



August 31, 2022

President's Annual Letter

Dear Members:

It is common knowledge that in 2017, O.R.S.A. introduced the foundation of our strategic plan consisting of 4 (four) pillars that would assist us in focusing on outcomes and measured results. At the beginning of this year, we decided to revisit the strategic plan and develop a "refresh plan" to help guide our endeavors now until 2024. These areas continue to contribute to our mission, to ensure that individuals with Rett syndrome are enabled to achieve their full potential and enjoy the highest quality of life within their communities.

Despite the significant impact COVID-19 has had on our organization and community, collectively we have persevered, allowing us to reach our goals for 2022. I would like to take this opportunity to provide an update on each pillar;

### **Pillar #1**

#### **Increasing Family Networking and Support**

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

*Accomplishments:*

- Revised our new family resource welcome package
- Updated the birthday card program
- Hosted 8 professional AAC communications webinars
- Developed a Quality of Life and Advanced Care Planning resource center
- Updated our website content
- Created more resources and checklists
- Provided educational webinars & podcasts
- Added educational recordings on our YouTube channel
- Ensured members not on social media receive our updates via email
- Conducted successful fundraising events

### **Pillar #2**

#### **Improving Health System Relations**

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

*Accomplishments:*

- Advocated and facilitated access to the first clinical trial for Rett syndrome in Canada, ANAVEX2-73, A study in Pediatric Patients with Rett syndrome
- Networked with several pharmaceutical companies regarding the opportunity for additional clinical trials in Canada
- Granted \$50,000.00 to Canadian researchers, Dr. Ellis and Dr. Zani from the Hope Fund Account
- Partnered with Dr. Rastegar from the University of Manitoba to make available organ donation
- Partnered and developed a National Neurological Strategy for Canada with the National Health Charities Canada



### **Pillar #3**

#### **Create Awareness Strategies**

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

*Accomplishments:*

- Continued collaboration with the Canadian Rett syndrome associations, and several organizations outside of Canada
- Coordinated the October awareness campaign including Proclamations within our Province
- Created more social media presence
- Represented Canadians at International conferences and meetings

### **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:*

- Elected a Pediatric Physician as a current board member
- Restructured internally to fill vacant positions to maximize output

I would like to acknowledge the dedication of the Past President, Executive Committee and Board of Directors, and thank them for their efforts and valuable contribution over the year. Likewise, I would like to thank the volunteers, parents, members, supporters, and professionals that helped make 2022 a very successful year. It is an honour to be the President of the Ontario Rett Syndrome Association.

I look forward to seeing 2023 continue the upward trend of success.

Best regards,

Sabrina Millson,  
O.R.S.A. President