



SPRING 2019

Rett GAZETTE

Accelerating Research.
Empowering Families.



RETT SYNDROME
ADVANCEMENTS

OUR
COMMUNITY'S
ACHIEVEMENTS

NO
LIMITS



OUR
CHILDREN'S
ABILITIES





Melissa Kennedy

Twenty years ago nearly all research for Rett syndrome was in the early idea stage. The gene that causes Rett syndrome had been identified but there was so much yet to understand. Today, after investing millions of dollars in research and supporting the development of the Natural History Study, we have a more complete understanding of Rett syndrome, and we see a brighter future for those living with Rett syndrome. The light at the end of the tunnel is shining brighter; it cannot come soon enough. Like you, we are eager for a world without Rett, and we continue to pursue research to that end.

And while we pursue a cure for our children, Rettsyndrome.org continues to provide families with access to expert resources and information to enhance their lives today. We want to see families live with NO LIMITS.

Within these pages, you will see the impact we are making in research and family empowerment. This year's funded research covers the gamut of our research strategy to create life-changing treatments and a cure for those we love. With more compounds in clinical trials, we must prepare our clinics and families to take advantage of these opportunities. So we have committed to enhance our clinical network infrastructure; building a bridge between families, available research and high quality care. With the release of the Rett Syndrome Primary Care Guidelines, we have begun working to ensure that families experience "best in class" care for their child.

We do not do this work alone. The support of families like yours is what makes these advancements possible. Every event, fundraiser, and initiative you participate in moves us closer to the goal of a cure. Thank you for partnering with us on our mission.

With hope and gratitude,

Melissa Kennedy

Melissa Kennedy
Executive Director



Steve Kaminsky, PhD

As many of you have heard, I am retiring this month as Chief Science Officer at Rettsyndrome.org. I am not settling down, but shifting gears to accomplish some things I've wanted to for years. First up — a 450-mile solo kayak ride on the longest river on the East coast in a boat I built.

Reflecting on my seven years at Rettsyndrome.org, I cannot help but get excited about how far research has come. For the first time several major drug companies are testing drugs to treat and cure Rett syndrome. Five years ago there were virtually no clinical trials in Rett syndrome; this is remarkable progress!

As I marvel at this progress, I remember what got us here. Discovering that MeCP2 was associated with Rett syndrome launched a global effort to understand how it affects Rett syndrome. Basic research disclosed many of the actions of this gene and outlined pathways to treat Rett syndrome. Faith and commitment in these discoveries moved them into translational medicine and pre-clinical testing to prove there were possible treatments for Rett syndrome, and the perseverance of researchers and clinical investigators testing new concepts and drugs has brought us the many clinical trials of 2019. Because of this hard work we are on the precipice of great things for our loved ones.

Working for RSO has been tremendously fulfilling. Meeting many of the Rett families has been one of the most rewarding things in my life. Leaving is hard, but if I learned one thing from all the Rett families, it is that you never let go of your dreams. I still have dreams calling, and I will begin to chase them.

Smilin...

Steve Kaminsky

Steve Kaminsky, PhD
Chief Science Officer



2018 IMPACT REPORT

Relentless pursuit of the eradication of Rett syndrome requires working together with researchers, clinics, pharmaceutical companies and families. Rettsyndrome.org is grateful for your support and proud of the progress we have made together.



\$48M INVESTED IN RESEARCH TO FIND A CURE THROUGH 2018

12K
DONORS



89%

OF EVERY DOLLAR FUNDS RESEARCH AND FAMILY EMPOWERMENT



\$2M RAISED FROM 118 EVENTS AND INITIATIVES

32

ACTIVE RESEARCH STUDIES



76

POST-DOCTORAL RESEARCHERS MENTORED THROUGH FELLOWSHIP PROGRAM



329K

UNIQUE VISITS TO RETTSYNDROME.ORG



233 NEW FAMILIES JOINED RETTSYNDROME.ORG



GLOBAL EDUCATION EFFORT: **3K** INDIVIDUALS FROM **55** COUNTRIES TUNED IN TO WEBINARS

250 INDIVIDUALS ATTENDED RSO ED DAYS



AWARDED HIGHEST RATINGS:



Our Research

Rett syndrome is an incredibly complex brain disorder. Since no two individuals with Rett syndrome are the same, we need multiple treatment approaches. Pharmacological interventions are certainly critical, but children and adults will also need neuro-habilitative therapies, such as occupational and physical therapy, as part of their treatment. Our funded research targets the full spectrum.

NEWLY FUNDED RESEARCH

We continue to fund the best and the brightest researchers from around the world. We are proud to introduce the new research we are funding this year.



Nerve Growth Factor
Dr. Cattaneo will use a variant of NGF called hNGFp in mice to see if RTT-like behaviors can be minimized and brain function increased.
Antonino Cattaneo, PhD
Scula Normale Superiore



Remote Rehabilitation Program
Dr. Lotan is studying the effectiveness of home-based programs to enhance functional abilities of girls with Rett syndrome.
Meir Lotan, PhD
Ariel University



Non-MECP2 Mutation Study
Dr. Hannan will study mutations of a brain protein called GABABR that have recently been linked to Rett syndrome in individuals that do not have a MECP2 mutation.
Saad Hannan, PhD
University College London



Exploring the Role of Astrocytes
Dr. Muotri will study the effectiveness of a drug called Actemra in reducing levels of Interleukin-6 (IL-6), a protein that negatively impacts neurons at high levels in RTT.
Alysson Muotri, PhD
University of California San Diego



Enhancing Respiratory Receptors
Dr. Levitt will study a compound in mice that aims to make certain respiratory receptors more responsive to dopamine, which controls breathing.
Erica Levitt, PhD
University of Florida



Screening Compounds in RSO's Steven. G. Kaminsky Scout Program
Dr. Hanania is doing research on potential drug candidate compounds. This is a unique program that increases the pace of testing, allows for potential treatments to move more quickly into clinical trials, and creates partnerships with pharmaceutical and biotech companies.
Taleen Hanania, PhD
Psychogenics, Inc



Wearable Devices
Dr. Peters will study a non-invasive wearable device that is worn at home and used to track important features of RTT.
Sarika Peters, PhD
Vanderbilt University Medical Center



Clinical Outcome Measures
Dr. Buchanan will refine clinical outcome measures using anxiety biomarkers, such as cortisol level, heart rate variability and inflammatory markers. Dr. Buchanan's goal is to improve diagnosis and treatment of anxious behaviors in RTT.
Carrie Buchanan, MD
Greenwood Genetic Center



Understanding Rett Syndrome
Dr. Zhou will work to better understand precisely how MECP2 mutations lead to the neurologic symptoms seen in Rett syndrome.
Zhaolan (Joe) Zhou, PhD
University of Pennsylvania



Telehealth Support
Dr. Downs will develop an online resource that parents, caregivers, therapists, and clinicians can use to increase physical activity in individuals with Rett syndrome.
Jenny Downs, PhD
The University of Western Australia



Seizure Biomarkers
Dr. Fu is investigating seizures in Rett syndrome in a new way. His group will use clinical data from the Natural History Study and mouse models to determine characteristics that can predict seizures.
Cary Fu, MD
Vanderbilt University Medical Center



Rett Syndrome Clinical Trials

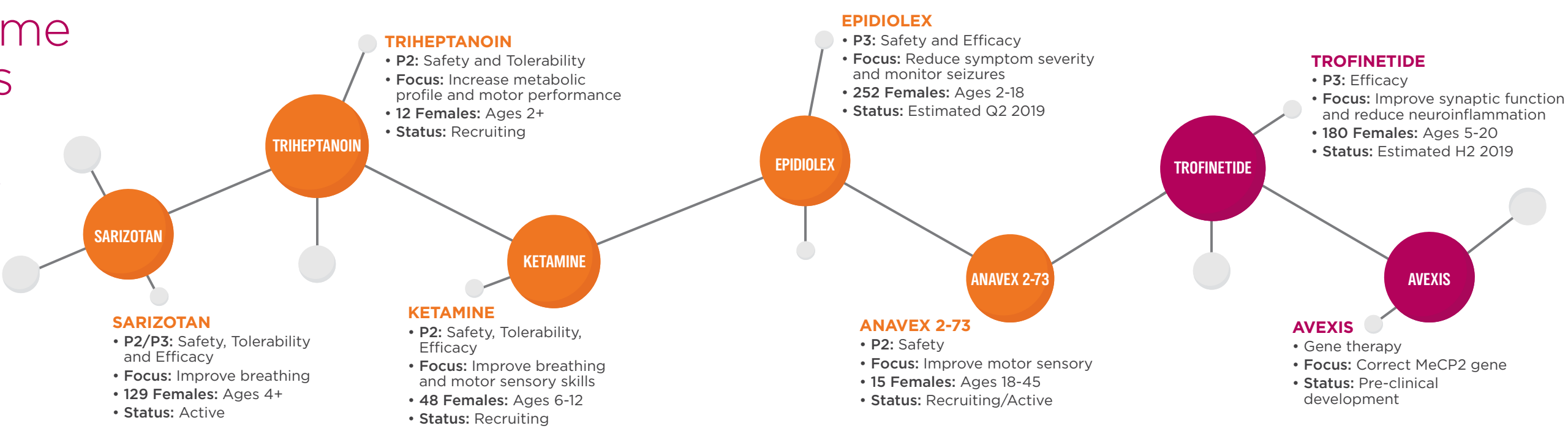
RSO is happy there are a variety of trials available and in development. We strongly encourage you to work with your care team to determine which trial is best for your child.

The following are U.S. clinical trials for Rett syndrome. For further details and a complete list of Rett syndrome trials, visit [ClinicalTrials.gov](https://clinicaltrials.gov).

P = PHASE

= ACTIVE CLINICAL TRIALS

= UPCOMING CLINICAL TRIALS



Dr. Marsh, CHOP Rett syndrome clinic team and families

CLINIC SPOTLIGHT:



Children’s Hospital of Philadelphia was awarded a *Rettsyndrome.org Clinical Research Center of Excellence* award in 2017

Register for RSO’s Ed Day with the CHOP team: www.rettysndrome.org/education.

Dr. Eric Marsh is the Medical Director at the Children’s Hospital of Philadelphia Rett syndrome clinic. The clinic provides care for nearly 100 individuals with Rett syndrome in the northeast U.S. The clinic employs a comprehensive care model which ensures all aspects of care are addressed. They use a collaborative approach, with family input being an important part of the process.

A first visit to the Rett clinic includes a full medical history, physical exam, as well as discussions about major concerns, therapies (home and school), clinical trials, and the latest research. Families then meet with the genetic counselor, other physicians, therapists and a social worker if needed.

Dr. Marsh and his team are involved in a number of research projects. They are a Natural History Study site, and the lead site collecting information using EEG to analyze visual and sound stimuli to learn more about how Rett syndrome progresses. The clinic is also participating and enrolling patients in clinical trials on Ketamine and Anvavex 2-73 for Rett syndrome. They are preparing for the clinical trials of cannabidiol and trofinetide as well.

Dr. Marsh and his team will be hosting Rettsyndrome.org at the May 18 Ed Day. “We are excited to be teaming up with RSO for the upcoming Rett Day,” says Dr. Marsh. “We are looking forward to having conversations about different clinical aspects of Rett, approach to care, and the ongoing research in Rett syndrome.”



SakkuBai Naidu, MD

In Appreciation

Rettsyndrome.org would like to acknowledge SakkuBai Naidu, MD for her dedicated service to patients with Rett syndrome and research. Dr. Naidu trained as a pediatrician and neurologist, and was among the first to describe the

natural history of Rett syndrome. She and Dr. Hugo Moser, a past president of Kennedy Krieger Institute, founded the Institute’s Rett Syndrome Clinic in the 1980s and organized the first international research conference on Rett syndrome, held at Kennedy Krieger in 1985. Dr. Naidu spearheaded research on Rett syndrome that continues to this day. Dr. Naidu recently retired as director of the Institute’s Rett Syndrome Clinic. We thank her for being a fearless advocate for those with Rett syndrome.



Dr. Naidu at John Hopkins in 1985

CREATING FAMILY-CENTERED TRIALS

Pharmaceutical companies are becoming aware of the need to make the trial process easier for families to participate. Rettsyndrome.org is proud to be a formal advisor to GW Pharmaceuticals as they work to develop a family-centric clinical research trial for individuals with Rett syndrome.

“GW values working with a foundation that focuses on family empowerment and education to enhance the quality of a clinical trial.”

Volker Knappertz, MD
Chief Medical Officer,
GW Pharmaceuticals





Honoring Dr. Steven Kaminsky

In March, Chief Science Officer Dr. Steven Kaminsky announced his retirement. We are grateful for Steve's faithful service over the last seven years, advancing research toward the treatment and cure of Rett syndrome. Steve was instrumental in making a connection between trofinetide — a compound developed under the Department of Defense to treat soldiers with traumatic brain injuries — and a possible benefit for individuals with Rett syndrome.

One of Steve's most notable contributions to Rett syndrome research was developing RSO's proprietary Scout Program, which

was designed to rapidly identify potential treatments from existing pharmaceutical compounds. Multiple compounds screened through the program have moved into clinical trials, both in the U.S. and abroad.

In honor of Steve's ingenuity, integrity and compassion, RSO is officially re-naming this program the Rettsyndrome.org Steven G. Kaminsky Scout Program to serve as a lasting reminder of Steve's dedication to Rett syndrome.

We honor Steve for his service and wish him all the best.



The Rett syndrome Primary Care Guidelines are intended to help families partner with their child's care team to address their child's medical needs. It was a labor of love for Paige Nues, RSO Director of Family Empowerment, Dr. Mary Jones and Katie Hale of UCSF Benioff Children's Hospital, with additional input from the Rett centers across the country and NIH Natural History Study sites. The goal is for families to use the guidelines to create an informed partnership with their primary care providers. Families are always going to be the best advocate for their daughters and sons; this is not meant to replace that. This is another tool to achieve meaningful and maximal health and well-being. There are many different ways to use it. We hope it becomes part of the family health-care binder. In some cases, families may simply hand it off once to their primary care provider. In other cases, families may need to provide a selectively highlighted copy to their provider at each visit to focus on the needs of the moment. We welcome any feedback to make the guidelines as useful as possible.

Download yours today at
www.rettsyndrome.org/pcg.



Blazing Trails in Rett: From the 60s to Today

The first paper on Rett syndrome was published in 1966 by Dr. Andreas Rett in Germany. In the 60s and 70s, if your child had Rett syndrome in the U.S., there were very few resources available. Each family had to blaze their own trail.

Donna is one of these trailblazers. She and her late husband Cam had six daughters. Her 5th daughter, Ella, was born in 1966. Ella developed normally at first; though Donna recalls she didn't have the same energy as other babies. After a year of age, Ella exhibited more concerning signs; an imbalance in her eyes and uncontrollable hand movements. Ella never developed more than four words, but she did learn to walk. Donna and Cam took Ella to see a neurologist who left them devastated and without answers. Together they faced her scoliosis, back surgery, seizures, reflux and behavioral issues.

Back then, few states had school programs for children with disabilities. Cam took a new job in Pennsylvania because it was the first state to mandate classroom participation for the severely intellectually impaired. They moved to Philadelphia, and Ella went to a special education school. With no diagnosis and no effective medications or behavior modification available, Ella's behavior worsened. Donna and Cam made the very difficult decision to move Ella into an institution to get the treatment she needed. "The decision was gut-wrenching," Donna shared. It was here, however, that a geneticist officially diagnosed Ella at age 18 with Rett syndrome. Donna was relieved to have a diagnosis.

Today Ella is 52 years old and healthy. Her behavior issues are managed, and she is very affectionate and loves to get hugs and kisses from Donna. Ella loves music and will dance and sway while the music plays.

Donna (now 85) sees Ella every weekend. "Every week I go I feel like I'm filling up her gas tank." Donna added, "I can comfort her and make her smile and giggle." Donna says the facility is taking good care of Ella and likely because Donna has been very involved. Donna's tireless advocacy, fundraising, and work to improve the quality of life of Ella and those around her has led the institution to make Ella's cottage the model for the rest of the campus.

We are thankful for pioneers in Rett syndrome, like Donna, whose passionate care for their daughters in an era with little support and information has helped pave the path for the rest of us.



Ella, 6 years old



Ella, 35 years old



Ella & Donna



IRENE AROUND THE WORLD

"We must continue to hope for a cure but also accept: I have a disabled daughter, she has Rett syndrome. We must keep living despite this reality."

Those words express the heart of Walter and Laura after their daughter, Irene, was diagnosed with Rett syndrome. As avid travelers, they wanted to share the love of discovering new places with Irene. They would not let Rett syndrome or a wheelchair hinder them. They bought an RV that could accommodate Irene's electric wheelchair and set off to travel the world. Together, they have explored Poland, Greece, Holland, France, Spain, Germany, UK, Turkey, Morocco and most of the United States.

Irene's favorite so far is Morocco — seeing the sunset from the back of a camel. She also enjoyed visiting the remains of the ancient civilizations she studied at school in Turkey and Greece, and dipping into the warm sea for long swims. Next on the agenda is Santiago, Spain and Greece.

Irene has been traveling with her family for 20 years. Walter and Laura say that *"a little spirit of adaptation"* is really all that is needed to visit these wonderful places. Walter, Laura and Irene, we are a bit jealous AND you inspire us!



WHO'S
INSPIRING
US!

GAMING FOR RETT

Aurora Peachy is an entertainer and gamer on Twitch.tv — a live streaming video platform focused on gaming. She is also a step-mom to Annika, who has Rett syndrome.



Inspired by amazing, bright-eyed Annika, Aurora turned her live Twitch.tv platform into an opportunity to tell the world about Rett syndrome. She has been hosting a yearly fundraiser through Twitch.tv since 2015 and the gaming world has contributed over \$14,000 to Rett research. Aurora shared *"Knowing that we're improving people's lives fills me with joy. It just feels good to give back!"*

What a unique way to engage online communities in advocacy. Aurora, you inspire us!

NEXTGEN RETT ADVOCATE

Julia Wymbs is in 6th grade and already doing an amazing job of helping those with Rett syndrome.

Julia's aunt Jennifer had Rett syndrome. She passed away in 2015 and to honor her, Julia decided to dedicate a school project and half of the funds raised from her work to Rettsyndrome.org. As part of a school project, Julia designed and created tissue holders that she was able to sell. Her grandma, Lorraine, shared with us how touched she was by this gesture. Lorraine said that what is important *"isn't the amount she raised but the heart and thought she gave."* We couldn't agree more. Julia, you inspire us!



HANNAH PAINTS FOR RETT

Hannah (19) started painting seven years ago when her family was approached by a local artist who asked if they thought Hannah would like to paint with her.



Hannah started painting and loved it. Despite her RTT diagnosis, Hannah has some purposeful hand control and once she grabbed the brush she didn't want to let go. She paints several times a month. One painting in particular portrays a girl on her knees praying. At the time, Hannah's dad was undergoing cancer treatment and Hannah's parents believe she painted that for him.

As the popularity of her paintings increased, a local art gallery agreed to showcase Hannah's art where an original painting was auctioned off. They continue it every December. This past year Hannah sold several originals and many prints. Hannah's parents are thankful for her God given gift. Hannah, you inspire us!



WHO INSPIRES YOU? Share your story with us, email tfrank@rettsyndrome.org.



*Parents have many questions about daily care for their children with Rett syndrome. So we are introducing a new Gazette feature: **Rett Answers**. Jane Lane has worked with Dr. Alan Percy in the UAB Rett syndrome clinic for 25 years. She has extensive experience with the Natural History Study and in her role, she educates families and medical care teams about common and often complex medical problems seen throughout the lifespan of those with Rett syndrome. As always, please consult your own physician to discuss care-related questions for your child.*

Q1
**CONSTIPATION:
WHAT CAN FAMILIES DO TO PREVENT AND TREAT CONSTIPATION?**

Constipation is a common concern. It is important to recognize that bowel movement frequency can vary widely. We advise patients in our clinic to have a goal of a soft, easily passed stool every 1 – 1.5 days. Monitor your child's typical patterns and note any changes. Symptoms of constipation include:

- Irritability, Distended and/or hard abdomen, Straining, Poor appetite, "Rabbit pellet" consistency stools, Abnormally large stools, Rectal bleeding, Increased gas, UTI's

Early intervention is extremely important to prevent and correct constipation. Effective prevention and treatment involves a combination of 3 things: diet, medications and activity. High fiber diets are strongly encouraged but rarely enough to prevent constipation with Rett syndrome. Often, OTC medications are needed to prevent this common problem.

Laxatives: Miralax™, lactulose, milk of magnesia, senna, or mineral oil can be used daily. Adjust the dose to get the desired effect.

Suppositories: Glycerine or bisacodyl suppositories are also effective to prevent and treat constipation.

Enemas and Herbal treatments: Use with caution. Routine use of enemas can lead to worsening constipation and herbal treatments may interact with other medications.

Activity is an important preventative measure. Encourage walking, or standing throughout the day. If your child does not walk, try laying them on their side to make passing stools easier.



HAVE A QUESTION?
*Submit your questions to
info@rettsyndrome.org.*

Medical Disclaimer: All information provided is for informational purposes only and is not intended to serve as a substitute for the consultation, diagnosis, and/or medical treatment of a qualified physician or healthcare provider. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

Q2
**G-TUBE:
HOW DO YOU KNOW WHEN IT'S TIME?**

You should work closely with your physician to decide if a g-tube is indicated. Our clinic often recommends a second procedure, called a fundoplication, be done at the same time to prevent reflux and maximize the effectiveness of the g-tube. A g-tube may be recommended under the following conditions:

- Aspiration pneumonia: This is suspected when there is coughing while eating or drinking and can be confirmed by a swallow study. Oral feedings put them at risk for aspirating into the lungs. It is important to only modify the food or drink with guidance from a feeding specialist.
- Prolonged feeding times of 1 hour or longer
- Chronic dehydration or inadequate fluid intake
- Chronic medication refusal or inability to ingest oral medications
- For weight gain in preparation for scoliosis surgery
- Malnutrition: Your physician, nurse or dietician can determine this

Common myths about g-tubes and fundoplication:

- **They can't eat by mouth once the g-tube is placed.**
FACT: As long as they are not aspirating, they can still eat by mouth with a g-tube.
- **They can't swim or take a bath once a g-tube is placed.**
FACT: Both are possible after the tube tract between the skin and the stomach heals.
- **If they pull it out, I will NEVER be able to put this back in by myself.**
FACT: The feeding or surgical team will teach you to do this. It's as easy as putting in a pierced earring once you are taught and can get over that first anxiety.
- **They can't throw up if they have a fundoplication.**
FACT: A fundoplication tightens the opening between the stomach and the esophagus so that it's more difficult for stomach contents to go back up but still possible.

**UPCOMING EDUCATIONAL
OPPORTUNITIES**

We offer several live webinars and in-person events to empower you with knowledge and resources. Learn more at www.rettsyndrome.org/education

- 5/11** RettEd Webinar — *Adulthood - Living and Lifestyle Options* with Jenny Downs, PhD, Michelle Stahlhut, PT, PhD, Theresa Bartolotta, PhD, CCC-SLP
- 5/18** RSO Ed Day — *Hosted by Children's Hospital at Philadelphia*
- 6/11** RettEd Webinar — *Nutrition Strategies* with Suzanne Geerts, MS, RD, LD
- 6/22** RSO Ed Day — *Hosted by Boston Children's Hospital*
- 7/9** RettEd Webinar — *Genetics of Rett Syndrome and the MECP2 Gene* with Steve Skinner, MD and Hannah Warren
- 7/20** RSO Ed Day — *Hosted by Katie's Clinic at UCSF Benioff Children's Hospital*
- 8/13** RettEd Webinar — *Caring for the Caregiver* with Sarika Peters, PhD, Marie Bateh, PT and parent panel.
- 9/10** RettEd Webinar — *20 Years! Research and Basic Science Update* with Huda Zoghbi, MD
- 10/8** RettEd Webinar — *Communication Guidelines* with Gill Townend, Researcher
- 11/12** RettEd Webinar — *Orthopedics and Scoliosis* TBA
- 12/10** RettEd Webinar — *Clinical Trials Enrollment & Updates* with Tim Benke, PhD

**Past webinars are available at
www.rettsyndrome.org/RettEd**

Reaching For The Cure:



Sharing Your Journey

After her daughter Sonia's Rett diagnosis, Julie felt very isolated and alone. But after reaching out to Rettsyndrome.org, she felt comforted by the support she received. Julie wanted to raise awareness, and she learned she could create an RSO personal page to share with others about Sonia's journey with Rett syndrome. She was able to personalize her story and upload photos and videos with ease. Julie emailed her personal page to family, friends and colleagues and was blown away by their response. Not only did they step up to help emotionally support her family, but they gave generously to help advance research to cure Rett syndrome. To date, Julie's page "Sonia's Hope for Future" has raised over \$11,000.

To start a personal page visit
www.rettsyndrome.org/personalpages.



Raising a Hand, Vol. 2

David Clements and Kevin Black are teaming again up to produce Raising a Hand Vol. 2 – a star-studded book of musicians and artists raising a hand for Rett syndrome. Like their first book, which included Clint Black, Blake Shelton, Pat Benatar, Dolly Parton, Jimmy Buffet, Melissa Ethridge and hundreds more, all proceeds from this photographic music festival will go to Rettsyndrome.org.

Pre-order Raising a Hand, Vol. 2 and consider dedicating a page to a loved one.

Visit www.raisingahand.com.



Henry Perez and daughter Lily at 2018 FL Stroll

Florida Strollathon Exceeds \$1 Million

The weather is not the only thing that has been hot in Florida over the past nine years; the fundraising has been on fire! Families in Florida have participated in the Coconut Creek & Lakeland Stroll since 2009 and have raised over \$1 million for Rett syndrome research! It has taken a lot of work on the part of the event chairs and faithful families who are committed to a cure for Rett syndrome. It has not been without losses along the way. This year, Lakeland Stroll event chair Charity Proffitt lost her daughter Skylar. We send her our love and remain steadfast in our drive to find a cure.

Florida will hold their 10th Annual Strollathon on November 2, 2019 in Melbourne, FL.

A Community Engaged

Going the Distance for Rett

Last fall, KC Byers led the charge to raise awareness about Rett syndrome by riding 2,600 miles across the country in honor of his step-daughter Katelyn and all those affected by Rett. The ride began outside San Diego, CA and along the way, several riders – including Rett families – joined KC for a leg of the journey. Alan Shukovsky, the father to son, Grayson (Rett), met KC in Houston and rode to the finish line in Jacksonville, FL. Because of these riders' efforts, the Rett Ride Across America raised over \$110,000 for Rett syndrome research! We're thankful for their support & dedication!



Rett Gets Rocked

What would it take to get you to run for 24 hours straight? For Jay Murry, all it took was meeting Ellie McCool and setting his mind to join the fight against Rett syndrome.

Jay met Ellie while working as a Special Education Paraprofessional. He taught her for three years and during that time was both impressed and intrigued by her spirit. Jay could see the difficulties she experienced, and yet her eyes displayed an upbeat and encouraged spirit. He wanted others in the St. Louis area and beyond to know about Ellie and Rett. He decided to host a 24-hour ultramarathon called Rett Syndrome Gets Rocked!

Jay worked with Washington University's Athletic Department, their Rett Spectrum Clinic and local media outlets to plan, promote and execute this one of a kind event last October. In 24 hours Jay totaled 61.5 miles. The money raised went to support research and the Rett clinic.



FORE! A Cure

Each spring, dedicated golfers hit the links all over the country to raise funds and awareness for Rett syndrome. More than 5 tournaments take place, and each has their own special flare for fundraising and awareness. Golf Fore a Cure Event Chair, Karli Hughes shared, "We as a family knew that we had to get involved in the fight against Rett syndrome. We refused to sit around feeling sorry for Emily and for ourselves. That's how Golf Fore a Cure came to life. We have an amazing support group. It's a wonderful feeling when you get people on board with what we feel is the greatest cause!"

We're so thankful to all of our Spring golf event hosts, committees, sponsors, donors and golfers for helping us raise nearly \$500,000 each spring on the course!

WANT TO START YOUR OWN EVENT? Email JVventura@Rettsyndrome.org.



☎ (800) 818-7388 | 🌐 www.rettsyndrome.org | 📘 /rettsyndrome | 🐦 /rettsyndrome | @rettsyndromeorg | 📺 /irsfoundation



We have an exciting year planned with events around the country that you and your loved ones can participate in. To see a complete list of all our events visit www.rettsyndrome.org/events.

- | | | | |
|------|---|-------|--|
| 5/4 | 12th Annual St. Louis Strollathon
St. Louis, MO | 6/22 | RSO Ed Day
Boston, MA |
| 5/4 | 3rd Annual Iowa Strollathon
Ankeny, IA | 6/28 | Rip it for Rett
Scarborough, ME |
| 5/5 | 11th Michigan Strollathon
West Bloomfield, MI | 7/20 | RSO Ed Day
Livermore, CA |
| 5/11 | 2nd Annual Tennessee Strollathon
Athens, TN | 7/28 | Scramble for a Cure
Bellaire, MI |
| 5/13 | 10th Annual Ella Foard Golf Tournament
Charlotte, NC | 8/1-4 | NW Rett Foundation Ed Day
Portland, OR |
| 5/13 | 7th Annual Charamella Golf Tournament
Norristown, PA | 8/18 | Cruise for Cora Rett Syndrome
5K run and walk
Canton, MN |
| 5/17 | Great Rett Shootout
Woodlands, TX | 8/31 | 6th Annual Pennsylvania Strollathon
Millvale, PA |
| 5/18 | RSO Ed Day
Philadelphia, PA | 9/14 | Raise a Glass Against Rett
Olathe, KS |
| 5/21 | Samantha Corpus Golf Tournament
Danville, CA | 9/22 | 14th Annual Portland Stroll
Portland, OR |
| 6/1 | 3rd Annual Maryland Stroll
Rising Sun, MD | 9/28 | 16th Annual Cincinnati Stroll
Cincinnati, OH |
| 6/15 | Siera's Scramble
Shepherd, MI | | |