

**BECOME A
FREE LIFETIME
MEMBER**



**A strong membership
allows O.R.S.A. to continue to be a
powerful advocate and voice for all
individuals, families, and friends
affected by Rett syndrome.**



YOU CAN HELP BUILD HEALTHY TOMORROWS

- Join the Board of Directors
- Join a committee
- Volunteer your time at an event
- Attend or host fundraising events
- Spread awareness of O.R.S.A. and Rett Syndrome
- Make a donation



@OntarioRettSA



@OntarioRettSyndromeAssociation



@ontrettsyndromeassociation



Ontario Rett Syndrome Association



@ontariorettssyndrome

Ontario Rett Syndrome Association

P.O. Box 50030 London, ON N6A 6H8

Charitable #89017 8999 RR0001

Phone 519.474.6877

www.rett.ca



Ontario
Rett Syndrome
Association
Building Healthy Tomorrows



1 in 10,000

are affected by RETT SYNDROME,
a debilitating neurological disorder
usually caused by a mutation
of the MECP2 gene

WHO WE ARE



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 agencies and individuals. The Association provides support and advocates for individuals living with Rett syndrome and their families Provincially and Nationally.

OUR CORE MISSION

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

WHAT IS RETT SYNDROME?

Rett syndrome (RTT) is a rare genetic neurological disorder that occurs almost exclusively in females; even rarer in males. It is estimated that 1 in 10,000 are affected by RTT, usually caused by a mutation of the MECP2 gene on the X chromosome. It leads to severe impairments, affecting nearly every aspect of the individual's life: their ability to speak, walk, eat, and even breathe easily. Other medical issues encountered included seizures, muscle stiffness, osteoporosis and scoliosis. The hallmark of RTT is near constant repetitive hand movements. RTT is usually recognized in children between 6-18 months as they begin to miss developmental milestones or loss abilities they had gained also known as regression.



WHAT WE DO

SUPPORT

- Provide families with helpful resources and assist with connecting them to other local families and the Rett syndrome clinics.

CARE & EDUCATION

- Fund and support Rett syndrome clinics in Canada.
- Host educational conferences and symposiums for families, caregivers, researchers and health care professionals.
- Provide webinars, podcasts and up-to-date information via our website, social media platforms and email.

RESEARCH

- Provide funding for Canadian research initiatives through the Hope Fund.

- Developed, launched and maintain the Canadian Rett Syndrome Registry.



- Liaison with Investigators and

clinical trials in Canada.



ADVOCACY

- Partner with advocacy groups in lobbying government on rare disease initiatives.

FUNDRAISING & SPREADING AWARENESS

- Host signature fundraising events and facilitate 3rd party fundraising events.
- Obtain community proclamations to support October awareness and arrange for landmarks and buildings across Canada to light up Purple in October.

CN Tower, Toronto, Ontario



QUALITY OF LIFE & ADVANCE CARE PLANNING

- QOL/ACP Resource Centre
- Assist the University of Manitoba in developing a bio-bank repository to conduct Rett syndrome research.