

ONTARIO RETT SYNDROME ASSOCIATION

STRATEGIC PLAN-2025-2030

Achieving our Mission by adhering to our Vision and Values

05 November 2024

Our Mission

The Ontario Rett Syndrome Association 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.

Our Vision

The Ontario Rett Syndrome Association is a sustainable, dynamic, caring and professional organization.

- It builds on its history and experience in serving as a lead resource for information, research, advocacy, and support to all those affected by Rett Syndrome.
- It is committed to constant growth and ensuring the provision of a diagnostic and care clinic to every family, promoting research.

Statement Of Values

In fulfilling our mission, we value those we serve, volunteers, Board members, partners, and funders. We constantly strive to demonstrate our values of:

SUPPORT

- Provide emotional support and guidance in a nurturing environment.
- Be sensitive to the well-being of others.

INTEGRITY

- Ensure that our actions match our values and take responsibility for our actions.
- Interact with others in a fair and honest manner.

OUTREACH

- In a positive and assertive manner, provide education and awareness to our families and other stakeholders.

- Strengthen our connections with government and the medical/research communities.

COMMITMENT

- Constantly strive to achieve our vision.
- Establish relationships with a long-term perspective.

RESPECT

- Foster an environment where the needs of Rett families are met with care and consideration.
- Work to ensure that individuals with Rett syndrome are able to find their place in society and achieve their full potential.

Strategic Outcome Areas

4 pillars to measure results and outcomes, by 2030:

1. Family Networking and Support

To ensure clarity for the organization on means to empower and support caregivers and their loved ones with Rett syndrome

2. Health System Relations

To ensure that our families are supported through the health system

3. Awareness Strategies

To raise profile and visibility of O.R.S.A. nationally and internationally

4. Organizational Transition and Stability

To ensure that the foundation, support, and oversight of all O.R.S.A. activities and practices are in place and reviewed regularly.

Key Result Area:

Pilar 1-Family Networking and Support

To ensure clarity for the organization on means to empower and support caregivers and their loved ones with Rett syndrome

Measurable Outcome Required	Possible Activities	Timeframe 2025-2030	Responsibility and Report/Update Schedule
To create and provide educational resources	<ul style="list-style-type: none">• Educational sessions, events and conferences• Webinars• Accessing existing resources outside of O.R.S.A.• Checklists	2025-2030	Executive
Access and utilizing Research Advisory Committee to update and clarify research developments	<ul style="list-style-type: none">• Monthly meetings with sponsors and partners• Annual touch point with advisory committee• Annual touch point with grant recipients	2025-2030	Executive (as required)
Family-to-Family Networking	<ul style="list-style-type: none">• Reportage of these activities by Outreach• Cracker barrel discussions at Conference• Committee chairs provide Outreach with ideas for parent and family engagement• Social events	2028	Committee and Event Chair at least two weeks prior to event (start of conference planning for input and after conference to report on outcomes)

Key Result Area:

Pilar 2-Health System Relations

To ensure that our families are supported through the health care system

Measurable Outcome Required	Possible Activities	Timeframe 2025-2030	Responsibility and Report/Update Schedule
10% of Ontario doctors have an understanding of Rett syndrome (total of 80,000 doctors in Ontario)	<ul style="list-style-type: none">• Build network with existing doctors• Target dev. Peds and ped neuro• Establish contact list of diagnosing physicians and specialists• Contact College of Physicians and Surgeons of Ontario• Conference (College of Physicians and Surgeons of Ontario)	2030	Executive
20% of families are aware of suggested medical services in Ontario	<ul style="list-style-type: none">• Web content• Email Blasts• Social posts• Mail (for aging population)	2030	Communications Committee
Raise \$100,000/year for research grants	<ul style="list-style-type: none">• Hope Fund	yearly	Fundraising
~200 patients registered on registry (CRSR)	<ul style="list-style-type: none">• Ask other provincial groups• Web content• Social Media• E-Blasts	2030	Communications Committee

Measurable Outcome Required	Possible Activities	Timeframe 2025-2030	Responsibility and Report/Update Schedule
	<ul style="list-style-type: none"> • Webinars • Clinicians 		
Rett syndrome included in complex care clinics	London clinic to accept patients over 18 years of age Navigating the Health care system Centre of excellence (COE) for Canadian clinics by O.R.S.A. and IRSF	2030	Executive/Outreach
Clinical Trials	Facilitate the conduct of Clinical Trials in Canada	2030	Executive
World Rett Congress	Host an international congress for professional and families all around the world all focused on Rett syndrome	2028	Executive

Key Result Area:

Pilar 3-Awareness Strategies

To raise profile and visibility of O.R.S.A. nationally

Measurable Outcome Required	Possible Activities	Timeframe 2025-2030	Responsibility and Report/Update Schedule
Increase number of engaged medical professional involved with O.R.S.A. by 100%	• Conferences/congress	2028	Conference
	• Hosting Medical Symposiums	2028	Lobbying
	• Hosting Webinars	2030	Medical Advisory
	• Medical Website / Lobbying Committee	2030	Committee
	• Medical advisor as a board member	2030	Executive
Increase active donor list by 15%	<ul style="list-style-type: none"> • Stewardship improvements (donor recognition) • Change website to have recurring donation option 	2030	Communications committee
Increase website traffic by 50%	<ul style="list-style-type: none"> • Use social media more effectively • Additional content for parents • Additional content for medical • Transparentness to members 	2030	Communications committee
Establish procedure for provincial and municipal proclamations (Rett Syndrome Day)	<ul style="list-style-type: none"> • October Rett Awareness Month • National Proclamation poster • Maintain list of municipalities who have proclaimed 	2030	Communications committee

Increase membership to sustain conference level support	<ul style="list-style-type: none"> • Redefine membership and incentives 	2030	Outreach and Executive
Rebrand O.R.S.A. looks	<ul style="list-style-type: none"> • Rebrand logo, colours scheme and name 	2025	Executive and Communications

Measurable Outcome Required	Possible Activities	Timeframe 2025-2030	Responsibility and Report/Update Schedule
A schedule of Board policy review and updating is in place	<ul style="list-style-type: none"> • Finalize procedure • Annual training • Develop mentorship program 	2030 yearly 2030	Executive
A comprehensive orientation/reorientation plan and schedule exists for all Board and Committee members	<ul style="list-style-type: none"> • Establish options for consideration • Determine materials required • Establish execution plan • Training material • Mentorship program with rotating schedule 	2030	Executive
O.R.S.A. has defined, purposeful membership categories in its bylaws (including donor (relationship) management)	<ul style="list-style-type: none"> • Dedicated Board discussion required • Research what others do (Imagine Canada, McConnell Foundation, Volunteer Toronto) – it’s about benefit of membership • Update Bylaws 	2030	Outreach