

2021



Rett GAZETTE

Accelerating Research.
Empowering Families.

ALL IN FOR *a cure*



International
Rett Syndrome
Foundation

www.rettsyndrome.org

Advancing Best-in-Class
Care & Clinical Trials **p4**

Clinical Trial
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ASCEND
2022 **p12**



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Scan this QR code to learn more about our Gazette features.



ALL IN. EVERY DAY IRSF IS ALL IN TO FIND A CURE FOR RETT SYNDROME AS WE EMPOWER FAMILIES.

Melissa Kennedy
Chief Executive Officer

OUR RETURN TO IRSF

Many of you know that our Foundation's roots were firmly planted by the International Rett Syndrome Association (IRSA) in 1983. Through a series of collaborative efforts and mergers, we became the International Rett Syndrome Foundation — known to many as [Rettsyndrome.org](https://rettsyndrome.org). Recently, we reclaimed our organization's name: International Rett Syndrome Foundation (IRSF) to honor that history. Our two-pronged mission — to fund groundbreaking research and help empower families living with Rett syndrome — continues to be our North Star, and that is how we will create a world without Rett.

ALL IN FOR A CURE

Over the last year, our Foundation has funded promising gene replacement and gene therapy research as well as research that is looking for new ways of treating the course of Rett syndrome. Throughout the world, we are supporting labs and new trainees who are dedicating their careers to the study of Rett.

Recently, we launched our Centers of Excellence Network, giving our clinics a platform to work together to improve quality of care and advance clinical research. And with the support of clinical investigators throughout the country, we assumed stewardship of the legacy Natural History Study database. Building upon it with data collected during regular clinic visits at our Rett Syndrome Centers of Excellence, we formed the Rett Syndrome Registry™ — with involvement from the FDA and industry to ensure that it will enhance drug development and clinical trials.

ALL IN FOR FAMILIES

In addition to supporting families with resources and monthly educational webinars, we are THRILLED to be gearing up for ASCEND 2022 — the first national meeting hosted by our organization in almost six years. We will be in person with a great line-up of speakers and interactive sessions. You'll be able to connect with other families, grab a cup of coffee with a Rett syndrome researcher or the director of one of our Centers of Excellence, and mingle with industry partners and companies that are investing in Rett syndrome. We can't wait to see you there!

We are grateful to you for your involvement and engagement with our Foundation. Everything we do is made possible because of your support. It is truly our honor to serve you and your family.

With Hope and Gratitude,

Melissa Kennedy,
Chief Executive Officer

2020 IMPACT REPORT

INTERNATIONAL RETT SYNDROME FOUNDATION is laser-focused on creating a world without Rett syndrome. We are relentlessly driven toward a cure. By accelerating the best research and breakthrough discoveries in Rett syndrome, we help families thrive through resources, advocacy, and empowerment. Your support makes all of this possible. Thank you!

73%
\$2,829,379
Contributions/
Grants



27% \$1,021,571
Special Events

81%
\$1,996,963
Programs



10% \$236,333
Advocacy & Fundraising

9% \$232,512
Admin

\$51.1M INVESTED IN RESEARCH
THROUGH 2020

\$3.85M RAISED TOWARD A
CURE + FAMILY SUPPORT

81% OF EVERY DOLLAR
FUNDS RESEARCH
AND FAMILY
EMPOWERMENT

583K
UNIQUE VISITS TO
RETTSYNDROME.ORG

3745 UNIQUE VISITS TO NEWLY
LAUNCHED RETT RESEARCH READY™

243 NEWLY
DIAGNOSED
FAMILIES
REGISTERED
WITH IRSF.

30+ IRSF AT-HOME
RESOURCES
GENERATED
38,000 VIEWS

200+ COUNTRIES & TERRITORIES
UTILIZED IRSF RESOURCES

41 ACTIVE IRSF
GLOBAL
RESEARCH
PROJECTS

1400
COMMUNICATION
GUIDELINES
DISTRIBUTED

AWARDED
HIGHEST
RATINGS:



Advancing Best-in-Class Care & Clinical Trials

IRSF LAUNCHES CENTERS OF EXCELLENCE NETWORK

IRSF is thrilled to welcome:
Carmen Luna
Clinical Network Development Manager



This spring, IRSF designated 15 Centers of Excellence across the U.S. in response to the need for families to easily identify and access clinics that provide expert care for their loved ones living with Rett syndrome. Centers of Excellence provide medical services and are designed to be multidisciplinary in nature, offering specialty care such as neurology, gastroenterology, genetics, physical medicine, speech therapy, and more either in the clinic or by referral.

This new designation is part of IRSF's commitment to helping families thrive by receiving expert clinical care related to Rett syndrome. **Our goal is that most families living with Rett syndrome will have access to a Rett syndrome expert by 2024.**

The Centers of Excellence Network aims to improve care for individuals living with Rett Syndrome by developing consensus-based care guidelines and support for clinical trials. While each Center of Excellence operates independently, IRSF created this network to collaborate by sharing knowledge, resources, and experiences among clinics and participate in clinical research projects together.

"The infrastructure created by our Centers of Excellence partners allows us to aggressively engage in clinical research," says IRSF CSO Dominique Pichard, MD, "This is the only way to make treatment options and curative therapies a reality for ALL families living with Rett syndrome."

Each Center of Excellence participated in a rigorous application process and met criteria established by the IRSF Medical Advisory Board, including:

- A physician director with expertise in Rett syndrome care
- Health care services that meet the unique needs of individuals with Rett
- Involvement in clinical trials
- Ongoing contribution to a clinical registry

"We are delighted to be part of this internationally recognized team of experts who are dedicated to improving the lives of individuals and their families living with Rett syndrome."

~ Constance Smith-Hicks, MD PhD, Director, Rett and Related Disorders Program, Kennedy Krieger Institute

These clinics already provide outstanding service to many of the families in our Rett community. Check out the list below to find and connect with the clinic nearest you.



UTSouthwestern
Medical Center

UAB



VANDERBILT KENNEDY CENTER

Washington
University
in St. Louis

RUSH UNIVERSITY
MEDICAL CENTER

Gillette
Children's
Specialty Healthcare
120 YEARS OF CAN

Kennedy Krieger Institute

UCSF Benioff Children's
Hospitals
Redefining possible.

Boston
Children's
Hospital
Until every child is well

Greenwood
Genetic Center

The Children's Hospital
of Philadelphia

Children's Hospital
Colorado

The Children's
Hospital
at Montefiore

crnd
Center for Rare Neurological Diseases

Texas Children's
Hospital

The Center of Excellence designation is a two-year term and may be renewed.



Rett Syndrome Registry™

POWERING YOUR DATA TO UNLOCK TREATMENTS AND A CURE

IRSF is building the Rett Syndrome Registry™ to help families share their information with physicians, researchers, and industry to create a world without Rett.

Designed with guidance from the Food and Drug Administration (FDA), the Rett Syndrome Registry™ has two components: caregiver reports and clinical data collection. The FDA and pharmaceutical companies consider this powerful combination the optimal platform for clinical trial design. Further, Hive Networks is contributing its expertise in organizing health data to ensure that the Registry becomes a reliable tool for researchers and industry to discover actionable insights into Rett. In this way, the Registry will bring patients, researchers, providers, and industry together to cure Rett syndrome.

IRSF Centers of Excellence will collect patient care data for the Rett Syndrome Registry™ as part of each patient's regular care visit. The Registry will continue to build on the critical work that the NIH-funded Natural History Study accomplished over the last 15 years.

Because Rett is a rare disorder, every family is an essential partner in Rett treatment research. We need broad participation from our community in the Registry to create a dataset that captures the diversity within Rett that scientists need to devise treatments and cures for everyone with Rett.

Sign-up to learn more about the Rett Syndrome Registry™ and get connected with your nearest IRSF Center of Excellence.

www.rettsyndrome.org/registry

**Rett Syndrome
Registry™**



ALL IN for a Cure

IRSF'S SCIENTIFIC STRATEGY IS **ALL IN**
FOR SOLUTIONS FOR EVERY RETT FAMILY.

By Dominique Pichard, MD, Chief Science Officer

Thanks in part to the investments made by our Foundation and legacy foundations, we're now in an exciting time for Rett syndrome. Research has advanced our knowledge of Rett syndrome and created new and improved treatment approaches. Clinical trials are progressing.

But at IRSF, we won't stop until we have completely changed the landscape for families living with Rett. We are ALL IN, ready to do whatever it takes to cure Rett syndrome.

For me, delivering on this commitment is more than a job duty. As a mother to a teenage girl with Rett syndrome, it's personal. I'm eager for a world without Rett, a world where all our loved ones are cured. At the same time, it's important to pursue treatments along the way to a cure so that those who are currently suffering may access life-changing benefits.

We want these treatments and cures in families' hands as soon as possible. And this will take an organization that is bold enough to take risks and never stop pushing boundaries. That's why IRSF invests in projects today that ensure Rett treatment development moves faster tomorrow. And our investments cover every stage of this process.

Longitudinal
Clinical
Data

Centers of
Excellence
Network

Rett
Research
Ready™

AT IRSF, WE ARE ADVANCING>>>

Vital, Innovative Research

IRSF invests in both *MECP2* restoration and identifying other new Rett targets. In doing so, we maximize the opportunities for Rett treatment development. IRSF currently has 41 funded researchers around the world working on Rett syndrome solutions.

41
FUNDED
RESEARCHERS

Pipeline Development

Today over 20 companies are investing in therapeutic solutions for Rett syndrome. We need even more. The more shots on goal, the more you score. IRSF is advancing promising ideas from research into the therapeutic pipeline. Over the next year, IRSF will be taking more shots on goal thanks to exciting partnerships with biotech and pharmaceutical companies. Together, we'll advance even more promising ideas from research into the therapeutic pipeline.

20+
COMPANIES
INVESTING
IN RETT

Clinical Trials

Qualified therapeutics will advance to clinical trials. IRSF's forward-thinking approach eliminates many of the challenges facing clinical research by collaborating with the key stakeholders in clinical trials, including Rett families, physicians, pharmaceutical companies, and the FDA. Our robust, national clinical infrastructure ensures that clinics have a chance to fully participate in trials. Importantly, we also work with pharmaceutical companies conducting or planning clinical trials to set them up for success.

15
CLINICAL TRIAL
SITES READY
TO PARTNER

Because of the complexity of Rett syndrome and how much it varies from individual to individual, we need more than one cure or approach to reach everyone with Rett. We are dedicated to advancing existing opportunities through the development pipeline, but we are equally dedicated to exploring new treatment options to reach every individual with Rett. It's **ALL IN** at every level for ALL with Rett.



Clinical Trial Update:

MORE PHARMACEUTICAL COMPANIES ARE INVESTING IN RETT SYNDROME

By Dominique Pichard, MD, Chief Science Officer

The future of Rett syndrome looks bright thanks to the work that IRSF is doing to build the current clinical trial landscape.

The first Phase 3 clinical trial just completed enrollment for Trofinetide, a drug that targets the underlying pathology of Rett syndrome. This is a big deal! Phase 3 is the last clinical trial phase a sponsor needs to conduct before applying for approval from the FDA. If the data from this trial demonstrate that the benefits outweigh the risks, Trofinetide could become the first FDA-approved treatment for Rett syndrome.

At the same time, we're seeing increased industry interest in Rett syndrome treatment development. Eight years ago, only one pharmaceutical company

was investing in Rett syndrome drug development. Today, over 20 have announced Rett syndrome programs. These programs represent a variety of treatment approaches that are in various stages of development (see graph to the right).

More clinical trials are likely in the near future. As such, we hope you will accept the mission of becoming a Research Partner by enrolling in our new Rett Syndrome Registry™ and learning about other opportunities through Rett Research Ready™.



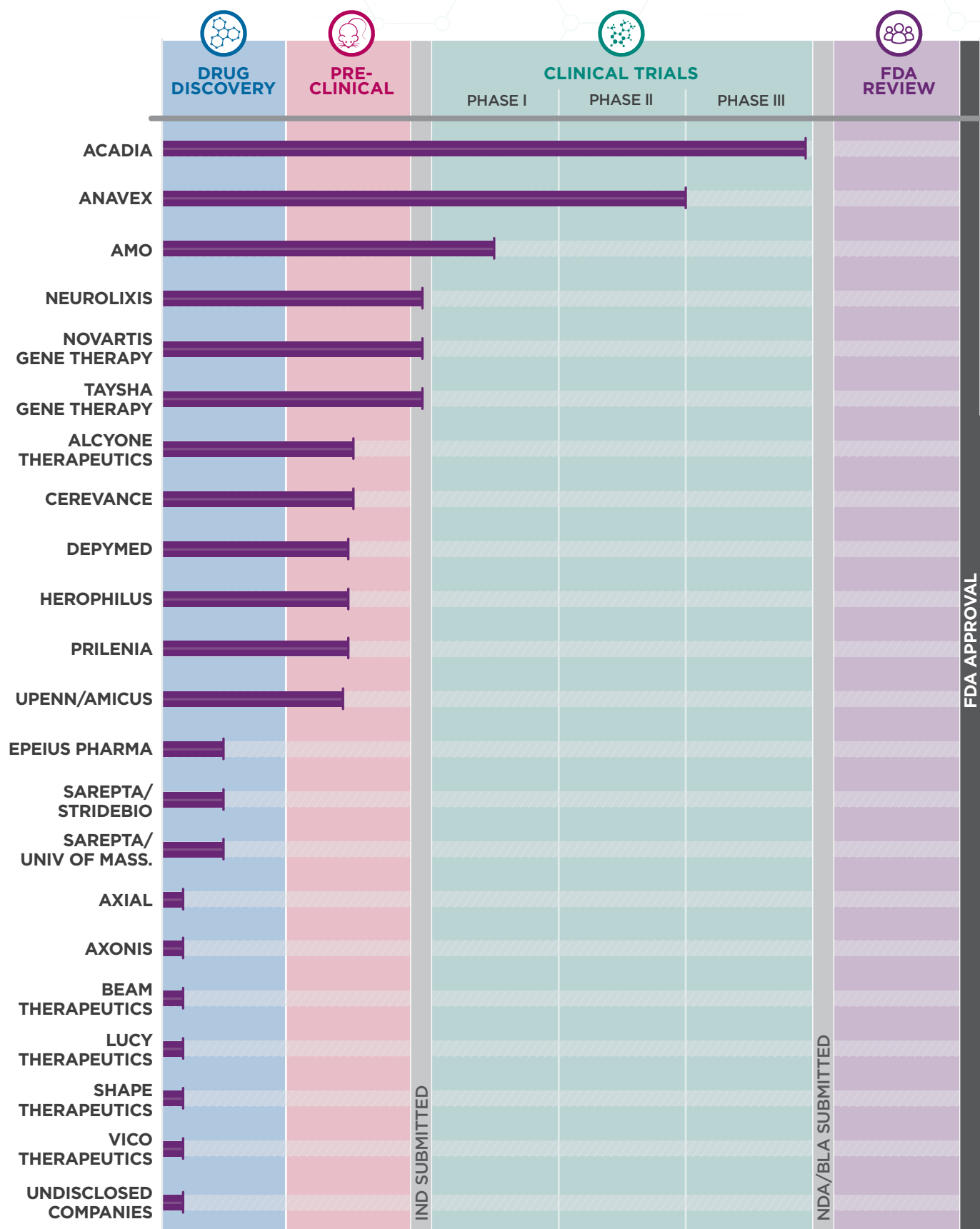
INSIDE THE LAB

IRSF funds innovative and important research to help create a world without Rett syndrome. Through our Inside the Lab series, you'll hear from our funded researchers about their exciting work and how it advances us toward a cure for Rett syndrome.

Read about X-Reactivation, RNA editing, drug development, and many other fascinating research topics.

Visit Inside the Lab: www.rettsyndrome.org/inside-the-lab.

COMPANIES INVESTING IN CLINICAL TRIALS FOR RETT





ALL
IN
FOR
a cure

ALL IN

We believe in a world where everyone with Rett syndrome can live to their fullest potential and their families can embrace life without fear, daring to dream about their loved one's future.

Rett is a complex disorder. It manifests in multiple ways, so it requires multiple solutions. IRSF works tirelessly to explore every promising lead, creating a robust pipeline of research, drug development, and clinical trials to innovate solutions for all. But we need your help.

WE'VE SET A BOLD GOAL:

Raise \$29 million over three years to advance treatments and a cure for those with Rett syndrome.

ALL IN *for a cure.*

IRSF is boldly committed to finding a cure for Rett syndrome. The science behind developing a cure is promising and possible. **To bring treatments and a cure home, we need to fund more critical research, more treatment development, and more clinical trials.**

WE'VE BEEN CHANGING THE GAME FOR DECADES

Through the support of our donors, IRSF has been investing in projects that profoundly impact foundational Rett syndrome research, resulting in discoveries and partnerships critical to our mission of finding a cure.

IRSF is advancing drugs and genetic approaches. Our established infrastructure, industry partners, and connection to Rett syndrome families allow us to advance clinical research toward a cure.

TOGETHER, LET'S GO ALL IN AND MAKE SURE NO FAMILY FACES RETT SYNDROME ALONE

Our families drive us. As we relentlessly pursue a cure, we come alongside families with support wherever they are on their journey. Each of them faces nearly constant challenges, from doctors' appointments and therapies to the burden of expenses and strained relationships. They all need compassionate and practical support, effective treatments, and ultimately, a cure.

Join with us to meet those needs as we make incredible strides forward in much-needed research — right now.

Will you go ALL IN for someone you love with Rett?

Together we can provide solutions for every family fighting Rett.

WE ARE BOLDLY COMMITTING TO RAISING \$29 MILLION OVER THE NEXT THREE YEARS TO

- 1 Increase investments in ground-breaking research that provides novel approaches to therapeutics
- 2 Advance research to flood the pipeline for treatments and a cure
- 3 Remove barriers to ensure clinical trials success

LET'S GO ALL IN.

For a cure. For families. For individuals with Rett all over the world.

Learn more visit rettsyndrome.org/all-in



THE WAIT IS OVER!

KEYNOTE SPEAKERS:



Dr. Huda Zoghbi
*Jan and Dan Duncan
Neurological
Research Institute*



Chris Ulmer
*Special Books
for Special Kids*

Join us for the

ASCEND 2022 RETT SYNDROME NATIONAL SUMMIT!

**GAYLORD OPRYLAND RESORT
& CONVENTION CENTER,
NASHVILLE, TN**

APRIL 27-30, 2022

Experience incredible sessions led by Rett experts, special keynotes, and activities designed to connect our community.

FEATURING RETT EXPERTS FROM AROUND THE WORLD!

SOME OF OUR SPEAKERS INCLUDE:



Dr. Meir Lotan
Ariel University, Israel



Dr. Alan Percy
University of Alabama at Birmingham



Dr. Karen Erickson
Center for Literacy and Disability Studies



Dr. Tim Benke
Children's Hospital Colorado



Dr. Jeff Neul
Vanderbilt University Medical Center



Dr. David Koppenhaver
Appalachian State University



Dr. Kyle Fink
University of California, Davis Medical Center



Dr. Theresa Bartolotta
Thomas Jefferson University

And many more!

SESSIONS:

- Special Needs Trusts
- Physical Therapy
- Genetic Approaches
- Adulthood
- Natural History Study & Beyond
- Primary Care
- Alternative Medicines
- Epilepsy & Rett Episodes
- AAC & Communication
- IEPs
- Research Updates and more!

Are you ready to ASCEND? Go to rettsyndrome.org/summit to register and then download our app to help you plan your visit to Nashville and connect with other Rett families!

Reserve your room at the Gaylord Resort or one of many surrounding accommodations.



NASHVILLE HIGHLIGHTS

- Country Music Hall of Fame
- Grand Ole Opry
- Ryman Auditorium
- Nashville Zoo at Grassmere
- Cheekwood Botanical Garden & Museum of Art
- General Jackson Showboat
- Gaylord Opryland Resort Gardens
- Kid Rock's Bar
- Opry Mills
- Andrew Jackson's Hermitage
- Wildhorse Saloon
- Tootsie's Orchid Lounge

Rett Syndrome Awareness Month

SPREAD THE WORD AND INVITE YOUR COMMUNITY TO GO **ALL IN** THIS OCTOBER

Raise your hand. Tell your story. Invite others to help create a world without Rett syndrome. With all of us — families, friends, researchers, companies, and advocacy organizations — doing our part, we can fight for families and accelerate research that leads to a cure.

RAISE AWARENESS!

The Rett syndrome community is small but mighty. Each year, awareness of Rett syndrome increases across the globe. Rett doesn't stop and neither do we! Here's how to get involved!

Sport our
2021 **ALL IN** for
a Cure t-shirt.



Download our Rett syndrome awareness one-sheet, social media posts, and profile frame.

Wear our temporary tattoos: **ALL IN** for a Cure.



RAISE FUNDS FOR A CURE!

IRSF goes beyond funding the research. We work with key stakeholders to make sure treatments get across the finish line to benefit families as soon as possible. Here's how you can help!



Start a Facebook Fundraiser!

Get your community on board and fundraise for a cure.



Create a Personal Page!

Share your loved one's story and raise funds at the same time.



Donate!

Give to support research toward a cure and to help families thrive.

Visit rettsyndrome.org/october to get started!



SURF'S UP, LAUREN!

Lauren (24) has always loved adventure and trying new things, including horseback riding, skiing, paddleboard, and swimming with dolphins and stingrays. When the opportunity came up for her to try surfing for the first time, I was hesitant and more than a little nervous (just like I am every time I let her try something new), but I'm so glad we decided to go for it.

Watching her ride the waves with the wonderful volunteers is something I never thought she'd be able to do back when I was first told she had Rett syndrome. It was amazing, and as usual, the smiles on her face let everyone know she was not only excited to do it but was having an awesome time!

Now the next question is ... what will Lauren's next adventure be?

Shared by Sherri Brady, mom to Lauren



KIRA'S FLORIDA ADVENTURE

Earlier this summer, our family took a road trip to Destin, Florida. Spending 14 months at home doing virtual school with Kira gave us time to reflect on the importance of creating memories as a family and seizing each opportunity to create adventures.

Perhaps the most exciting part of our trip was our time spent on the beach. With our new "adventure-chair," Kira got to truly experience the beach for the first time. She waded in the ocean up to her waist, joined in for family sunrise and sunset walks on the beach, and helped our two older children hunt for seashells.

From the moment we hit the sand, the smiles were endless. We couldn't get there enough. The "adventure-chair" also allowed Kira to get off the trails at an animal park and see the kangaroos, emus, and tortoises up close. It was truly an amazing experience, and we can't wait to find our next inclusive adventure.

Shared by Patty Mevis, mom to Kira

Speech-Language Pathologists & Educators:

RETT COMMUNICATION HELP IS ON THE WAY

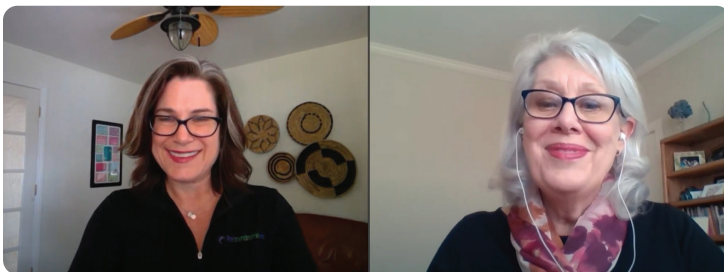
By Paige Nues, Director of Family Empowerment

The IRSF-funded evidence-based *Rett Syndrome Communication Guidelines* has provided parents, caregivers, therapists, and school educators around the world with **access to the best information, resources, and strategies to facilitate communication in those with Rett syndrome.**

This is an incredible resource for parents, communication partners, and ultimately for children/adults with Rett Syndrome... I wish I had it two years ago when first starting AAC for our daughter, Ann. It's comprehensive yet concise.

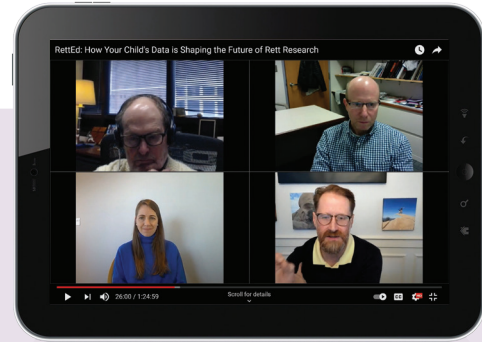
~Jack Kuwik, parent

Initially, parents and caregivers would purchase these guidelines for personal use or to pass them on to healthcare professionals and educators. In an effort to close that gap, IRSF will launch an educational initiative to further distribute the Communication Guidelines directly to professionals and build an educational support network for both experienced and up-and-coming healthcare professionals and educators!



This initiative will provide professionals with the latest information to improve communication in Rett syndrome and reduce the strain on families. Members will have access to a safe and secure cloud environment for education, training, facilitated communication, and problem-solving as well as opportunities to share resources that complement the guidelines. Keep an eye on www.rettssyndrome.org for the launch date!

This work has been supported by Novartis Gene Therapy.



IRSF DIGITAL EDUCATION LIBRARY

By Paige Nues, Director of Family Empowerment

Newly diagnosed? Living with an eye-rolling teen or a more mature adult with Rett? Want to understand symptom management or hear the newest conversations in genetics and gene therapy? You have questions and we have answers!

IRSF's ever-expanding online digital library (hosted on our website and YouTube channel) offers the latest expert advice on all pressing Rett-related topics. Our library allows you to connect on-demand with the specialists who research, treat, and advance us toward a cure for Rett, all from the comfort of your home or personal electronic device. Learn on your own time and then share with your care teams.

Rett topics include literacy matters, epilepsy, sleep, G.I. issues, nutrition, clinical trials, and more! Our 2021 educational program is made possible thanks to ACADIA, Novartis, and Taysha Gene Therapies.

Submit RettEd content requests for consideration to Paige Nues at pnues@rettsyndrome.org



World Rett Associations Leaders Forum



Many of us found new ways to connect during the pandemic.

Video calls with parents, grandparents, children, and friends became the norm while we couldn't be together in person. Doctor's visits were often virtual, and many businesses moved to online meetings. IRSF, inspired by these new models of communication, has decided to launch the World Rett Associations Leaders Forum. Many associations around the world are volunteer-led and look to our Foundation for resources and support. This new forum will be a space for like-minded leaders of Rett associations to easily collaborate and support each other to advance research, improve quality of life for families, advocate on global issues, and run effective sustainable associations with a spirit of cooperation.

Currently, the leaders of 24 associations in the Americas, Europe, Asia, and the Middle East have joined the World Rett Associations Leaders Forum and have committed to meeting online four times per year.



"... What you are doing is HOPE for all of us who love someone with Rett Syndrome.... In Portugal, Rett syndrome is not well known. Doctors took almost five years to find out that [Tatiana had Rett]. You are right now our only hope doing research to find a cure ..."

~ Dina Estassi, Grandmother to Tatiana

RettEd HERE'S WHAT'S COMING UP:

OCTOBER 12, PHYSIATRIST:
Therapies: PT, OT, Equipment and Interventions

NOVEMBER 10, NUTRITION:
Parent Panel with Dietitian Expert

DECEMBER 8, Occupational Therapy:
Hand Function, Feeding Therapy Goals and Modifications

JANUARY 11:
The Neuroscience of Music Therapy

Register online: rettsyndrome.org/education



ALL IN for 15 Years

John Corpus, former IRSF board member, has chaired the Samantha Corpus Golf Tournament for 15 years running and has helped to raise \$3.6 million in the fight to end Rett!

In 2021, he was honored with a Pinnacle Award, which recognizes an extraordinary contribution to the vision and mission of IRSF.

His 21-year-old daughter Samantha was diagnosed with Rett syndrome at age 3. She has played basketball in the Special Olympics, surfed with her brothers in Hawaii, and is currently attending a transitional school to further her learning. Whatever she does, she is ALL IN.

We're so grateful to John, his wife Kathy, their sons Julian (23) and Jacob (18), and the host of others — business associates and volunteers — who have modeled Samantha's example and given their all! In 2021, they hosted their final tournament and raised over \$400,000 — the most ever!

Forever part of our IRSF family, the Corpuses hold a special place in our hearts. Maybe they'll even make an encore return to the links.



"Being an aunt is a crazy combination of worrying like a mother, loving like a sister, and being fun and crazy like a friend. Being an aunt to a girl with Rett syndrome amplifies all of those feelings and left me searching for ways to support my niece, Alia.

I got involved with IRSF because they are intensely focused on research like a mother, they are dedicated to connecting families like a sister, and their events are super fun like a friend! From Strollathons to virtual trivia to live music, auctions, raffles, workouts, shopping, and more — every fundraising event allows me to channel my love for being an aunt into a fun, meaningful way I can help Alia."

~ Kelly Zwald, Aunt to Alia



"The International Rett Syndrome Foundation continues to be a perfect one-stop-shop for us on our journey. As your circle of influence grows, you can use IRSF to be a resource for them too."

*~ Sam & Sarah Ahlstrom,
hosts of pRETTy Happy podcast*



UPCOMING EVENTS CALENDAR

We have many great events coming up across the country, both in-person and virtual!
Find an event near you to help us create a world without Rett syndrome!

Oct 9

sMiles for Clare; NJ

Run, walk, or stroll on this one-mile course to overpower Rett!

Oct 9

Throw for Rett; Williamstown, NJ

Join this fun-filled corn hole event with raffle.

Oct 16

South Carolina Strollathon; Columbia, SC

Gather with other local Rett families to connect and Stroll towards a cure for Rett syndrome.

Oct 19

Bingo for Rett; Sparks, NV

Grab some friends and get your bingo cards ready as you play to help end Rett.

Oct 23

5th Annual Golf Fore a Cure; Lakeland, FL

Hit the links to help create a world without Rett.

Oct 23

14th Annual St. Louis Strollathon; St. Louis, MO

Gather with other local Rett families for a fun-filled day with a scenic stroll for Rett.

Oct 23-24

Rett Gets Rocked; St. Louis, MO

Jay Murray will compete an ultra-marathon (100 miles!) for Rett. Join him in the run.

Oct 23-24

SoCal Strollathon & Picnic; Virtual

Connect with other local SoCal Rett families via Zoom as they Stroll virtually.

Nov 6

2nd Annual Raise a Glass for Rett Virtual Gala

Join us for this virtual event uniting the entire community for a world without Rett.

Nov 30

Giving Tuesday

Donate during this 24-hour international day of giving to support IRSF.

Visit our online event calendar to see our full listings and check back often for new events being added.

www.rettsyndrome.org/calendar

Scan this QR code to learn more about our events and Gazette features.





www.rettsyndrome.org

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Cincinnati, OH 45246

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GET READY TO

Raise YOUR Glass!



SECOND ANNUAL

RAISE A GLASS FOR RETT SYNDROME VIRTUAL GALA

SATURDAY, NOVEMBER 6, 2021
8:00 PM EST / 7:00 PM CST

Join us LIVE from Houston for a memorable evening filled with entertainment, stories from our community, critical research updates, and more led by emcees Kassie Morell and Steve Wood. Special performance by Makayla Phillips, semi-finalist on America's Got Talent and Top 10 finalist on American Idol.

Don't miss the one event of the year that brings together our entire community! Tickets are \$50 and include a commemorative pint or wine glass.

Visit rettsyndrome.org/gala for more information.



MAKAYLA PHILLIPS

