



Ontario
Rett Syndrome
Association
Building Healthy Tomorrows

Who is O.R.S.A.?

The Ontario Rett Syndrome Association (O.R.S.A.) has been operating for over two decades. It funds Canadian Rett syndrome (RTT) research, educates the public about the condition and supports affected individuals and families. O.R.S.A. is Canada's largest charitable, not-for-profit provincial organization that concentrates on Rett syndrome. It is operated by a volunteer board of directors made up of parents of affected individuals and friends who support the organization's goals.

O.R.S.A. exists to ensure that children and adults with Rett syndrome are enabled to achieve their full potential and enjoy the highest quality of life within their community.

Why Support O.R.S.A. Now?

O.R.S.A. funds treatment advancements and research that provide thousands of people with hope.

In 1999 it was discovered that Rett syndrome is primarily caused by a sporadic mutation in the MECP2 gene on the X chromosome. In 2004, researchers at the Hospital for Sick Children (Sick Kids), the Centre for Addiction and Mental Health (CAMH) and the University of Toronto (U of T) identified an alternate form of the disease gene and protein for the neurodevelopmental condition Rett syndrome. O.R.S.A. aided in funding this research.

In 2006 O.R.S.A. partially funded the first Canadian Rett Syndrome Research Symposium. Since 2008, \$100,000 have been allocated to Canadian research. In 2011 Dr. Yaron Finkelstein received funding for his research project, entitled *Dose-Response Efficacy and Safety Analysis of Recombinant Human IGF-1 in Girls with Rett Syndrome*. This was a collaborative venture with Boston Children's Hospital. This study is currently in the second phase of drug trials.

In 2012, O.R.S.A. provided \$25,000 to fund a Canadian Rett Syndrome Research Symposium in Mississauga, Ontario. Twenty-five of the top Canadian researchers came together to share RTT research, both current and future projects. National research collaboration was established.

In 2014, O.R.S.A. established the Hope Fund, which will provide funding for Canadian Rett syndrome research. An initial grant of \$50,000 was announced for 2014.

Canadians with RTT receive excellent medical support at the three RTT clinics funded by O.R.S.A. – the Children's Hospital of Eastern Ontario (CHEO), Thames Valley Children's Centre London and Holland Bloorview Kids Rehabilitation Hospital (HBKRH) Toronto. These clinics provide diagnostic expertise, consultative services, clinical care and advocacy for children, youths and their families.

O.R.S.A. also funded the development of the Canadian Rett Syndrome Registry. Over \$90,000 has been dedicated to establishment and promotion of the registry. This national registry was launched in April 2014.

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It will collect information on the history of the disorder that will lead to future research projects. Most importantly, the registry is required for clinical trials to take place in Canada.

O.R.S.A. is a hard working, dedicated volunteer organization that receives its funds from memorial donations, private donations and fundraising activities. Every donation makes a difference in the lives of those affected by Rett syndrome.

What O.R.S.A. Funds?

1 - Family Support & Services

- **Rett Syndrome Clinics**
 - Children's Hospital of Eastern Ontario: \$20,000 (yearly)*
 - O.R.S.A.'s funding allows for the clinic's continued operation
 - Thames Valley Children's Centre: \$5,000 (yearly)*
 - O.R.S.A provides half the funding for this clinic yearly
 - Holland Bloorview Kids Rehabilitation Hospital (HBKRH), Toronto (yearly \$6,500.00)*
 - O.R.S.A. provides the funding for the RPN position that supports the clinic
- **Family Outreach Support \$2,000 (yearly)**
Local gatherings and activities
- **New Parent Member Package**
2nd edition RTT Handbook, The Book of Hope & Silent Angel DVD
Information folder with article and brochures

2 - Research

- **Canadian Rett Syndrome Registry**
A nation-wide registry launched April 2014
Development and Establishment: \$90,000.00 (three year project)
O.R.S.A. owns and commits to sustaining the registry: \$20,000 a year
Will facilitate Rett syndrome research and clinical drug trials
- **Research Grant Funding: the Hope Fund provides \$50,000 annually for Canadian Rett syndrome research (O.R.S.A. previously allocated \$100,000 to research since 2008)**

3 - Education & Awareness

- Bi-annual Conference: \$17,000 - 25,000
- Bi-annual Medical Professional Meetings: \$5,000
- Newsletter: \$3,000
- Website: \$1,200