



Get Involved

Your support can help families thrive and accelerate research for a cure.

GIVE. 90 cents of every donor dollar supports our mission.

FUNDRAISE. Start an online fundraiser, participate in an annual IRSF event, or even start your own.

SHARE THE VISION. Use your voice to raise awareness and advocate for our Rett families.

Get Started!
Scan this QR code to learn more about Rett syndrome.



ABOUT THE INTERNATIONAL RETT SYNDROME FOUNDATION

As the leading Rett syndrome research and advocacy organization, the International Rett Syndrome Foundation (IRSF) builds upon our nearly 40-year commitment to breakthrough discoveries and life-changing advancements in research toward a cure while supporting families affected by Rett syndrome. Through our legacy foundation pioneers, IRSF has invested over \$58M in research leading to identifying Rett syndrome's cause, demonstrating Rett syndrome is reversible in mice, and supporting the clinical trials that led to the first FDA-approved treatment. We fight for families living with Rett syndrome and a world without it.

Learn more at rettsyndrome.org.



rettsyndrome.org
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Rett syndrome

is a debilitating neurological disorder that leads to severe impairment and affects nearly every aspect of life.

Individuals with Rett develop normally for their first 6 to 18 months but then begin to miss developmental milestones or lose abilities they had gained, including their ability to speak, walk, eat, and even breathe.

Rett syndrome particularly affects speech, purposeful hand use, and coordination, leaving individuals trapped in their own bodies, understanding more than they can communicate.

Not a degenerative disorder — individuals can live to middle age and beyond — Rett syndrome can manifest a lifetime of additional issues, including:

- Breathing difficulties
- Cardiac issues
- Swallowing and digestive issues
- Scoliosis
- Seizures
- Repetitive hand movements while awake

Caused by a gene mutation on the X chromosome, Rett syndrome occurs in 1 in 10,000 female births with a growing number of males being identified.

The FDA recently approved the first-ever treatment to ease the signs and symptoms for Rett syndrome, but **there is no cure.**





RETT DOESN'T STOP. NEITHER DO WE.

The International Rett Syndrome Foundation (IRSF) is the leading research and family empowerment organization for Rett syndrome. We're on a mission to transform the lives of all those affected by Rett syndrome by accelerating research toward treatment and a cure while empowering families with the information, programs, and services they need to thrive.

We are relentlessly driven towards a cure.

"IRSF offered us educational resources, understanding and a new 'Rett Family.' We are no longer alone."

*~ Kathy Gole,
mom to Becky*

accelerating RESEARCH

We work with cutting-edge researchers and pharmaceutical companies to set up the next wave of Rett breakthroughs in pursuit of a cure.

Rett syndrome is a complex disorder that requires multiple approaches to change lives with treatment today while investing in the cure for tomorrow.

WE'VE BEEN AGGRESSIVELY ADVANCING DISEASE-MODIFYING AND POTENTIALLY CURATIVE RESEARCH FOR DECADES, FUNDING THE RESEARCH THAT:



Discovered the gene that causes Rett syndrome (MECP2)



Demonstrated the reversibility of Rett in mice



Identified and studied trofinetide, now the first-ever treatment for Rett syndrome



Establishes researchers across the globe focused on gene therapies and drug development

RESEARCH STRATEGY:

IRSF is committed to a full-spectrum approach, providing solutions for everyone living with Rett syndrome. We do this by investing in innovative research, working to build a robust treatment pipeline, and removing barriers to ensure clinical trial success.

20+
COMPANIES
INVESTING
IN RETT

35+
ACTIVE
RESEARCH
PROJECTS

18
ACTIVE
CLINICAL
TRIAL SITES



empowering FAMILIES

We provide families with the latest medical information, offer meaningful support, raise public awareness, and advocate for all those living with Rett syndrome.

WE HELP FAMILIES THRIVE BY:

- Hosting "a robust "RettEd" program featuring expert speakers on Rett-related care topics and opportunities for families to connect with one another.
- Creating a network of State Family Empowerment Representatives to provide 24/7 support for diagnosed families in every state.
- Publishing research-based resources to help families thrive, including the *Primary Care Guidelines* and *Rett Syndrome Communication Guidelines*.

"The outpouring of love we received from IRSF helped us to pick ourselves up and to help carry Maylee through this journey."

~ Mallorie & Nathan Stump, parents to Maylee