phantom Tea", a direct mail fundraiser offered by IRSF every fall for RTT Awareness Month.
- Encourage your school to start a circle of friends program that invites typical peers to form a network for children with disabilities at their school.
- Raise awareness via Rett Syndrome merchandise. We have t-shirts, hats, purple bracelets, RTT pins, car magnets, ties and totes. Call and order yours today.
- Thank your teachers and caregivers for all that they do, and give them a Rett Syndrome Handbook, a RTT t-shirt, bracelet or hat.
- Ask a local business to donate a portion of the proceeds of their sales to IRSF during a weekend this fall to promote awareness. Have them post a sign about RTT.

IRSF is working to raise awareness of Rett syndrome this October through a coordinated media outreach effort, public service announcements, and the distribution of Rett syndrome materials to the medical community and key legislators. We are also thankful to those of you that are **hosting an event, passing out educational materials, contacting the media, or making a donation in honor of a loved one.**

- Thank your physician for their support and provide them with awareness materials.
- Decide to hold a small informal luncheon, dinner or cocktails with friends, neighbors and family. Show a RTT video, and ask for contributions to IRSF for research.
- Commit to forming a network with other families in your area that are impacted by Rett syndrome. Think about hosting a Run for Rett, a Strollathon, or golf tournament next year to support more research and family support programs from IRSF.
- Invite someone to attend the IRSF Family Support Conference this Memorial Day Weekend.

TEA TIME!

The 12th Annual IRSF Phantom Tea will take place this October. This easy and fun event is a great way to raise awareness with friends and family and raise funds for IRSF programs at the same time. IRSF does most of the work for you, so it is an easy way to help. All you need to do is send out printed invitations and thank you notes to your mailing list of family, friends, neighbors, co-workers, customers, teachers, doctors, classmates, anyone at all! During Awareness Month, participants will drink a cup of tea provided in the invitation, toast IRSF and send a check for the cause. You will be astonished at the response! Please join us in this annual event.



IRSF PUTS A SPIN ON TEA WITH THE NEW "CARE AND CURE CAFÉ"

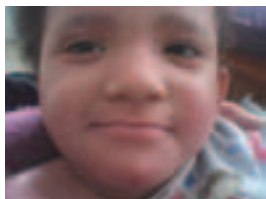


This year we're not only offering a chance to have a cup of tea with a Rett angel, we have a whole café! You can order your printed packets of Tea again this year and have a "Tea Party" OR hop online and have a Latté or Milkshake in honor of the Rett angel in your life! All available through the new IRSF Care and Cure Café!

This new virtual café allows families and friends to cheer to your special angel through a donation made online on the IRSF website. We will be launching the Care and Cure Café during October Rett Syndrome Awareness Month! You can order your Phantom Tea packets for your Tea party or blast an email out to your friends and family. You can provide them with a link to the online Café to get them involved in our mission to find a cure for Rett syndrome – and even personalize with a picture of your angel! It is fun and easy, and another way to share a cup of Joe with loved ones.

To set up your virtual coffee cup, or for questions, email jgrammer@rettsyndrome.org or call 513-874-2657.

In Honor of Angels



Mya Henry

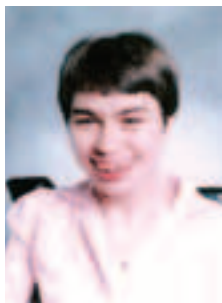
mother Tina and sister Shania. She loved going to school. She blew the cutest raspberries and would just stare at you with her most beautiful brown eyes. Tina's mom says "We miss her so deeply. She was the sweetest most precious angel. She taught us Love". Mya's 8-yr old sister, Shania, was very close to Mya and would lay around and talk with her all the time. Shania wrote, "Mya...God formed you so beautiful and special. I love you so much, you who would always cheer me up when you smiled. I can't wait to see you again in heaven and we will run and laugh".



Tera Gonzales

new of their ups and downs. She was strong in her own way. She would comfort her mother with a pat on the head, and would just smile when held close. She never just gave away her smiles – only when she thought they were needed. Tera was also the household food critic. They always tried to improve her life by cooking new foods, and she had a look that told you if she approved or not.

Tera is missed by many. She is mostly remembered for her courage, strength, love and beauty that she tried to show to everyone that met her.



Dawn Marie Ouellette

the police. Dawn's mother, Evelyn, invited the police in for a cup of tea assuring them Dawn did the screaming on her own and they could

Mya Henry, 5, also diagnosed with Cystic Fibrosis, passed away unexpectedly on April 10, 2008 from cardiac arrest. Mya lived at home with her

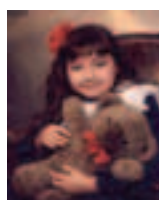
witness it if they just took the time. They accepted the invitation, and within moments, Dawn let go, which, as observed by the police, was prompted by neither physical abuse or words. They were never bothered again. The screaming, after what felt like a lifetime for her parents, did stop around age 4.

At 3 years of age Dawn was diagnosed as borderline autistic with CP, though her parents never saw her as fitting in with the other children in this same group. At age 8, she most enjoyed walking to the couch in such a way that when she sat down, she would sit on their dog (a very tolerant poodle who would just wiggle out from under Dawn and lay beside her). Dawn was giggling the whole time.

Her teachers always said that Dawn could look into your soul, her smile captured your heart, and her crying (without making a sound) could break your heart as well. Her mother lovingly cared for her, always kept her sweet smelling, hand-made bibs with snaps so the ties could never be tied too tight, and knew how to read when she was hungry or thirsty.

It was Dawn's multiple pneumonias by age 12 that prompted the Oulette's to move from cold Massachusetts to warm Florida (paradise for Dawn's dad!). This is where they received the gift of the diagnosis of Rett syndrome, and a VCR tape from IRSA about RTT. They call the diagnosis a gift because they then knew what to expect and what NOT to expect of her – which made life easier for them, though maybe not for Dawn.

Through scoliosis surgery and other challenges, Dawn never lost her smile. As she grew older, her eye contact improved. When someone would say "Hi Dawn" she would turn her head, look them right in the eye, and give them a great toothy smile, while her eyes sparkled. Everyone that new Dawn loved her!



Mesia Lynn Pride

her family, despite frequent hospitalizations with pneumonia, seizures, aspirations, surgeries, and eventually chronic lung illness and pancreatitis. Mesia was born a fighter and regardless of what went wrong, she never gave up. She continued to inspire everyone around her until she drew her last breath. Mesia exemplified the true meaning of "Silent Angels" with her ability to communicate without ever saying a word. There was a reverence much like would be

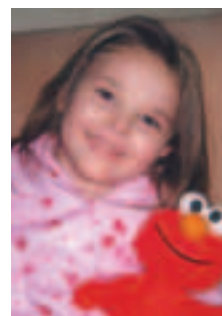
Mesia Lynn Pride, 27, died May 25, 2008 at Kosair Children's Hospital in Louisville, Ky. surrounded by her family. Each day of Mesia's life was truly a miracle. She courageously battled illness and defied the odds year after year.

She lived at home with her family, despite frequent hospitalizations with pneumonia, seizures, aspirations, surgeries, and eventually chronic lung illness and pancreatitis. Mesia was born a fighter and regardless of what went wrong, she never gave up. She continued to inspire everyone around her until she drew her last breath. Mesia exemplified the true meaning of "Silent Angels" with her ability to communicate without ever saying a word. There was a reverence much like would be

an angel on Earth, which always resonated when around Mesia. She had a unique ability to look straight into your eyes and connect with your soul.

These beautiful big bright eyes and the never-ending smile are what Mesia's family and friends miss the most. Even when her health worsened and took away the happiest things in the life, this once social little girl just re-adjusted her priorities, as she had done her whole life while living with Rett syndrome. Instead of going to school, a movie, church, shopping and rides in her wheelchair, Mesia was happy with her newfound way to happiness. She felt so much joy to have the opportunity to be home-schooled, watch movies (Disney her favorites) on the big screen, private piano concerts by her brothers, surround sound music, puppet shows by her little nephews, and shopping online. She was grateful for everything and never wanted pity. Mesia always gave. She asked for nothing.

Accordingly, Mesia's legacy of "always giving" was honored in her death. Mesia's organs and tissue were donated exclusively to IRSF, with the hope and prayers of her family that one day soon a cure will be found for all of Mesia's Rett sisters in life. To leave an online condolence, go to www.courierpress.com and search Mesia Lynn Pride guestbook.



Anna Shackelford

or anyone else in the world. She attended Happy Day School and was a member of Bethel Baptist Church. She also loved to swim, watch Wee Sing, listen to music, and swing in her backyard on a nice day. Anna taught many around her to enjoy the simple pleasures life has to offer, and to appreciate the value of family. You can view her memorial and sign the guest book at www.mem.com, enter last name Shackelford, first name Anna.

