

# HOW YOU CAN HELP

BECOME A FREE LIFETIME MEMBER



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



- Join the Board of Directors
- Join a committee
- Volunteer your time at an event
- Attend or host fundraising events
- Spread awareness
- Make a donation



@ORSAofficial



@OntarioRettSA



@OntarioRettSyndromeAssociation



@ontrettsyndromeassociation



Ontario Rett Syndrome Association



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Ontario Rett Syndrome  
ASSOCIATION OF CANADA



# 1 in 10,000

are affected by RETT SYNDROME,  
a rare genetic neurological  
disorder usually caused by a  
mutation in the  
MECP2 gene.

# WHO WE ARE



The Ontario Rett Syndrome Association (ORSA) is a volunteer, non-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

ORSA 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 is a rare genetic neurological disorder that occurs almost exclusively in females; even rarer in males. It leads to severe impairments, affecting nearly every aspect of the individual's life: their ability to speak, walk, eat, and even breathe easily. The hallmark of Rett is near constant repetitive hand movements.

There is currently no cure however, medical advancements are being made on medication to help with symptom control.

# WHAT WE DO

## SUPPORT

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

## CARE & EDUCATION

- Fund and support Rett syndrome clinics in Ontario.
- 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 and maintain the Canadian Rett Syndrome Registry.



Liaison with Investigators and Pharmaceutical companies to facilitate 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 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.