Rettsyndrome.org, a 501(c)3 organization, is the most comprehensive nonprofit dedicated to accelerating research for treatments and a cure for Rett syndrome and related disorders, while providing information and family empowerment. Rettsyndrome.org funds high-quality, peer-reviewed research grants and programs. The organization hosts the largest global gathering of Rett researchers and clinicians to establish research direction for the future. Rettsyndrome.org has earned Charity Navigator’s prestigious 3 star rating. The core mission of Rettsyndrome.org is to accelerate full spectrum research to cure Rett syndrome and empower families with information, education, and connectivity.

Join us in our mission
• Make a donation or volunteer your time
• Coordinate or participate in a fundraising event : Strollathon : Social event or gala : Golf tournament
Direct donations are appreciated online at www.rettsyndrome.org/get-involved/donate or mailed to: Rettsyndrome.org 4600 Devitt Drive Cincinnati, OH 45246-1104

YOUR HELP IS OUR HOPE!

Rettsyndrome.org has invested over $40 million in research since 1990
• The National Institutes of Health consistently supports Rettsyndrome.org funded research Rettsyndrome.org funded projects have consistently produced data recognized by the National Institutes of Health. This warrants five times more leverage of our research dollars through federal funding
• We have sponsored 2 of the top 10 drug trials in autism and related neurodevelopmental disorders cited by the scientific journal Nature Biotechnology, more than any other nonprofit

Rettsyndrome.org has been an amazing force in advancing our understanding of Rett syndrome research over the last 25 years. One day, we will have a great treatment for these girls.

The ‘Research to Reality’ is a really great way to capture our state of affairs with Rett syndrome. Research gave us the reality about how important this protein is for brain function.

DR. HUDA ZOGHBI

Rettsyndrome.org Accelerates Research
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Rettsyndrome.org Empowers Families Through
• Information, education, and connectivity for newly diagnosed families
• Connection to a national network of knowledgeable and caring volunteers and advisors
• Resources such as The Rett Syndrome Handbook, the most comprehensive resource guide with contributions from Rett experts around the globe; the First 100 Day Pathway; and our online knowledge library
• Family Conference and other educational opportunities
• Support for regional clinics and seminars on Rett syndrome

About Rettsyndrome.org
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**Rett syndrome**

- Is a rare non-inherited genetic postnatal neurological disorder affecting mostly females
- Affects seemingly normal girls usually starting when they are 6-18 months old
- Is caused by a mutation in MECP2, master gene for normal neurologic development
- Affects 1 in 10,000 live female births worldwide, it is more common than Huntington’s disease and Muscular Dystrophy
- Has a wide range of symptoms, with many autistic characteristics, often including the loss of speech, the ability to walk and the purposeful use of hands. Other symptoms include seizures, breathing irregularities and extreme anxiety

The hallmark sign of Rett syndrome is near constant repetitive hand movements. Cognitive assessment in children with Rett syndrome is complicated, but they understand far more than they can communicate to us, evidenced by their bright and attentive eyes, and ability to express moods and emotions.

RETTSYNDROME.ORG IS THE WORLD’S LARGEST PRIVATE SOURCE OF FUNDING FOR RETT SYNDROME RESEARCH, ADDRESSING THE FULL SPECTRUM OF THIS POSTNATAL NEUROLOGICAL DISORDER, WHILE ADVOCATING TO IMPROVE THE QUALITY OF LIFE FOR THOSE LIVING WITH RETT SYNDROME AND THEIR FAMILIES.

**RESEARCH STRATEGY AND MISSION**

Our strategy is to accelerate research and aggressively move more potential drug treatments to clinical trials by expanding basic discovery. We will translate foundational research into promising treatments.