



With your support, we can continue to blaze a trail in Rett syndrome research and family empowerment to transform lives.

**Join us in our mission:**

- Make a donation
- Coordinate a Fundraiser
- Participate in an Event
- Advocate for Rett syndrome

Visit [www.rettsyndrome.org](http://www.rettsyndrome.org) or call 1.800.719.8214

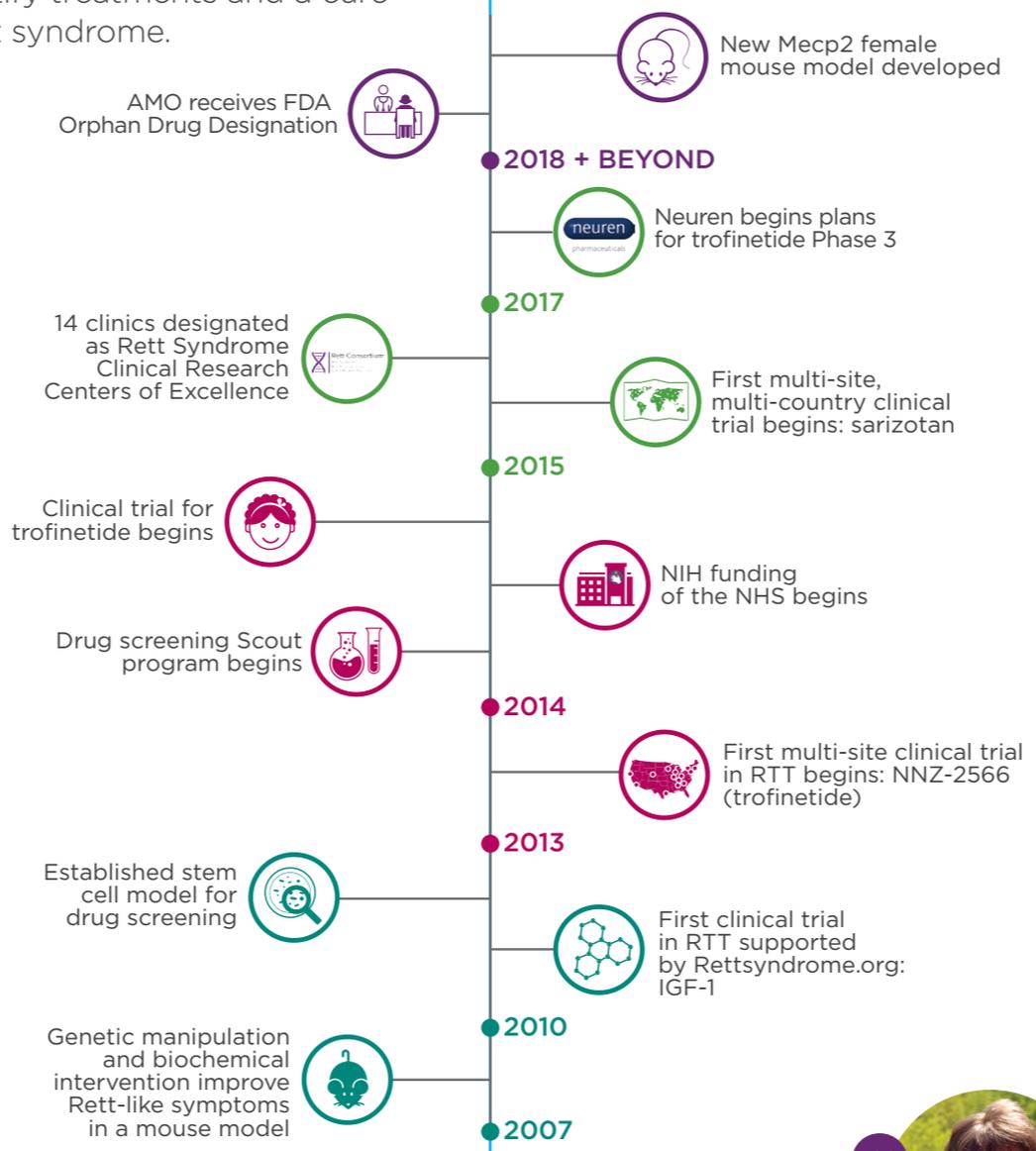
Rettsyndrome.org is a 501(c)3 organization dedicated to accelerating research for treatments and a cure for Rett syndrome and related disorders, while providing family empowerment. As a leading organization for Rett syndrome research, Rettsyndrome.org is committed to funding high-quality, peer-reviewed research grants and programs.



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 (800) 818-7388 [www.rettsyndrome.org](http://www.rettsyndrome.org)  
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**RESEARCH STRATEGY AND MISSION**

We aggressively pursue research to identify treatments and a cure for Rett syndrome.



Accelerating Research.  
 Empowering Families.

I am very thankful that Rettsyndrome.org has taken such a strong leadership role with advancing research. Their progress to get trofinetide to market is very exciting as it could finally be an answer to relieving some of Jill's daily struggles.





Imagine the symptoms of autism, cerebral palsy and epilepsy affecting one child who cannot speak... **this is Rett syndrome.**

#### RETT SYNDROME IS

A debilitating neurological disorder caused by a mutation of the MECP2 gene. It affects 1 in 10,000 female births. Rett syndrome is very rare in males. Children with Rett syndrome understand more than they can communicate.

#### Children often experience:

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

Symptoms may be more severe in boys.



Rettsyndrome.org is committed to empowering families. We offer resources, education, connections and support so families can make the best decisions for their child at any stage of life.



During this time of such tremendous progress in research, it is essential that we continue to provide services that support the families affected by Rett syndrome. We never forget that Rett syndrome affects the entire family and our dedication to them is unwavering.

*Melissa Kennedy, Executive Director  
Rettsyndrome.org*

Rettsyndrome.org is the only organization committed to research and family empowerment.

#### WE BELIEVE

- The cure for Rett syndrome depends on integrating both treatments and gene therapies with physical, occupational and speech therapies
- We have an obligation to support the families affected by Rett syndrome while relentlessly pursuing treatments and a cure.

#### WE HAVE

- Funded over \$44 million in research
- Invested over \$10 million in family programs and services
- Developed our proprietary Scout Program to screen compounds for potential use in Rett syndrome
- The Natural History Study for Rett syndrome with support from the NIH
- A clinical care network of 19 clinics that provide state of the art care to Rett syndrome patients

#### RECENT HIGHLIGHTS

- \$2.4 million awarded for 2018 research projects.
- 3 compounds tested in the Scout program in or planning for clinical trials
- Funding research into the early work of gene therapy
- Provide global access to Rett syndrome experts to families through online webinars.



*Photo by Paul Vincent Kuntz*

#### RETT SYNDROME CLINICS AND NATURAL HISTORY STUDY

Rett syndrome specialized care helps to improve a child's quality of life. Many Rett syndrome clinics also participate in the Natural History Study.



**For a full list of Rett Clinics and Natural History Study sites and contact information, visit [www.rettsyndrome.org/natural-history-study](http://www.rettsyndrome.org/natural-history-study)**

Girls and boys of any age are encouraged to participate in the Natural History Study!