



FALL 2019

Rett GAZETTE

Accelerating Research.
Empowering Families.



Standing with you today.

FIGHTING TO TRANSFORM YOUR TOMORROW.



Rettsyndrome.org
ACCELERATING RESEARCH, EMPOWERING FAMILIES.

Meet our Chief
Science Officer **p4**

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Melissa Kennedy

Welcome to the fall edition of the Gazette. I hope that you will find it helpful and inspirational! It's filled with old friends and new faces. We are grateful for the continued support of families, clinicians, and researchers who have been with us for years. We are also grateful for new partners who use their talent and dedication in the fight against Rett syndrome!

Standing with You Today

Rettsyndrome.org is committed to stand with you today because your family needs help *today*. Our resources and tools make living with Rett syndrome easier. **This year we published primary care guidelines for you to use with your physicians to ensure your child is receiving the best care possible.** We hosted 3 education days and 12 educational webinars this year. Our educational resources were accessed by over 1,600 people in 54 countries, covering every topic from self-care to the most current research. We also have state representatives available to help and support you, no matter where you live.

Transforming Your Tomorrow

We are committed to transforming your tomorrow and have made significant investments in compounds that we believe will meaningfully improve your child's quality of life. **Four of these compounds are in active clinical trials.** We regularly convene 20 of the world's leading clinicians to develop 'best-in-class' care guidelines that will advise specialists taking care of your child. We continue to invest in a clinical network so that you have access to clinics with expertise, no matter where you live.

I am thrilled to welcome Dr. Dominique Pichard as Chief Science Officer of Rettsyndrome.org. Dr. Pichard is a highly accomplished clinical investigator with experience working closely with the NIH and the FDA. She will sharpen our focus to further identify and invest in therapies aimed at curing Rett syndrome. Her passion and determination come from having a child with Rett syndrome. I am thrilled to have someone of Dr. Pichard's caliber on our team.

Our team has known for many years that Rett syndrome's complexities will require multiple interventions. **Our work has and will continue to cover all streams of Rett syndrome research so that every person with Rett syndrome may experience life-changing improvements.**

On behalf of our team and Board of Directors, know that we will stand by your side until there is a world without Rett syndrome.

With hope and gratitude,

Melissa Kennedy
Executive Director

New Board Members

Our Board of Directors is a passionate and highly skilled group of advocates who are committed to our mission. We are excited to introduce you to 4 new board members joining our team this year.



Lisa Monteggia, PhD

Dr. Monteggia is an acclaimed neuroscientist currently serving as Director of the Vanderbilt Brain Institute where she studies the role of MeCP2 in brain plasticity and behavior. Dr. Monteggia has received numerous awards, including a National Research Service Award fellowship, the Daniel X. Freedman Award, a Young Investigator Award from NARSAD, the Rising Star Award from the International Mental Health Research Organization, and the Daniel H. Efron Award from the American College of Neuropsychopharmacology.

Dr. Monteggia received her Bachelor of Science and Master of Science from the University of Illinois at Urbana-Champaign. She earned her PhD from the Chicago Medical School at Rosalind Franklin University and conducted postdoctoral research at the Yale Department of Psychiatry.



Joseph Horrigan, MD

Dr. Horrigan is Chief Medical Officer for AMO Pharma Limited and an Associate Consulting Professor at Duke University School of Medicine.

He is a pediatric neuropsychiatrist with over 30 years of clinical experience and 20 years of experience in the pharmaceutical and biotech industry. He formerly served as Head of Medical Research for Autism Speaks and as Vice President of Clinical Development and Medical Affairs at Neuren Pharmaceuticals. He was instrumental in launching Neuren's clinical trials for NZ2566, known today as trofinetide.

Dr. Horrigan has cared for over 100 patients with Rett syndrome and has worked with pharmaceutical companies to create clinical programs for Rett syndrome, Fragile X, and Angelman Syndrome.



Davis Pass, Pharm D

Dr. Pass is the Chief Operating Officer and Head of Commercial at Gelesis, is a biotechnology company developing a novel category of therapies for GI-related chronic diseases. Dr. Pass has more than 25 years of commercial expertise and business development across multiple therapeutic areas with a focus on diabetes, metabolics, and pain. He gained a broad range of commercial experience from his time with Johnson & Johnson, and Bristol-Myers Squibb. Prior to joining Gelesis, Dr. Pass served as Vice President of Marketing for Diabetes at Boehringer Ingelheim (BI), where he built and led a billion-dollar franchise. Dr. Pass received both his B.S. Pharmacy and Doctor of Pharmacy degrees from Philadelphia College of Pharmacy and Science.



Mitch Bleske

Mr. Mitch Bleske is Executive Vice President and Chief Financial Officer for Bremer Financial. He is responsible for all

financial management activities, including reporting, management of interest rate risk, liquidity, capital, wholesale funding, and investments. In addition, Mr. Bleske is EVP of Commercial and Ag Banking, with executive oversight of Bremer's commercial, agriculture, mortgage, insurance, and wealth management teams.

Mr. Bleske is actively involved in the community, serving on the board of Twin Cities Habitat for Humanity and working with the Midwest Rett Syndrome Foundation. He and his wife, Erin, have four children, one of whom was diagnosed with Rett syndrome at the age of 3.

Meet Our New Chief Science Officer, Dr. Dominique Pichard



Dr. Dominique Pichard

I am thrilled to be joining Rettsyndrome.org as the Chief Science Officer. Rett syndrome is near and dear to me and my family, as our oldest daughter, Catalina, has Rett syndrome. We received Catalina's diagnosis when I was still in my medical residency training, and ultimately it was this new diagnosis that influenced my decision to focus my career on research. After my residency training, I moved to the National Institutes of Health (NIH) to launch my research career.

The NIH is a truly unique place where basic science research labs are down the hall from patient clinic rooms, and the interaction between the lab scientists and the clinical investigators is woven into the fabric of daily work. Many of the discoveries at NIH occur because of this close collaboration. While at NIH, my research focused on studying rare diseases. I designed early phase clinical trials for rare diseases to bring new treatments to patients. I also worked with an international group to develop outcome measurement tools to be used in clinical trials in order to have standard measurements upon which to determine the success of the drugs we were studying. To accomplish this, I worked closely with pharmaceutical companies and the Food and Drug Administration.

I grew up in Maryland and now live in Annapolis, Maryland, with my husband and three children. I have had the good fortune of having strong Rett family support groups in the two cities I have lived in since Catalina's diagnosis. This strong connection with other families with Rett syndrome got us through the early years after her diagnosis. Our family enjoys outdoor activities, including boating, alpine skiing, cycling, and many other pursuits that involve being outside and

in motion. We are very fortunate that we have found a way to have Catalina join us on all of our outdoor adventures through adaptive solutions and the tireless efforts of therapists, instructors, and aides.

I am excited to merge my personal passion for solving the challenges of Rett syndrome with my professional experience. Working for Rettsyndrome.org is a truly unique opportunity. I am enthusiastic about Rettsyndrome.org's multifaceted approach: addressing the lab work that is so critical to our understanding of Rett syndrome and its possible treatments, testing those treatments in clinical trials, supporting neuro-habilitation, and identifying the best approach to improving the everyday lives of our children with Rett syndrome.

We are in a very exciting time in which we know the genetic cause of Rett syndrome, we are gaining a better understanding of all that this essential gene does, and we have pharmaceutical targets that we are testing in clinical trials. I am thankful to Dr. Steve Kaminsky, who made great strides in advancing this work. I had the pleasure of getting to know Steve during his time at Rettsyndrome.org, and ***I am honored to build on his foundation of excellence and integrity.***

As CSO, my goal is to focus all of my energy on identifying promising research breakthroughs for Rett syndrome and creating a scientific path forward towards our ultimate goal of treating this devastating disorder so our children and loved ones with Rett Syndrome can one day do more and struggle less with the challenges of Rett.



OUR COMMUNITY IS EXCITED ABOUT DR. PICHARD!

“On behalf of the Rett research community, I am pleased to welcome Dr. Pichard as the new Chief Science Officer at RSO. She brings new skills and experiences that will energize the challenges ahead as we all seek to find better treatments for our patients and families. I look forward to working closely with her.”

~ Dr. Tim Benke, RSO Medical Advisor, Director of Rett Syndrome Clinic at Children's Hospital Colorado

“Dr. Pichard has a great combination and balance of a clinical and basic science background... important skills to lead novel translational opportunities for Rett syndrome. She has the ability to effectively communicate and engage the community with scientists, something I found particularly important as the science is progressing fast with recent new technologies.”

~ Dr. Alysson Muotri, Director of the Stem Cell Program at USCD and a RSO-funded researcher

“Dr. Pichard is an intelligent, energetic, highly-respected colleague with an outstanding track record of scientific and therapeutic accomplishments. She is well connected at key levels throughout our community and brings an intimate understanding of the crucial role organizations such as Rettsyndrome.org play in driving the best science forward.”

~ Dr. Joe Horrigan, RSO Board member

“As a parent, I am thrilled to welcome Dr. Pichard. To have someone with her scientific background combined with the passion she brings as a mother with a daughter with Rett syndrome is an incredible addition to the entire Rett community. I look forward to seeing the immediate impact she will make for Rettsyndrome.org in continuing to advance our research agenda.”

~ Christian McMahan, RSO Vice Chairman and Father to Keilly (RTT)



Last spring Molly graduated as valedictorian of her class and started honors college. It hasn't been an easy journey, requiring great determination, perseverance, sacrifice, and a spirit of adaptability on the part of her entire family.

As parents and family members, we hope and pray the world will "see" our children and know, truly know, as we do that our children are "in there." Molly wanted to share a message to those living with Rett syndrome. We hope that you are inspired by Molly's message and will share with your loved ones living with Rett syndrome.



Molly, Graduation Day



Molly & Friends

Friend,

[You will] be great but exhausted. You may have problems getting people to believe in you. Your tenacious perseverance will pay off. Just because life brings challenges that make you feel like you have no voice doesn't mean you get to stay silent.

Talk louder, type faster, eye gaze longer, tap harder or even give the stank eye 🙄 until your "voice" is heard.

Do not live by the labels put on you. Live by your own labels. Do not be afraid to try things other people said you cannot do. There is always a way to adapt anything. Being able to adapt is how mankind has survived all these centuries. Being willing to adapt for every ability is what makes us human.

~Molly

"Intelligence is the ability to adapt to change."

~ Stephen Hawking

Universal Truths in Educating Our Loved Ones

By Robin Allen-Paris



I have had the unique experience of being my daughter Molly's primary 1:1 from K-12 in an inclusive classroom setting. Molly started college on August 26th, so my 1:1 position continues. I have learned many things along the way and believe there are some universal truths to educating people living with Rett syndrome.

Every Family Is Unique

The dynamics that make up our family, work, support, and access to education differ from individual to individual. What works for one will not work for all. You may not be able to duplicate Molly's form of education, but that doesn't mean the person you love with Rett syndrome cannot be educated. Education comes in many forms these days, and you do not need to be within the four walls of a traditional classroom to educate someone living with Rett syndrome.

UNIVERSAL TRUTHS

1 Everyone living with Rett syndrome can become better educated.

In the soon-to-be-famous words of Nadia Hionides, The Foundation Academy's founder and principal, "I'm happy as long as a student goes from A to B. I don't define their A and I don't define their B. As long as there is progress, there is success." You must find and support their A to B, and no one's A to B will be the same.

2 Processing time is essential

Please allow your child enough time to process what is being asked of them. In my world that means waiting at least 30 Mississippis before you ask again or clarify. Accept however they respond as an answer and react accordingly. This is incredibly important. If not given enough time, people with Rett syndrome may shut down and stop trying to answer you, which may perpetuate the belief they cannot be educated.

3 Find educators and therapists who believe in your loved one's abilities.

It's okay to ask for, even demand, new educators or therapists if those assigned to your child do not believe in their abilities. Once you have a great team and your child is making progress, consider sharing that information with others.

4 The love of preschool videos does not equate to cognitive abilities.

Many individuals with Rett syndrome watch preschool shows to give their brains a break from the constant processing. It is the same as typical people playing mindless games like Candy Crush. Use their love of videos to help educate them. Khan Academy is a great resource and it is free.

5 Bad days will come

There will be the good, the bad, and the downright ugly days at school (whatever school means for you). This doesn't mean a person with Rett syndrome cannot be successful while the craziness of Rett syndrome tries to disrupt their lives.

I have taken this wonderful, exhausting education journey with my daughter Molly, and I hope to share our knowledge further. Molly is starting a new journey in college, and I'm finding these universal truths still apply.

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

New Research Aimed at Females and Males Affected by MECP2 Mutation

This June, Rettsyndrome.org awarded research funding to further explore gene therapy via silent X reactivation and to develop new tools to diagnose and evaluate MECP2 Duplication Syndrome (MDS) in boys.



Dr. Jeannie Lee

Dr. Jeannie Lee and her team at Massachusetts General Hospital will spend the next two years building upon the discoveries from their previous work in silent X reactivation. X reactivation involves using drugs to turn “on” the silent yet healthy X chromosome, present in nearly all girls with Rett syndrome, in order to restore proper MECP2 levels in the brain. Dr. Lee has already shown that even partial restoration of MECP2 levels has a positive impact on Rett symptoms in mice. For this new project, they will be testing these X-reactivating drugs in a female mouse model they developed to better replicate the symptoms and severity of Rett syndrome in girls. They will work to determine an optimal drug protocol and to show that the X reactivation will significantly improve Rett symptoms. This is cutting-edge research, and we share Dr. Lee’s optimism that a treatment for Rett syndrome is within our reach.



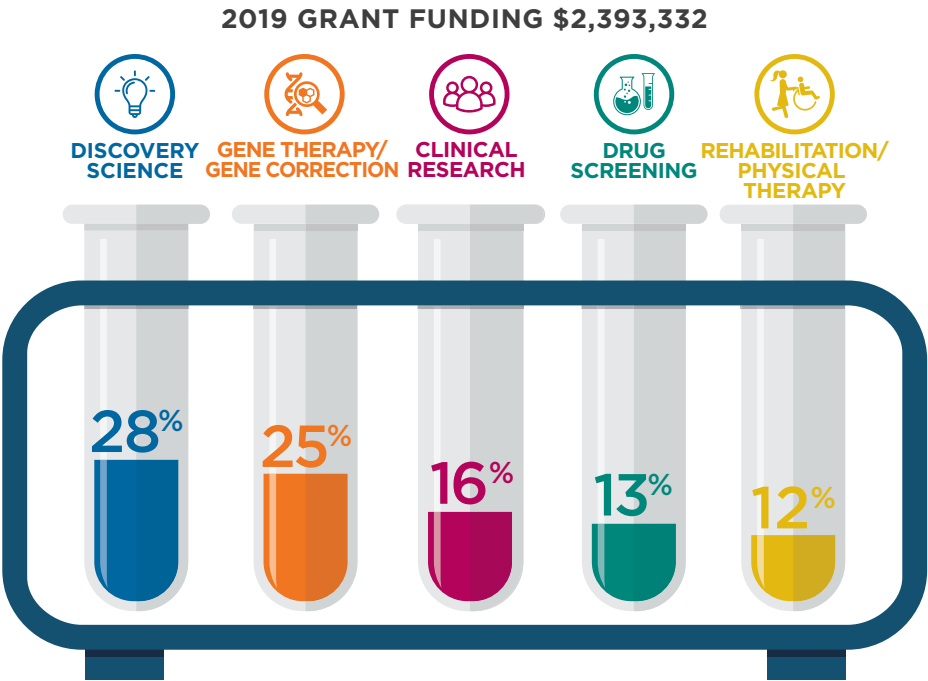
Dr. Davut Pehlivan

Dr. Davut Pehlivan is entering a 2-year fellowship under Dr. Hoda Zoghbi and Dr. Daniel Glaze at Texas Children’s Hospital. He will use data from the Natural History Study to develop tools to help diagnose and evaluate patients with MECP2 Duplication Syndrome (MDS). MDS is rare and primarily affects boys. Currently, there is no cure or treatment, and little information on MDS is available to families when they receive the diagnosis. The tools they develop will not only give clinicians and parents better insight into the course of the disease but could also be used to evaluate the effectiveness of MDS treatment medications in future clinical trials. We are proud to support Dr. Pehlivan in his clinical fellowship and believe his work in MDS will make a profound difference in the lives of the boys living with it.

NEW 2019 RESEARCH

This year we awarded nearly \$2.4 million in research grants (highlighted in the graphic to the right) and have 36 research studies in progress.

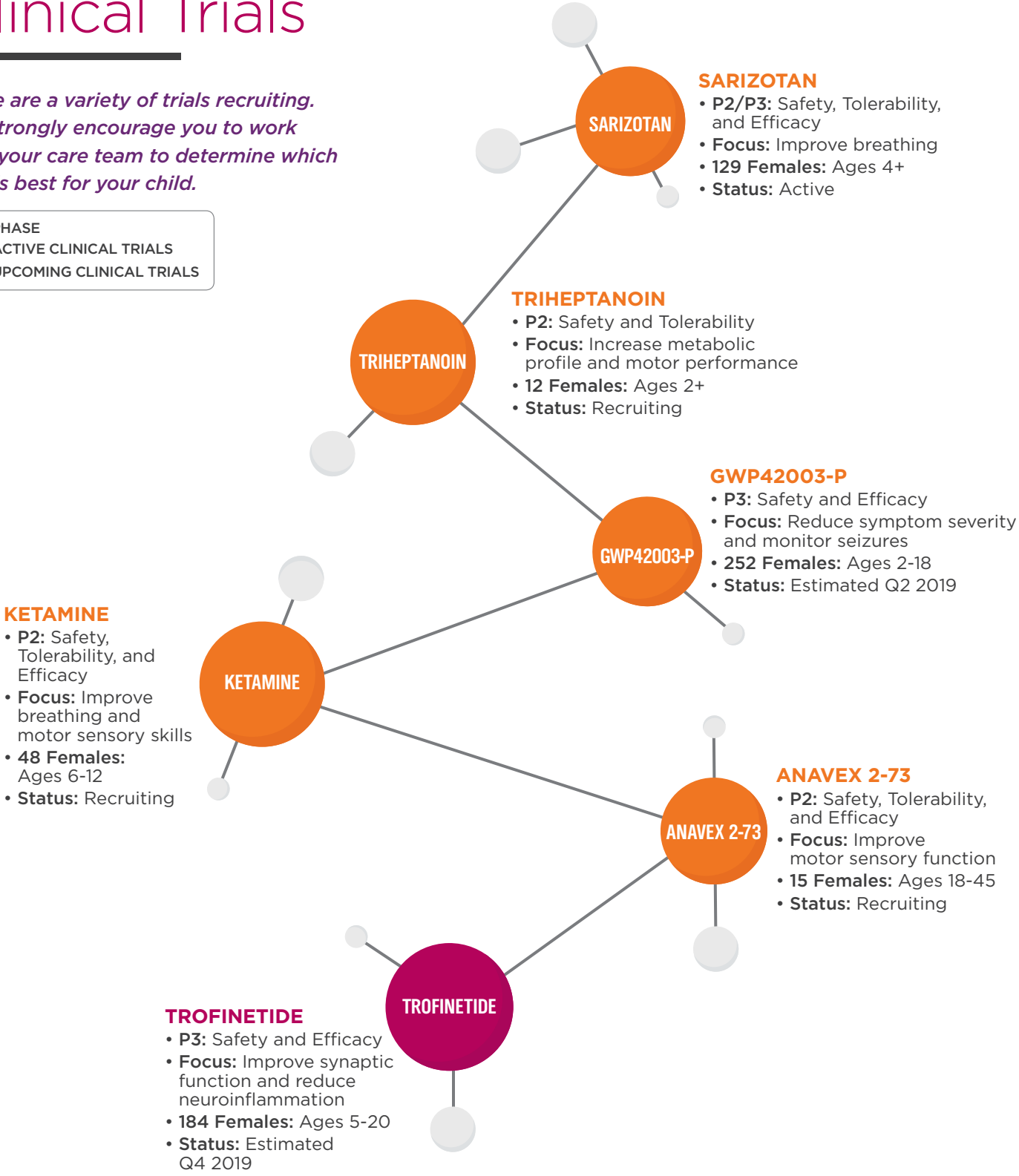
Our work continues to cover all streams of research to ensure that everyone living with Rett syndrome has a chance of improving. Because of your support, we have invested \$49 million in research since 1999.



Rett Syndrome Clinical Trials

There are a variety of trials recruiting. We strongly encourage you to work with your care team to determine which trial is best for your child.

P = PHASE
● = ACTIVE CLINICAL TRIALS
● = UPCOMING CLINICAL TRIALS



Clinical trials can and do change. Visit Rettsyndrome.org often for updated information and to view available non-drug studies.

When Molly met Jill: Rett syndrome connection becomes fast friendship

Molly Prichard jokes that she and best friend Jill Black met through “online dating.”

But Molly and Jill’s story isn’t about two single people wishfully texting back and forth through a dating app. It’s about two moms with girls newly diagnosed with Rett syndrome who found each other and, at the same time, found a new sense of hope.

Their story starts just last spring, when Molly’s daughter, Ruby, was diagnosed with Rett. Overwhelmed and in search of support, she started visiting Rett groups on Facebook and posted a message looking for other girls of a similar age who were newly diagnosed. (Ruby turned 2 in October.) Jill’s husband had posted about their daughter, Emma, who is only a few weeks younger than Ruby and who was diagnosed in May. And that’s how Molly first met Jill.

“I felt an instant connection with Jill,” says Molly, who lives near Sarasota, Fla. “The first day I was talking to her, I felt more comfortable telling her about our experience than I felt telling friends that I’ve had for 20-plus years. ... I felt like, ‘Jill is my person.’”

“We pulled each other out of the dark places we were in,” says Jill, who lives in Lawrenceburg, Ind. “[Molly] is the best friend that I have. I feel like I’ve known her my whole life.”

Just a few weeks after Molly and Jill met online, they planned a visit that has led to several more.

Now, as they each learn to navigate through medical, emotional, and logistical ups and downs, Jill and Molly encourage parents to seek support from other families.

“Don’t be afraid to reach out to people,” Jill says. “Know that there are people out there who are feeling and experiencing the same things you are. They may be looking for someone to lean on too, just like we both were.”

Read more of Molly and Jill’s story at www.rettsyndrome.org.



Left to Right: Jill, Emma, Ruby, and Molly



Supporting Our Families

One way that RSO empowers families is through our volunteer Family Empowerment Representatives. We have representatives in nearly all 50 states and reps for dads, single parents, grandparents, and Spanish-speaking families who are there for you in your darkest hours, to celebrate your wins, and to point you to available resources.

MEET TWO OF OUR FAMILY EMPOWERMENT REPS:



Caitlyn Barbier – North Carolina

- Mother to Lexi (4) who has Rett syndrome
- RSO Family Empowerment Rep since 2019

“There was a lot of confusion for us when we [were diagnosed], and if there’s an opportunity to help other newly diagnosed families navigate through, I want to help.”

~ Caitlyn



Susan Lee – Birmingham, AL

- Mother to Alyssa (11) who has Rett syndrome
- RSO Family Empowerment Rep since 2011

“To be able to reach out to families and be a resource to families is an honor and a privilege because I feel like I get to be part of each of these families.”

~ Susan

FIND YOUR STATE REP HERE:

<https://www.rettsyndrome.org/for-families/resources/state-resources/>

Raise a Glass Against Rett: Kansas

This September, our very own Samantha Brant hosted the 3rd Annual Raise a Glass Against Rett Syndrome in Kansas City. What began as a small fundraiser in a brewery became a 200-person event at a winery, and this year, it grew to over 350 supporters packing the house at Austin’s Bar & Grill, raising over \$40,000 for Rettsyndrome.org. Samantha’s commitment to hosting a family friendly, community-wide event in honor of her daughter, Macy, is unique and inspiring.



Shop from Your Heart

We are thankful for the many companies that partner with Rettsyndrome.org to advance our mission. When you buy our partner products, a portion of your purchase goes to support our research and families. Now is a great time to get an early start on your holiday shopping!



- 1 T-shirt**
Order Rettsyndrome.org's NEW t-shirt and tell the world about Rett syndrome.
- 2 Beaded Wire**
Jessica Gomes, owner of the Beaded Wire, designs beautiful crystal jewelry for all occasions. Check out her special Rett syndrome line that includes a stunning new earring set. Perfect stocking stuffer!
- 3 Bravelets**
Our children with Rett syndrome are brave each and every day! Support them with your very own Bravelet.
- 4 TyLuxCosmetics** is dedicated to offering exquisite products with luxury in mind. All its skincare products are thoughtfully curated to provide lavish, aromatic, guilt-free gratification.
- 5 The Adventures of Bug & Boo**
Denay Hooks, mom to Hannah, decided to imagine a different life from Rett syndrome. Join Bug and Boo on an adventure under the sea where Bug's rare disease and wheelchair "go away" and she can do things her body doesn't typically allow.
- 6 Shauna**
This is an endearing story by BK Fulton about his relationship with his sister, Shauna, who has Rett syndrome.

Don't forget Amazon Smile! Visit smile.amazon.com, select Rettsyndrome.org as your charity of choice, and shop as you always do. A portion of purchases will benefit our children with Rett syndrome.

Find all these amazing products and more online:
www.rettsyndrome.org/shop



Alex and Ani Shop 'til you drop!

That's exactly what we did this summer with Alex and Ani as we teamed up with them for Charmed by Charity events in Atlanta, St. Louis, and Boston. Thank you, Alex and Ani, for allowing us to spread awareness and raise funds for Rett syndrome with your beautiful jewelry!



Creating a World without Rett

Because we represent a rare disease, it's essential to let the world hear about Rett syndrome so they can help us end it.
Get started by visiting www.rettsyndrome.org/get-involved.

REQUEST AN ANGEL CARD

Our redesigned Angel Cards are a great way to raise awareness. Provide us with a photo of your child, his or her name, and a fun fact, and we'll produce a digital PDF that you can have printed. We even have a cool new option for boys!

BE THEIR VOICE



Create a Personal Page in honor of someone you love with Rett Syndrome. Then share this page with family, friends, and co-workers to help OVERPOWER Rett and find a cure.
Personal pages aren't just for individuals — recently, StorageMart set up a personal page for an employee's daughter to raise funds and provide a matching donation.

INTERESTED IN SUPPORTING OUR CAUSE THROUGH YOUR PRODUCTS OR HOSTING AN EVENT?
We can help! Contact Jackie at jventura@rettsyndrome.org.



Sharing Knowledge to Empower Families

By Katie Busch

Education is the passport to the future, for tomorrow belongs to those who prepare for it today.
~ Malcolm X

A critical element of Rettsyndrome.org's mission is to help you be successful as parents, caregivers, therapists, and teachers. We believe that keeping you informed with the latest Rett syndrome information is one key to your success.

Our RettEd webinars and Ed Days are designed to keep you in the know. We are excited to share that over 1,600 people, including parents, grandparents, therapists, teachers, caregivers, clinicians, and regional associates from around the globe, have participated in the educational opportunities offered so far this year.

Rettsyndrome.org Ed Days

Families came from hundreds of miles away to attend Ed Days in Pennsylvania, Massachusetts, and California. A North Carolina family that came to our Boston Ed Day decided to become one of our North Carolina Family Empowerment Representatives.

Although Rettsyndrome.org works with local clinics and, when possible, the regional associations to shape the Ed Day agenda, each site works to make their day unique. The Bay Area Ed Day was a hands-on experience at Camp Arroyo. Those with Rett and their caregivers were given a chance to try hippotherapy and equine therapy, and to experience eye-gaze technology with local experts. Philadelphia's Ed Day was located near Sesame Place, so they held a dinner with Cookie Monster. One attendee said, *"The time at Sesame Place was great; it allowed people to hang out as families and friends rather than caregivers and panelists. It was awesome! I wish more families had attended both."*

Each of our Ed Days offered the chance to connect with a local Rett Clinic team and included opportunities to connect with other families. We are thrilled with the turnout and interest in Ed Days.

RettEd Webinars

RettEd Webinars offer an opportunity to hear from experts and parent panels, as well as ask the questions that matter to you. Some of this year's topics include Sleep, Research Update, Nutrition, IEP, and Genetics. All past webinars are available on our website so that you can watch, rewatch, or share them with others.

To view our RettEd recordings or to register for upcoming webinars, visit www.rettsyndrome.org/education.

2020 Lineup

Rettsyndrome.org is committed to educating our families, care teams, and the medical community by sharing current research, best practices, and creating opportunities for families to connect with one another. We've got an amazing lineup planned for 2020.



Join us for a fantastic year of live RettEd webinars.

January: In Spanish: ¿Qué es el síndrome de Rett?

February: Rett Syndrome Research Update

March: Walking and Rett Syndrome with Dr. Meir Lotan

April: Maximizing Neuroplasticity in Therapies

May: Mini Brains in Space - Pushing the Limits of Science with Alysson Muotri

June: Reactivating the Silent X

July: Longevity in Rett Syndrome

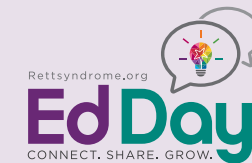
August: What Hurts? Understanding Pain and Rett Syndrome

September: Life Hacks for Rett Syndrome

October: Clinical Trial Update

November: Communication in Rett Syndrome

December: What Do They See? Vision in Rett



We're partnering with clinics and regional associations across the country to host four Ed Days next year.

East Coast Rettsyndrome.org Ed Day —
in partnership with Kennedy Krieger Institute
June 6, 2020 - Baltimore, MD

Northwest Rettsyndrome.org Ed Day —
in partnership with the Northwest Rett Syndrome Association
August 15, 2020 - Vancouver, WA

Southeast Rettsyndrome.org Ed Day —
in partnership with Greenwood Genetic Center
Fall, 2020 - Greenwood, SC

Midwest Rettsyndrome.org Ed Day —
in partnership with Rush University
October 10, 2020 - Chicago, IL



2020 RettGetaway - Save the Date!

Rettsyndrome.org is pleased to announce we are partnering with the Mosca Foundation to host the 2020 RettGetaway, centered around an adapted surfing day on June 20, 2020 in San Diego. This will be an amazing experience for our children and loved ones. More details to come!

9th World Rett Congress
Queensland, Australia
September 30 - October 3, 2020

The Rett Syndrome Association of Australia is excited to announce the 9th World Rett Syndrome Congress. Get the latest in research and clinical innovations and drugs. Seminars will be presented by world-renowned experts in Rett. The event will include social events, entertainment, and much more. Rub elbows with the best in the field and get to know Rett families from around the world.

<http://rettworldcongress.org/>

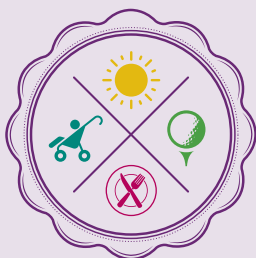


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UPCOMING EVENTS

We have events happening around the country that you and your loved ones can participate in.

November 9th

Reach for a Cure: Houston
Boots & Bling Gala
Houston, TX

November 12th

Rett Ed Webinar: Orthopedics
"A Focus on Scoliosis & Hips"

December 3rd

Giving Tuesday

December 10th

Rett Ed Webinar: Clinical Trial
Enrollment & Opportunities Update

February 28th, 2020

Rare Disease Day

March 1st, 2020

Napa Valley Marathon
Napa, CA

March 21, 2020

Cammy Can
Chicago, IL

For a complete list of events, visit our event calendar at
www.rettsyndrome.org/events