

ONTARIO RETT SYNDROME ASSOCIATION STRATEGIC PLAN

2022 to 2024

Achieving our Mission by adhering to our Vision and Values

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This Document

Due to the ongoing Covid 19 pandemic the Ontario Rett Syndrome Association's Board of Directors, on November 16, 2021, voted to extend and adjust, as necessary, the 2017-2022 O.R.S.A. Strategic Plan to the year 2024.

This refreshed 2022-2024 plan is a high-level guide that lays out the Governance policies (Mission, Vision and Values) and the key priority areas for the Board's work. Action and operational plans will be created or revised by Committees including the Executive to achieve the stated strategic result requirements.

This document is intended as a bridge document. It is an update, by the O.R.S.A. Board and staff, of the 2017-2022 strategic plan. It is the hope of the Board that by 2024 there will be an opportunity to return to a more comprehensive process for the creation of a 2025-2030 strategic plan.

Celebrating Our Past – Looking Forward

Despite functioning in a Covid 19 environment since March 2020 O.R.S.A. has continued to be true to its Mission and to those it exists to serve.

O.R.S.A.'s accomplishments, since the onset of the Covid pandemic, are remarkable and well documented on our website at: <https://www.rett.ca/news/2021-year-in-review/2021/>

As directors of the O.R.S.A. Board we stand on the shoulders of a remarkable collection of leaders who have preceded us.

The Ontario Rett Syndrome Association (O.R.S.A.) was incorporated on July 26, 1991. Launched from a small group of parents, the organization has grown tremendously over the past 30 years. O.R.S.A. has funded and supported 3 Rett syndrome clinics, has awarded over \$600,000 in research grants, organizes educational events, runs the Canadian Rett Syndrome Registry and provides resources for families. <https://www.rett.ca/news/o-r-s-a-turns-30-2/2021/>

What will the next 30 years hold for individuals with RETT, their families, friends, and caregivers?

What will O.R.S.A.'s accomplishments be from 2022 – 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.

Our vision is assured because:

- The direction of The Ontario Rett Syndrome Association (O.R.S.A.) is provided by strategic and business plans. These plans are based on our values and our current bylaws. Our plans are monitored and refreshed regularly for results and desired impact.
- We are knowledge based and informed by our members and partnerships through conferences and regional workshops.
- A professional approach to organization management exists.
- All members of the organization are actively involved.
- We ensure that resources are available to provide exceptional care and service for individuals with Rett syndrome and their families.
- We celebrate contributions and successes related to the achievement of our Vision with clients, partners, and each other.
- We have effective relations with medical and research communities, governments, media, community partners and the general public.

Ontario Rett Syndrome Association 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 To 2024

Our Strategic Areas for measured results and outcomes, by 2024, remain:

Family Networking and Support

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

Health System Relations

To ensure that our families are supported through the health system

Awareness Strategies

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

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: 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 2022-2024	Responsibility and Report/Update Schedule
To create and provide educational resources	<ul style="list-style-type: none"> • New member package with resources • Conference educational sessions • Webinars • Podcast • Accessing existing resources outside of O.R.S.A. • Checklists • Quality of life and advance care planning resources and support 	2022-2024	Executive Board and Conference Chair
Access and utilizing Research Advisory Committee to update and clarify research developments	<ul style="list-style-type: none"> • YouTube video clips posted Facebook page and website • Webinars • Podcasts 	2022-2024	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 	2024	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: Health System Relations

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

Measurable Outcome Required	Possible Activities	Timeframe 2021-2024	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) 	2024	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) 	2024	Communications Committee
Raise \$100,000/year for research grants	<ul style="list-style-type: none"> • Hope Fund 	yearly	Fundraising
300 patients registered on registry (CRSR)	<ul style="list-style-type: none"> • Ask other provincial groups • Web content • Social Media • E-Blasts • Webinars 	2024	Communications Committee

Measurable Outcome Required	Possible Activities	Timeframe 2021-2024	Responsibility and Report/Update Schedule
Rett syndrome included in complex care clinics	<ul style="list-style-type: none"> • Clinicians <p>London clinic to accept patients over 18 years of age Navigating the Health care system Clinic satisfaction survey action plan Centre of excellence (COE) for Canadian clinics by O.R.S.A. and IRSF</p>	2024	Executive/Outreach
Clinical Trials	Facilitate the conduct of Clinical Trials in Canada	2022	Executive

Key Result Area: Awareness Strategies

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

Measurable Outcome Required	Possible Activities	Timeframe 2022-2024	Responsibility and Report/Update Schedule
Increase number of engaged medical professional involved with O.R.S.A. by 100%	• Conferences (ours and speakers)	2022	Conference
	• Hosting Medical Symposiums	2024	Lobbying
	• Hosting Webinars	2022	Medical Advisory
	• Medical Website / Lobbying Committee	2024	Committee
	• Medical advisor as a board member	2022	Executive
Increase active donor list by 15%	• Stewardship improvements (donor recognition)	2022	Communications committee
	• New parent package (schools) and fundraising kit (tips to engage with media)	2022	
	• Change website to have recurring donation option	2022	
Increase website traffic by 50%	• Use Social Media more effectively	2022	Communications committee
	• Additional content for parents	2022	
	• Additional content for medical	2022	
Establish procedure for provincial and municipal proclamations (Rett Syndrome Day)	• October Rett Awareness Month	2022	Communications committee
	• National Proclamation poster	2022	
	• Maintain list of municipalities who have proclaimed	2022	
Increase membership to sustain conference level support	• Redefine membership and incentives	2022	Family Networking and Support Committee

Key Result Area: 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.

Measurable Outcome Required	Possible Activities	Timeframe 2022-2024	Responsibility and Report/Update Schedule
O.R.S.A. has formal partnerships and/or representation at 3 government committee tables	<p>Explore groups that have already started formal partnerships (Canadian Organization for Rare Disorders), umbrella organizations, Imagine Canada (for contacts and training)</p> <ul style="list-style-type: none"> Actively pursue through Autism Ontario, etc.?? federal health committee via Neurological Health Charities Canada 	Initiate 2022	Executive
O.R.S.A. undertakes staffing initiative and plan	<ul style="list-style-type: none"> Deal with current staffing situation (roles and responsibilities to be defined – job description and required competencies; executive/staff limitations) Actively encourage volunteers to join the Board or committees Conversation with a Human Resource Practitioner (such as Investing in Neighbourhoods, Management Advisory Services) Trillium Grant Review policies and procedures 	<p>2022</p> <p>Initiate 2022</p> <p>Annually</p>	Executive

Measurable Outcome Required	Possible Activities	Timeframe 2022-2024	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 	2022 Annually 2022	Governance Chair?
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 	2022	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 	2022	Family Networking and Support Chair?