



Ontario  
Rett Syndrome  
Association  
Building Healthy Tomorrows

## October is Rett Syndrome Awareness Month

### WHAT IS RETT SYNDROME?

Rett syndrome (RTT) is a neurodevelopmental condition characterized by the loss of spoken language and hand use, as well as repetitive hand movements. This disorder is congenital, seen in infancy and occurs almost exclusively in females. It is believed to occur in one in every ten thousand female births. There is currently no cure but advancements in treatment and research provide thousands of people with hope.

Rett syndrome is not degenerative and many individuals live long into adulthood. All children and adults with Rett syndrome need full-time assistance with every aspect of their daily lives. Individuals with RTT understand far more than they can express. They experience a full range of emotions and show their engaging personalities as they take part in social, educational and recreational activities at home and in the community. Recent advancements in augmentative and alternative communication are allowing individuals with Rett syndrome to engage and communicate in new and exciting ways.

### WHO IS O.R.S.A.?

- The Ontario Rett Syndrome Association (O.R.S.A.) is a volunteer, not-for-profit charity for parents, caregivers, researchers, medical professionals and other interested support agencies and individuals.
- O.R.S.A. is comprised of Board of Directors of parents and caring citizens.

### OUR MISSION

The Ontario Rett Syndrome Association (O.R.S.A.) exists to ensure that children and adults with Rett Syndrome achieve their full potential and enjoy the highest quality of life within their community.



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## **O.R.S.A. SERVICES & SUPPORTS**

- Provides all new parents/guardians membership with a complimentary parent package with important Rett syndrome information and resources
- Hosts conferences and medical symposiums focused on advancements in treatment and research
- Operates a Resource Centre for individuals and families affected by Rett syndrome
- Provides an information-based web site and newsletter
- Funds and supports the Rett syndrome clinics at the Children's Hospital of Eastern Ontario located in Ottawa, the Thames Valley Children's Centre located in London and Holland Bloorview Kids Rehabilitation Hospital located in Toronto
- Provide caring support and networking through the Family Outreach Coordinator
- In 2014, launched the Canadian Rett Syndrome Registry to collect information about the course of Rett syndrome, and facilitate future research studies and clinical drug trials
- Assists with connecting families to Rett syndrome clinics, the Canadian Rett Syndrome Registry, regional representatives as well as other families and supports
- Provides funding for Canadian research, and in 2014 announced the establishment of the Hope Fund to provide \$50,000 for Rett syndrome research

## **HOW TO SUPPORT O.R.S.A.**

- Join O.R.S.A.
- Make a donation or volunteer your time
- Attend or host a fundraising event
- Make others aware of Rett syndrome and O.R.S.A.

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