



August 23, 2023

Dear O.R.S.A. Members:

Welcome to our annual general meeting. Thank you for joining us this evening.

If I could describe the past year in one word, it would be historic!

On March 10, Acadia Pharmaceutical announced FDA approval for the first commercially available treatment for Rett syndrome in the U.S.A. Then more recently, we were notified that Acadia acquired the international rights to Trofinetide. Meaning, Canada could possibly see this drug approved by Health Canada by fall 2024. Next, we witnessed another first when, Taysha Gene Therapies, administered gene therapy to a Rett individual in Canada. These milestones sparked new excitement and renewed hope back into our community. The year 2023 will forever represent how collaboration efforts by many dedicated individuals resulted in a better quality of life for our loved ones with Rett. These dynamic teams encompass many people with different skillsets who can achieve positive results. I would like to challenge you, our members, to consider volunteering your time to help O.R.S.A. with our mission. We are here to ensure that individuals with Rett syndrome are enabled to achieve their full potential and enjoy the highest quality of life within their community. This is a very rewarding position where you would have the opportunity to give back to your community and shape the future of Rett syndrome in Canada.

As O.R.S.A. continue to follow our strategic plan, we have highlighted the accomplished activities that align with our values and mission below.

Pillar #1

Increasing the Family Networking and Support

To provide clarity for the organization to empower and support caregivers and their loved ones with Rett syndrome.

Accomplishments:

- Sponsored the first AAC camp for our members
- Provided real time support for families and clinicians
- Enhanced website content
- Created more resources, checklists and activities
- Provided virtual educational webinars
- Uploaded video recordings to our YouTube channel
- Ensured all members receive updates via email and social media

Pillar #2

Improving Health System Relations

By ensuring that our families are supported through the health system.

Accomplishments:

- Facilitated recruitment for ANAVEX2-73, A study in Pediatric Patients with Rett syndrome
- Assisted Taysha Gene Therapies in recruitment efforts

- Advocated for access of Daybue, the 1st commercially approved treatment for Rett syndrome by Acadia Pharmaceuticals
- Networked with other pharmaceutical companies regarding the opportunity for additional clinical trials in Canada
- Awarded Canadian researchers, Dr. Ellis and Dr. Zani, \$100,000 dollars from the Hope Fund
- Granted Canadian researchers Dr. Rossignol and Dr. LeRoux, \$50,000 dollars from the Hope Fund
- Succeeded with Ministry of Health funding to support the Holland Bloorview Rett clinic

Pillar #3

Create Awareness Strategies

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

Accomplishments:

- Collaborated with our Canadian associations, and several organizations outside of Canada
- Coordinated the October awareness campaign including Proclamations within Ontario
- Ensured O.R.S.A. is more visible on social media
- Attended the International Rett Syndrome Foundation 2023 scientific meeting

Pillar #4

Support Organizational Transition and Stability

By ensuring that the organization, support, and oversight of all O.R.S.A. activities and practices are in place and reviewed regularly.

Accomplishments:

- Conducted successful fundraising events, both signature events and 3rd party events
- Gained more sponsors to support O.R.S.A.'s mission
- Restructured committee members and vacant positions internally
- Completed review of O.R.S.A.'s by-laws and policies and procedures.

Your board of directors have worked tirelessly to provide these opportunities to you. Thank you for all your hard work! Your commitment to our community is truly inspiring.

Many thanks to the parents/guardians, members, supporters, and professionals that helped make 2023 another wonderful year for O.R.S.A. As we start connecting in-person again, I have no doubt 2024 will be another successful year proving that we are #STRONGERTOGETHER!

Best regards,



Sabrina Millson
O.R.S.A. President