IRSF *is the world's largest private source of funds for Rett syndrome research addressing the full spectrum of this developmental disorder while advocating to improve the quality of life for the patients and their families.*

THE IRSF ORGANIZES AND HOSTS:

- **The IRSF Scientific Symposium**

The world's largest annual meeting of leading Rett syndrome researchers and clinicians gathered 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.

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 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.
- In 2010, the first disease-modifying human clinical trial began, a risk investment made by IRSF in conjunction with other notable research institutes, paving the way for further clinical trials.
- 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.

WHAT IS RETT SYNDROME

Rett syndrome is a genetic neurological disorder that occurs almost exclusively in females and becomes apparent after 6-18 months of early normal development. It results in a regression that leads to lifelong impairments. Those inflicted with this disorder have multiple dysfunctions: speech is lost, seizures develop and scoliosis occurs, many develop irregular breathing patterns, and more than half of the girls and women lose their ability to walk. Those diagnosed with Rett syndrome require maximum assistance with even the most basic daily activities. The hallmark sign of Rett syndrome is near constant repetitive hand movements while awake.

RESEARCH FOCUS

IRSF is dedicated to helping develop new treatments to improve quality of life for individuals with Rett syndrome and ultimately reverse RTT. We support and facilitate research into the causes, treatments and a cure by:

- Promoting interdisciplinary cooperation.
- Funding cutting edge basic, translational and clinical research.
- Organizing research symposia and meetings.

IRSF PROVIDES:

- A toll-free 1-800-818-RETT (7388) 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.