

About IRSF

The International Rett Syndrome Foundation (IRSF) is the largest and most comprehensive not-for-profit organization for parents, scientists, interested professionals and others concerned with Rett syndrome. IRSF is a 501(c)3 corporation established by the merger of the International Rett Syndrome Association and the Rett Syndrome Research Foundation.

The mission of IRSF is to fund research for treatments and a cure for Rett syndrome while enhancing the overall quality of life for those living with Rett syndrome by providing information, programs and services.



Information, Programs & Services

Research progress

- Rett syndrome is the only autism-spectrum disorder with a known genetic cause.
- The MECP2 gene mutation was discovered in 1999
- Rett syndrome is often characterized as the "Rosetta Stone" of brain disorders that will help unlock treatments and cures for other brain disorders including autism, schizophrenia, bi-polar disorder, Parkinson's, anxiety and autonomic nervous system disorders.
- In 2007, a landmark study showed the reversal of Rett syndrome in a genetic mouse model. This experiment established the principle of reversibility of RTT, suggesting many symptoms of Rett syndrome and related disorders are reversible, even at late stages.
- The search for treatments is more crucial now than ever. Our goal is to identify drugs and other therapeutic approaches to make this a reality for the individuals and families affected by Rett syndrome.

Your help is our hope!

- Make a donation or volunteer your time
- Coordinate a fundraising event. Possibilities include:
 - IRSF Strollathon
 - Social event or Gala
 - Golf Tournament or a Walk/Run for Rett

IRSF will provide you with the assistance you need to make your efforts a success. Call us at 1-800-818-RETT, or visit www.rett Syndrome.org to learn more.



IRSF
INTERNATIONAL
RETT SYNDROME
FOUNDATION

4600 Devitt Drive
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**Research
Family Support
Advocacy**



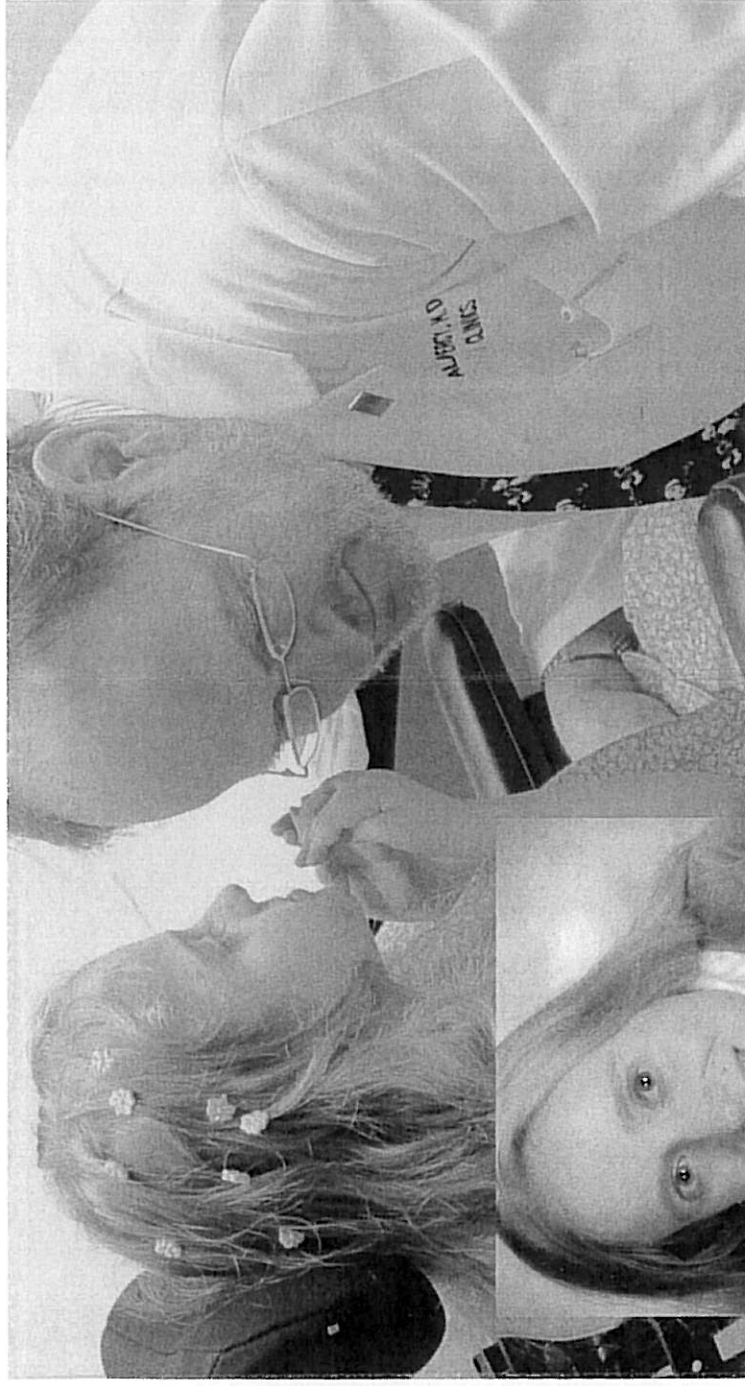
IRSF is the world's largest private source of funds for biomedical and applied research of Rett syndrome. The foundation directs at least 92% of each dollar donated to program services.

Annually, the IRSF organizes and hosts:

- **The IRSF Scientific Symposium** The world's largest annual meeting of leading Rett syndrome researchers and clinicians gather together to exchange the latest information and to establish research direction and priorities.
- **The IRSF Family Conference** Annually, families from across the nation and the globe come together to bond, learn and face the future together. This conference provides continuing educational opportunities and connections to parents, family members, therapists, teachers, physicians and other individuals involved in the day-to-day care of individuals with Rett syndrome.

In addition, IRSF provides:

- A toll-free 1-800-818-RETT number for families to call to receive informational resources and emotional support.
- The Rett Syndrome Handbook, the most comprehensive resource guide with contributions from Rett experts around the globe.
- Maintenance of comprehensive patient database.
- Public awareness and advocacy materials.
- Electronic and printed newsletters.
- Support for regional clinics and seminars on Rett syndrome.
- Informational web site and online discussion forums.
- Professional referral services.
- National network of knowledgeable and caring regional representatives and advisors.



Research Family Support Advocacy



What is Rett Syndrome?

Rett syndrome (RTT) is a devastating neurological developmental disorder that is seen in infancy and occurs almost exclusively in females. It is usually caused by a mutation of the MECP2 gene on the X chromosome. Rett syndrome is found in all racial and ethnic groups throughout the world, and in every socioeconomic class. Rett syndrome affects one in every ten to fifteen thousand live female births. Early developmental milestones appear normal, but between 6-18 months of age, there is a delay or

regression in development, particularly affecting speech, hand skills and coordination.

A hallmark of Rett syndrome is repetitive hand movements that may become almost constant while awake. Other features may include seizures, irregular breathing, swallowing difficulties, and curvature of the spine. Many individuals with Rett syndrome live long into adulthood. There is currently no cure.