

# Rett Link

A Publication from the  
Rett Syndrome Association of Illinois  
[www.rettillinois.org](http://www.rettillinois.org)

Linking the Rett  
Community Together  
Winter/Spring/2009

## 2008 Annual Dinner Dance & Auction

by Marie Kral  
'08 DDA Event Co-Chair



October 4<sup>th</sup> marked the Rett Syndrome Association of Illinois' 19 Years of *Caring and Sharing* Annual Dinner, Dance and Auction. Over 300 family and friends gathered to support the Annual Fund-raising Event at Drury Lane Oak Brook, IL. We have raised over \$53,000, which is funding that will enable the RSAI to continue to support quality initiatives in our Rett Syndrome community.

Our Annual Event was again co-chaired by Marie Kral and Michele McGovern. Although this Event has taken place annually since 1989, this is the fifth consecutive year that Marie and Michele co-chaired this Event! Many volunteers generously offered their time and talent to assist in

coordinating the event: Kay Borchardt, Mike Borchardt, Camille Buzinski, Leslie Chatwood, Carol Conboy, Lisa Faul, Sharon Haas, Cheryl Jagen, Paul Jochim, Frem Jodoin, Gary Kral, Kevin Kral, Shannon Lahey, Maryann Lanan, John McGovern, Maureen McGovern, Megan McGovern, Corki Meade, Courtney Pryor, Philip Pryor, Joanne Richards, Tim Selover, and a great group of Student Volunteers - Julie Bell, Kate Burnier, Elen Chenski, Laurel Collinet, Jessica Everaert, Kyle Freischlag, Katie Gordon, Katie Ilich, Alex Anne Mastroni, Megan McGovern, Lauren Minardi, Kant Pandya, Jamie Pine, Mary Prasnikar, Allison Rogala, and Jerry Scott. "WOW" - What a GREAT Team!!!

A special "Thank You" to:

- Drury Lane for their expertise and generosity, and to the staff of Drury Lane for their excellent food preparation and service
- Dean & Suzy Anderson of Midwest Conference Service / Audio, Visual, and Technical Assistance, Signage and Tribute Banner
- Carol Conboy - Flower Centerpieces
- Frem Jodoin of Jimmy's Place / Table Wine
- Caffé Baci - for the chocolate fruit-filled truffles
- Karyn & Tom Lisowski / Tribute Video
- Linda Lahey / Rett Syndrome Angel Bracelets & Book Marks/Journals

*(continued on page 14)*

**Rett Syndrome Association of Illinois**  
**Celebrating 20 Years of Caring and Sharing**  
**1989 - 2009**

# Founder's Message

by Paul Jochim

Celebrating 20 years of service to the Rett community.

It's hard to believe RSAI has been around since 1989.

I was thinking about all that RSAI has accomplished in 2008. It was a great year because of many people volunteering and helping out at our events and supporting us.

In 2008 we held our 19th annual Dinner Dance and Auction, our 15th annual Family and Friends Swim Day, our 5th annual Zoo Day. Several RSAI members played in the 1st annual Buddha Golf outing for Rett Syndrome (a fund raiser), we sold tickets to the Six Flags Great America Coasters for a Cause (another fund raiser) and helped sponsor the International Rett

Syndrome Foundation conference in downtown Chicago. Since 1992 we have promoted October Is Rett Syndrome Awareness month and help co-sponsor 2 Rett Syndrome Natural History Studies at Rush University Medical Center. Thanks to everyone on the board of directors and all the volunteers and donors that helped make a difference in 2008.

Now 2009 is here and we are looking for more supporters and partners. There is more we want to do and must do to improve the lives of our

daughters and to help families that are struggling. You may have an idea on how we can get more awareness for Rett or an idea for a fund raiser. Please get involved and help make a difference.

I look forward to seeing you at our events and thanks again for your support.



## Equipment Exchange

1. 60 cans of PediaSure with Fiber **Enteral** Formula Vanilla, expires April 2009. Must arrange for pick up. Contact: Marie Kral, 630-910-7446 or kraldg@sbcglobal.net.

2. Wenzelite Tilt/Recline Chair with Traveler Base. Lightweight stroller with front swivel wheels and oversized rear tires; blue/purple fabric. Donated by the **Megan Sawyer** family. Contact Marie Kral—630-910-7446 or kraldg@sbcglobal.net—to arrange for your own shipping or pickup.

3. Tumble Forms 2 Trestander. Contact Valerie Stevens at 630-675-6921.

REMINDER: Anyone who would like to donate an item, please write a description of the equipment along with your contact information and forward it to Pjochim@aol.com. Any costs associated with shipping and/or receiving the equipment will be worked out between the two parties involved. *It is the responsibility of the receiving party to ensure that the item is safe and appropriate for their situation.*

## IRSF 25<sup>th</sup> Annual Conference

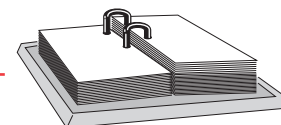
This year's conference, *Celebrating the Torch Within* is being held May 22-25 the Lansdowne Resort & Spa in Leesburg, Virginia. featuring leading experts in the field of Communication strategies in Rett syndrome like Susan Norwell and Linda Burkhart. Top physician specialists from the Kennedy Krieger Institute Rett Research Center at Johns Hopkins such as Dr SakkuBai Naidu will share their collective knowledge around assessment and treatment of common medical issues. Hear about the direction of research from leaders like Dr Carolyn Schanen. Please visit our website at [www.RettSyndrome.org](http://www.RettSyndrome.org) to learn more and register. See flyer for more details.

## RETT SYNDROME ASSOCIATION OF IL

One Tower Lane • Suite 1700 • Oakbrook Terrace, IL 60181

Phone: 630-645-2280 • Fax: 630-573-5205

## Calendar of Events



### 2009

March 8	16 <sup>th</sup> Annual Family & Friends Swim Day
April 25	10 <sup>th</sup> Annual Run for Rett
May 2	4 <sup>th</sup> Annual Six Flags Great America <i>Coasters for a Cause Day</i>
May 16	2nd Annual Strollathon for Rett Research
June 14	20 <sup>th</sup> Annual Family & Friends Picnic
August 7	2nd Annual Buddha's Golf Outing
August (TBD)	10 <sup>th</sup> Annual Hammer Open Golf Outing
October 3	20 <sup>th</sup> Annual Dinner Dance & Auction
October 11	6 <sup>th</sup> Annual Family Zoo Day

Watch for a flyer in the mail with more details for these upcoming events or check our website at [www.rettillinois.com](http://www.rettillinois.com)

# Run for Rett

## *Celebrating Ten Years On the Run*

by Diane Ross

Join us in celebrating our tenth anniversary of the Run for Rett. We need you to help make this our best year ever. You can help by bringing ten friends, donating an extra ten dollars, getting ten sponsors, telling ten people about the run, handing out ten brochures for the run, dropping off brochures at ten fitness clubs or service clubs. This list is endless of how you can help support this great event.

Saturday, April 25, in Busse Woods in Elk Grove, we will be celebrating ten years of success. You can run, walk, or volunteer for either the 5K (3.1 miles) or the one mile fun run/walk. Watch the mail in late March for the Run for Rett brochure. Please call 847-524-7540 if you have any questions.

# Strollathon

by Marcia Adamski

**S**AVE THE DATE: The Second Annual *Emma and Friends Strollathon* is set for May 16, 2009. The Stroll will be held at the Midlothian Meadows Forest Preserve located at the corner of 159th Street and Pulaski Avenue.

The committee is looking for volunteers to assist in the planning and execution of the Stroll. If you can help, please contact Marcia Adamski at [Strollathon@yahoo.com](mailto:Strollathon@yahoo.com).

The first ever *Emma and Friends Strollathon*, May 2008, brought in over \$16,000 for the IRSF with approximately 50-75 people in attendance. We hope the 2009 Stroll will surpass last year's totals in funds raised and overall attendance.

Mark your calendar, and we will see you there.

*The surest path to happiness is losing yourself in a cause greater than yourself.*

# Hammer Open

## *RSAI Received \$3000 Donation*



Juergen Huellen, the Hammer Open Committee Chairman for the Knights of Columbus, Council 11091 gives a check to Paul Jochim for \$3000 for the Rett Syndrome Association of Illinois. A big thank you goes out to all the 119 golfers and the 30 sponsors who participated in this year's 9<sup>th</sup> Annual Hammer Open: "golf outing making it such a big success in raising money for Rett Syndrome research."

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# PUNS – THE BASICS

## *From The Arc of Illinois, Family to Family Health Information & Education Center*

- PUNS stands for Prioritization of Urgency of Need for Services.
- PUNS is a list of the people in Illinois with developmental disabilities who need services.
- PUNS is for everyone who may need help from the government to pay for developmental disability services now or in the future.
- PUNS is the first step toward getting services in Illinois. If you are not on the PUNS list, you are not on the waiting list for services.
- To get on PUNS, you need to set up a date to meet with a Pre-Admission Screener. These screeners will ask questions about you and your needs. These questions are part of the PUNS survey. All screeners work for Independent Service Coordination Agencies or ISC's. To get on the PUNS list, you must have a developmental disability. If you don't know if you have a developmental disability, the screener will help you.
- To find your ISC, you can call Illinois Life Span at 1-800-588-7002. You can also call DHS at 1-888-DD-PLANS.
- When your PUNS survey is done, you are on the list. This doesn't mean that you will get the services you need. It just means that you have made the first step.
- Some of the services that people may need are:
  - In-Home Supports
  - Respite Care
  - Job Coaches
  - Group Homes
  - And many others
- There is not enough money to give everyone in Illinois the services they need. Right now, many people are working on a fair way to choose who gets services.
- Don't forget to update your PUNS form every year. Only people (families) who have completed the PUNS - and keep it updated - have a chance of getting "picked" to receive services.
- If you have questions or need help, you can call Illinois Life Span at 1-800-588-7002.
- If you want more information about PUNS or Home-Based Services, go to the Family Support Network website at [www.familysupportnetwork.org](http://www.familysupportnetwork.org)

2/8/09 The Arc of Illinois Family to Family Health Information & Education Center



## 5<sup>th</sup> Annual Fall Family Zoo Day

*by Kathy Medley*

The 5th Annual Fall Family Zoo Day was held October 12, 2008 at Brookfield Zoo. Nine families attended and we all had a wonderful time. The weather was bright and sunny, and very warm. Our first stop was everyone's favorite, the Dolphin Show. Other favorites included the monkeys, giraffes, exotic fish and the indoor jungle.

After spending several hours viewing the animals, we all enjoyed a restful backyard barbecue at the McGovern's house. We feasted on hamburgers and hot dogs and had plenty of time to visit with each other.

The next Zoo Day is scheduled for Sunday, October 11, 2009. Please be sure to mark your calendar and plan to join us.



# What's New in Nutrition: Vitamin D in Rett Syndrome

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by Kathleen J. Motil, M.D., Ph.D.  
The Blue Bird Circle Rett Center  
Texas Children's Hospital  
USDA/ARS Children's Nutrition Research Center  
Baylor College of Medicine  
Houston, TX

Suzanne Geerts, M.S., R.D.  
UAB Rett Syndrome Clinic and Civitan-Sparks Clinics  
University of Alabama at Birmingham (UAB)  
Birmingham, AL

“Vitamin D plays an important role in the nutritional health of girls and women with Rett syndrome,” says Dr. Kathleen J. Motil, one of the Rett experts who traveled from Baylor College of Medicine, Houston, TX, to attend the recent Rett research clinic held at the Rush University Medical Center.

Dr. Motil reported that the American Academy of Pediatric currently recommends that all children who ingest less than 1000mL/day (~32 oz/day) of vitamin D-fortified milk or specialized nutrition formulas should receive a vitamin D supplement of 400 IU/day. Children who have milk allergies/intolerances or refuse to drink milk are at risk for vitamin D deficiency. Vitamin D promotes bone health and prevents vitamin D deficiency rickets, a nutritional bone disorder that continues to occur in infants, children, and adolescents in the United States because of inadequate dietary vitamin D intake and decreased exposure to sunlight. Vitamin D also promotes host resistance against infections and may prevent some forms of autoimmune disease (e.g., multiple sclerosis, rheumatoid arthritis), cancers (breast, ovarian, colon, prostate), and diabetes.

Girls and women with Rett syndrome have an even greater need for vitamin D because they have lower bone mineral density and are at increased risk for bone fractures compared with unaffected individuals. Vitamin D is important because it facilitates the intestinal absorption

of dietary calcium for deposition into bone. Dr. Motil says that, while some girls and women with Rett syndrome have adequate vitamin D body stores, others have insufficient or frankly deficient blood levels of vitamin D, based on her recent studies of bone mineral content in these individuals. “Our girls have low vitamin D levels for the same reason that unaffected children have low vitamin D levels; they consume inadequate amounts of milk and dairy products and they have negligible sun exposure,” she says. In addition, the use of seizure medications may contribute further to vitamin D insufficiency.

Dr. Motil recommends that all girls with Rett syndrome receive four 8-oz glasses of milk or four cans of a recognized commercial formula to meet their daily vitamin D needs.

If they are unable to meet their vitamin D needs with food sources, then they should receive a supplement in liquid or pill form that provides 400 IU units of vitamin D daily. “Individualized product selection advice is available through your pediatrician, gastroenterologist, registered dietitian, or pharmacist,” says Ms. Suzanne Geerts, a registered dietitian who also traveled from Birmingham, AL, to Chicago for the Rett research clinic. If parents want to know the vitamin status of their daughter, they can ask their physician to order two blood tests, 25-hydroxyvitamin D and parathyroid hormone (PTH) levels. If blood tests are performed, Dr. Motil requests that the results be faxed to her at 713-798-7109 to help address the questions regarding vitamin D needs in girls and women with Rett syndrome who require seizure medications.

## Wanted: Family Articles

The newsletter is always looking for family articles and pictures for publication in our upcoming editions of the *Rett Link*. Please submit them to PJoachim@aol.com.

If your family hasn't been featured in our family column, we encourage you to submit your story about your daughter. Many people have commented how much they

appreciate those family write-ups.

We all go through struggles and some times we think we might be the only one going through it. But we are not alone. So please share your family write-up or your vacation trip and help someone else.

If you have any questions, please email me at PJoachim@aol.com or call 847-310-8876. All pictures will be returned.

# 1<sup>st</sup> Annual Buddha's Golf Outing

Friday, August 1, 2008 Poplar Creek Country Club, Hoffman Estates, Illinois—The raucous fundraiser formerly known as BUDDHA'S BASKETBALL BLOWOUT "GOIN' TO THE RACK" FOR RETT SYNDROME has gone golfing. The pandemonium revelry jumped from the hardwood to the fairway wood.

The event raised nearly \$15,000 for research. Over 90 golfers participated in the event with many more partaking in the pre- and post-golf festivities. Of course, Stephanie Schlueter and Jill Jochim were on hand to enjoy a fun-filled afternoon.

The 4-person "shamble" format was won by Gary Kazmer, Steve, Griffin, Lim Labarge and John Boyle. Jim Luke took home the honors in the putting contest. Thank you to all who participated in making this a successful event. Special thanks also to our event sponsors.

All will be welcome and encouraged to come out and play this coming year at a new course on Friday, August 7, 2009!



The Rett families would like to thank this year's sponsors: David Ferrino (Bully Hill Winery), Greg Sondag and Ron Gabaldon (InnerWorkings), Jim Siwek (Maxemail.com), George Pappagerorge and David Haymes (PHL), Mike Cipolla (CharterSteel), Ray Khatib & Marty Bauer (Khatib & Assoc.), Mike Sorensen & Leo Lesniak (GBL), Greg Semmer (Kinsella Landscape), George Keppler (Bovis), Richard Zisook and Alan Lev (600 Lake Shore Drive), John Sheridan (McHugh), Rich Horwath (STI), Joe Villanti (Metro. Arch), Mike Janis (QDG), Warren Johnson (WJA), Joe Drennan and Mike Jannusch (Sedgwick's), Jimmy Waldron (ThemReps), Tom Jacobs (T & K), Joe Minyard (Mad Croc), Joe Ferrino (Landor), Jerry Lavey (The Gym), Aaron Lavey (Website), Mike Gallo (FPO), Chuck Blum (the "Serene"), and all who volunteered.



# Rett Syndrome Natural History Study by Marie Kral, IRSF Local Clinic Coordinator Chicago/Rush

The Rett Syndrome Association of Illinois (RSAI) continues to sponsor the:

- International Rett Syndrome Foundation Clinics Research Program
- National Institutes of Health Rare Diseases Clinical Research Network
- Rett Syndrome Natural History Study

hosted at Rush University Medical Center by Peter Heydemann, MD, Director, Section of Child Neurology.

Over 70 families were scheduled for Study visits at the Chicago/Rush October 25-26, 2008 Clinic Event. The ever-popular Lunch/Panel Discussion, hosted by RSAI both Clinic days, provides a great opportunity for our families to network as well as interact with the Panel of visiting Rett syndrome Clinicians.

We have reached an amazing milestone of 100 Families participating at our local Chicago Clinic Event:

Illinois	36
Indiana	10
Iowa	4
Kansas	1
Michigan	22
Minnesota	3
Missouri	6
Ohio	8
Wisconsin	10

Participants ages 12 and under: 69 (through 10/08 seen twice annually\*\*)

Participants ages 13+: 31 (seen annually\*\*)

Our continued gratitude to Dr. Peter Heydemann, who was host to a prominent and highly knowledgeable team of Rett syndrome experts/researchers.

Participating Clinicians/Teams:

- Baylor College of Medicine: Jeffrey Neul, MD, PhD.; Kay Motil, MD, PhD.; Judy Barrish, BSN, RN
- University of Alabama at Birmingham: Alan Percy, MD; Jane Lane, RN, BSN; Suzanne Geerts, RD, MS
- Greenwood Genetic Center: Steve Skinner, MD; Joy Graham, RN; Fran Annese, LMSW

Thank you also to our special volunteer from Rush Pediatric Neurology: Debra Michalak, RN Practice Administrator, for, among many things, her coordination of the Rush facility and staff, assistance during the "Check Out" of the forms/Consents necessary for the Rett Syndrome Natural History Study, troubleshooting, etc., etc. We are thankful also

to several other volunteers: Kathy Serikaku, OT (Measuring, etc.); Gary Kral; Shannon Lahey; The McGovern's – Michele, Johnny, Danny, their cousins Andy and Brad Muno, and Kristen and Lauren O'Malley; Kant Pandya; and, Cassie Wells.

Thank you also to the participating families who are dedicated to the Study by attending and completing the required paperwork. Your participation benefits our entire Rett Syndrome Community.

Several papers have been published sighting data already gathered from the Natural History Study. If you would like to have these publications forwarded to *(continued on page 14)*



# 19<sup>th</sup> A Dinner Dance & A



# Annual Auction Celebration



# Thank You to Our DDA Cash Donors

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Catherine R. Marose  
Steve Sopocy

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Gerry Lockhart – 65th Birthday  
Marissa Noelle Goodhew – Con-  
firmed Rett Syndrome Diagnosis

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*We truly appreciate all donations and wish to also extend our gratitude to those who were not included in this list.*

# Where Does My Money Go?

by Mary Anne Ehlert, CFP • Protected Tomorrows, Inc.®

We were warned that the price of groceries was increasing and it did. We were warned that educational costs were increasing and it did. These are only two examples of increased prices; we see more and more on the horizon everyday. For most of us, our incomes didn't increase accordingly. So what can we do? We still need these products but how do we figure these and all the other "extras" into our budget?

The first step is to take a realistic and honest look at what you spend every month and compare it to your monthly income. You can't try to make ends meet until you know exactly what you're bringing in every month and how you're spending it. But remember, the key to this is realistic and honest numbers and it isn't just going through your checkbook to come up with these numbers. You will need to do some digging and searching to come up with accurate figures.

Some of the figures may surprise you. For example, think of all the gifts you probably buy. These include, holidays, birthdays, showers, weddings, graduations, christenings, etc. The list goes on and on. When we talk about food and groceries, we're not just talking about the weekly "big" trip to the grocery store. What about the quick trips in between? Be honest about what you spend in restaurants and yes, this includes trips through the drive-through! Don't forget the special programs for your kids: park district programs, dance classes, music lessons, etc. List all your expenses in categories for a given month. Remember, be honest about writing everything down and do not underestimate your spending. It all adds up.

If you ask yourself "Where does all my money go?" just take a look at your list. What about giving up a trip or two a week to the specialty

coffee house? How about one less DVD rental a week? Can you cut two trips to the fast food lane a week? This list will help you look for ways to cut your monthly expenses. The goal is not to place you on a tight budget, but to make you aware of what you are spending.



*Mary Anne Ehlert is the President and Founder of Protected Tomorrows®, an advocacy company that provides comprehensive life planning that addresses the educational, residential, financial, legal, health care, government benefits, employment and recreational needs of the individual with special needs. For more information, contact info@protectedtomorrows.com or visit www.protectedtomorrows.com.*



## Save the Date

**Saturday, October 3, 2009**  
**Rett Syndrome Association of Illinois**  
**20 Years of Caring & Sharing**  
**Annual Dinner, Dance and Auction**  
**Drury Lane in Oakbrook**

For more information call or email:  
Marie Kral (630)910-7446 or Michele McGovern (708)447-3961  
kraldg@sbcglobal.net mmcgovern6@sbcglobal.net

## 2008 Annual Dinner Dance & Auction *(continued from page 1)*

- Dee Fritz / Graphic Design
- VISOgraphic / Program Book Printing
- Jon Fey / Superior Awards
- A-Z Entertainment / DJ & Auctioneer

The generosity and participation of so many of our RSAI families and friends made this annual event quite extraordinary! The Donor Lists reprinted in this newsletter highlight just how well-supported the RSAI is in our Illinois community.

Several people/organizations were recognized during the evening for their continuing, generous financial support of RSAI:

- Adam “Buddha” Lavey - Platinum Angel Sponsor. We are very grateful to Adam for his many years of incredible generosity in raising funds for research – over \$115,000 to date.
- Golden Heart Home Health, Inc. – Jeff & Jennifer Lomibao
- Knights of Columbus, St. Margaret Mary Council # 11091 of Algon-

quin, IL, Annual “Hammer Open” Event – Tom & Nola Schlueter

- Knights of Columbus, St. John Council # 3738 of Westmont, IL

Dr. Peter T. Heydemann, MD, Section Director, Pediatric Neurology, Rush University Medical Center was recognized for his continuing support of the RSAI-sponsored IRSF Natural History Study semi-annual Clinic Events. Dr. Heydemann has generously hosted the semi-annual Clinic Event at his Rush University Medical Center Clinic.

Kathy Serikaku was also recognized as an outstanding Volunteer for her caring support of our Rett syndrome community. Kathy is a 30-year veteran Occupational Therapist and has volunteered at all of our semi-annual Clinic Events since April 2006 assisting the Baylor Team.

Our Annual Event is a time to pay Tribute to our girls and women and the many families facing the daily challenges of Rett Syndrome. We are grateful to each of you for your par-

ticipation; we could NOT have done it without you – your many contributions of time, talent, and resources culminated in another successful event.

Save the Date – Mark your Calendars! The RSAI “20 Years of Caring & Sharing” Annual Dinner, Dance and Auction will be held October 3, 2008 at Drury Lane Oakbrook.

The Rett Syndrome Association of Illinois strives to provide funding for research, awareness and education, and family informational support and networking activities. The Rett Syndrome Association of Illinois is a not-for-profit 501(c)3 Charitable Organization and your donations are tax deductible to the extent allowable by law.

Contact Marie Kral, 630-910-7446 - [kraldg@sbcglobal.net](mailto:kraldg@sbcglobal.net); or Michele McGovern, 708-447-3961 - [mmcgovern6@sbcglobal.net](mailto:mmcgovern6@sbcglobal.net) if you would like more information about participating in the RSAI Annual Fundraiser. All are welcome – every contribution does make a difference!

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## Rett Syndrome Natural History Study *(continued from page 7)*

you via e-mail, please contact Marie Kral ([kraldg@sbcglobal.net](mailto:kraldg@sbcglobal.net)).

Our original schedule included six Clinic Events between April 2006 and October 2008. Fortunately, we have been granted an extension from the NIH to include one additional Chicago/Rush Clinic Event, scheduled for the weekend of April 25-26, 2009. We have also just received confirmation that the protocol of the Study has been adjusted, which will allow us to enroll additional families:

\*\*Families currently participating in the Study have been notified of a change in the protocol for frequency of return visits. For the April 25-26, 2009 Clinic, families with children ages 5 and under will con-

tinue to be seen twice-annually and those participants over 6 will be seen once annually. Please contact Marie Kral if you have any questions about scheduling for the upcoming Clinic.

A proposal has been submitted seeking a 5-year renewal of the NIH-funded Study – which would extend the Natural History Study through Spring 2014. This not only will allow us to continue scheduling visits for those families already participating, it will also give us the opportunity to continue to enroll many more families to the Chicago Local Clinic. We will be informed of the status of the continued funding before Spring 2009.

If you would like to confirm your place on the wait list, or be

added to the wait list, please contact Marie Kral, [kraldg@sbcglobal.net](mailto:kraldg@sbcglobal.net), or phone 630-910-7446 (between the hours of 9-5 only please). Openings will be filled by qualified participants on a first-come basis.

The Clinic Event is sponsored by the RSAI, which covers the cost to host the “Rett Teams” as well as the Group Meeting room rental and media services, all of the supplies, the lunches/snacks/refreshments, etc.

*Your donations to RSAI are welcome to support the upcoming IRSF Local Clinic Research Program/ Natural History Study Event or for any of RSAI's quality Programs.*

**M**y fellow parents of a child with special needs face many challenges, but none is more pressing than our concern about what will happen to our child in the event of our death or incapacity. Because parents of children with special needs often have a difficult time making these decisions, procrastination and avoidance may result. Too often, nothing gets done until very late in life, if the parents live long enough and have their mental capacity. Estate planning for a family that includes a child with special needs can be much more complicated than for other families. A "simple" plan will not suffice, but the opportunity to make a real difference in the life and future of our children with special needs should motivate us to plan, carefully, and early. No one knows how many days any of us have.

## **Getting Started:**

Sometimes the problem of inertia is heightened by parents' concern about getting the plan "right" the first time. Once a plan is initially prepared, it is easy to make changes or amendments as times, needs and understanding change. For instance, the selection of a guardian for a minor child might favor grandparents, uncles or aunts. As time goes on and family dynamics change, the child's brothers and sisters may be more logical choices. It may even be advisable to allow the decision about caretakers to shift from one generation to the next as the child's siblings become mature, responsible and ready to take on the future needs of the child with special needs.

## **Elements of the Plan:**

In preparing the plan, the usual documents should be completed, including advance directives, such as a "Health Care" Power of Attorney and "Property" or Financial Power of Attorney, a will, Short Term Guardian Declaration (delegating your authority to some one

else when you are out of town), Stand By Guardian Declaration (delegating your authority in event of your disability). While most people prefer simplicity in their documents, when there is a child with special needs in the mix, a "simple" will not be sufficient to provide for that child's needs. There should be a comprehensive plan to provide for those needs, and it will include a "special needs trust", and possibly two such trusts (there are two kinds).

A special needs trust has a two-fold purpose -- providing for management of assets for the child with special needs, while protecting the child's eligibility for means-tested government benefits, such as SSI and Medicaid. To the extent that medical care, food, shelter, etc. are not otherwise provided, the trust can even help to ensure coverage for basic needs.

The funds in a special needs trust are usually available for "extras," (as opposed to necessities,) during our child's lifetime. These extras might include vacations, companions, televisions, or massage therapy, to name a few. It may also provide for typical family gifts on behalf of our child with special needs, and charitable contributions to organizations that either provide or may provide in the future for our child with special needs.

As part of the planning process, parents of a special needs child should consider the potential for public benefits in the future to ensure that they are not lost. This may include Supplemental Security Income (SSI,) food stamps, housing, home based support, and possibly other resources. Most parents, however, want to go further. If the availability of public or other benefits was ever diminished in the future, most would hope that the money in the trust would be available to provide for even basic necessities. With proper planning before death or incapacity, parents can include such provisions.

## **What Else Do You Need?**

Parents of a child with a special needs should also be thinking about another important planning instrument -- a care plan, (also called a "letter of instructions" or "letter of intent") established by the family to make a future guardian and trustee aware of the child's needs. This care plan should be updated every year, and a copy should be kept with the trust and other planning documents. A good, current care plan will describe the educational, social, medical, financial, and other issues faced by our child with special needs. It will also describe our child's needs and his or her ability to attend to those needs on a daily basis. Any special and even basic information should be included, as well as information that will be helpful to the trustee and guardian when considering our child's housing and social situation. In addition, it is a good idea to include information about the family's hopes and wishes for the beneficiary's transition from minority to majority and adulthood.

As an additional benefit, proper preparation and "funding" of a trust during the parents' lifetime may help avoid the probate process upon the death of the parents. During the planning process, there may even be an opportunity to minimize or eliminate state or federal estate taxes, and in some cases even to help plan for the parents' own future long-term care needs.

## **Use Qualified Professionals:**

It is important to contact professionals who are knowledgeable in this area, as the rules are both complex and fluid. Services vary by state and often by region, and programs in place (*continued on page 16*)



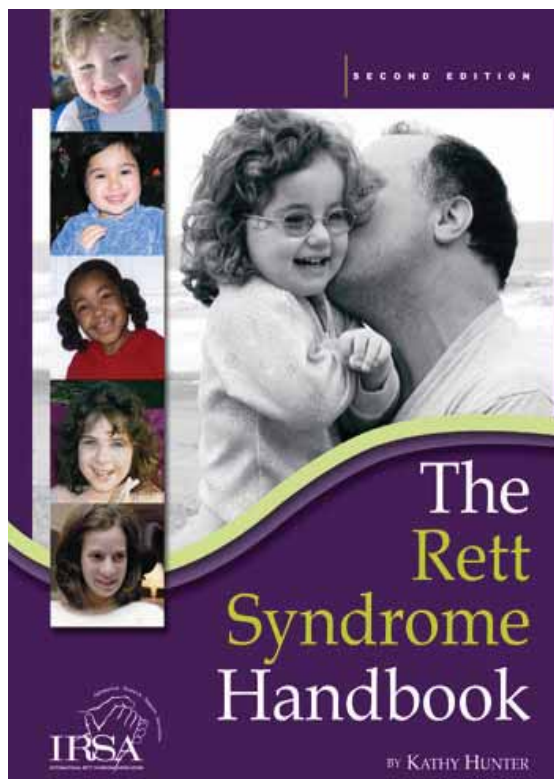
*Brian Rubin, attorney & father of a 26 year old son with autism*

# Constant Contact

by Susan Reedquist

Please sign-up to receive information on up-coming RSAI Events through your email. Hi, my name is Susan Reedquist and I have been a RSAI board member for three years. I have volunteered to create and manage our on-line emailing initiative beginning in February 2009. In the beginning, my objective is to bring you timely information on the wonderful social activities, fundraisers, and conferences RSAI brings to your family. As we proceed through the first year we will expand our content to include those topics most beneficial to you.

I will be setting up a link on our website: [www.rettillinois.org](http://www.rettillinois.org) where you can opt-in to receive these email up-dates. You will be able to reply to me whenever you have questions, comments or suggestions. I look forward to meeting you on-line and in person at our next event!



## Rett Syndrome Handbook, Second Edition

This is the book that every parent, grandparent, teacher, therapist, doctor, and caretaker must have! Anyone who is in the life of a loved one with Rett syndrome should own a copy of this book (called by many the "Rett Syndrome Bible").

Order your copy at  
1-800-818-RETT or at the  
website: <http://www.rettysyndrome.org>  
**Special Price \$30.00 (Plus S&H)**

## Estate Planning (continued from page 15)

today may not exist, or may be quite different next year.

The trustee and guardian must be armed with information and strategies as well. The details of the administration and taxation of the Special Needs Trust can be quite involved, and a qualified professional should be consulted to assist in that process. Please email (Brian@SpecialNeedsFuture-Planning.com or Brian@BrianRubin.com) to receive a manual on the administration of special needs trusts, as well as other reading material on this topic. One of the best sources to locate an experienced special needs planning attorney, is to contact The Arc of Illinois ([www.thearcofil.org](http://www.thearcofil.org)), or visit the web site of The Special Needs Alliance ([www.SpecialNeedsAlliance.org](http://www.SpecialNeedsAlliance.org)), the national, non-profit, association of experienced special needs planning attorneys. Membership is by invitation only, and most members are themselves parents or siblings of someone with special needs.

## RSAI Officers & Directors

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Kathy Medley	<i>Secretary</i>
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Published by the Rett Syndrome Association of Illinois. The purpose of the association is to inform and educate others about Rett syndrome and serve as a support system for families in Illinois.

Rett syndrome is a neurological disorder affecting 1 in 10,000 live, predominantly female births. Development is normal until at least 6 months and is followed by a regression that leads to severe disabilities. The cause of Rett syndrome is a defect in the *MECP2* gene. There is no known treatment or cure.

## Policy Statement

We welcome ideas from readers on various techniques of daily care, education, and general suggestions that individuals have found helpful. This exchange of ideas is encouraged. Parents and others have the choice to decide if they want to follow through with any of these suggestions.

We do not, however, as an association, 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.

Material in the RSAI newsletter may be reproduced with permission. Information and all submissions and correspondence regarding the newsletter should be directed to Editor Paul Jochim (847) 310-8876 or **contact us** on-line at [www.rettillinois.org](http://www.rettillinois.org).

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