

Rett syndrome is a rare disease and many don't know it exists.

The first step to fueling research and helping families is telling the stories of those living with Rett.

Whether you're having coffee with a friend, hosting a small event at your house, or speaking to thousands of people online, you can make a difference in the fight for a cure.

Here's how to talk about it:

Start Personal

Speaking from personal connection and experience changes statistics into story. It's not about a faceless number. It's about a family member or a friend.

Keep People Informed

People rarely act on something they've heard once. It takes time to build a meaningful connection. Make Rett a regular topic of conversation with your friends, neighbors, and coworkers.

Connect People to Their Passion

Everyone is different. Some may want to give time. Others may want to give money.

See reverse side for all the ways to get involved.

Highlight Impact

IRSF has been making a difference for over 40 years, thanks to the generous people who lend their support. Here are major achievements to talk about:

- Funded the discovery of the gene that causes Rett syndrome (MECP2) and its reversibility
- Funded the first gene therapy research in Rett syndrome and the first Rett syndrome clinical trial
- Funded the clinical trials that led to the first-ever FDA-approved treatment for Rett syndrome
- Convened parents and experts to publish the Rett Syndrome Handbook
- Designated 18 Rett Syndrome Centers of Excellence

85% of all donations to IRSF go directly to funding research and family programs. Generosity makes this amazing work possible.

Get Involved

with IRSF

No matter your gifting or passion, there's a way for you to support IRSF and help change lives.



Give a one-time gift, setup recurring donations, or choose one of our unique donation methods.



Events

Fundraising events raise awareness and connect people to the cause.



Fundraise

We've created lots of fun, sharable, and effective ways to raise funds for finding a cure.



Let your elected officials know their constituents care about our cause.



Raise Awareness

More awareness means more support for families and more funding for critical research.



Shop

Support IRSF through the IRSF Shop and our friends who give back.



Contact Us

rettsyndrome.org/get-involved (513) 874-3020 info@rettsyndrome.org



Volunteer

We are always looking for volunteers to help with events across the nation.