

# Every STEP OF THE WAY

Wherever you are on your Rett Journey, IRSF is here to help you thrive.



## THE RETT JOURNEY





#### NEWLY DIAGNOSED

You are not alone. Register with IRSF and connect with our family empowerment team. Rett parents themselves, they will be your guide to what comes next.

- Receive your Rett Syndrome Toolkit for new parents, including the Rett Syndrome Handbook and guide to your first 100 days.
- Choose a Rett clinic from our Center of Excellence network to ensure best-in-class care for your child.
- Join our Parents of Newly Diagnosed (PONDS) Facebook Group, moderated by parents, a place to connect with families at the same stage in the Rett journey.

## MAKE CONNECTIONS

An entire Rett community is ready to embrace you and your child as members. Deepen your connection with other Rett families by:

- Connecting with your local family empowerment representative to learn about state and local resources vetted by parents, for parents.
- Attending one of our many in-person family events, including RettEd Days, RettAways, the national summit, and local fundraising events like the Strollathon.
- Registering for our RettEd Webinar series with families from around the world.

## QUALITY OF LIFE

Our team is here to help you and your loved one with Rett thrive. Beyond our RettEd Video Library, explore our resources on these topics:

- Communication: Use learnings from our research-based
  Communication Guidelines and ensure your SLP has completed our Continuing Education Program.
- Education: Learn IEP strategies and use our educational resources to create the best learning environment for your loved one with Rett.
- Lifecare Planning: Prepare for the future with guidance on legal, financial, and benefits planning as your child grows into adolescence and beyond.







### **OFFER HOPE**

Join with IRSF to support other families on their Rett Journey and accelerate research towards treatment and a cure.

- Join the Rett Syndrome Registry and use the *my*Rett Trial Finder tool to participate in clinical trials.
- Fundraise to support IRSF's mission by creating a personal or Facebook fundraising page, supporting an event, or even starting your own.
- Become a PONDS group mentor or volunteer to share your knowledge as a family empowerment rep.
- Advocate for Rett syndrome by contacting your state rep to ensure federal funding for Rett research or petitioning for October to be declared Rett Syndrome Awareness month in your state. But most importantly, share your story.



Contact Samantha Brant at sbrant@rettsyndrome.org or (513) 494-8145

HERE TO HELP.



