



Ontario
Rett Syndrome
Association
Building Healthy Tomorrows



Honourable Marvin Junkin
Mayor
Town of Pelham
20 Pelham Town Square, P.O. Box 400
Fonthill, ON L0S 1E0

March 10, 2020

Request for Proclamation

Dear Mayor Marvin Junkin or City Clerk

On behalf of the Ontario Rett Syndrome Association (O.R.S.A), and the diagnosed individuals living in the Town of Pelham, I am writing to request your proclamation of the month of October as Rett Syndrome Awareness Month.

Rett Syndrome is a rare neurodevelopment condition that affects mainly females (1 in 10,000 births) and is caused by a mutation in the X chromosome. Individuals with Rett syndrome will lose some if not most acquired skills including speech, and gross and fine motor skills. Some never develop the ability to walk or even talk.

O.R.S.A. exists to ensure that children and adults with Rett syndrome are enabled to achieve their full potential and enjoy the highest quality of life within their community.

This observance gives us a means to focus attention in making it possible for O.R.S.A. to continue public awareness and advocacy, provide parent/family support, operate the Resource Centre, fund research projects through the Hope Fund, host conferences, maintain the Canadian Rett Syndrome Registry, and fund three Rett syndrome clinics in Ontario that provide medical assistance.

If you need anything further, please don't hesitate to contact me by email: smiguel@rett.ca or phone at 519-474-6877.

Thank you for taking the time to consider recognizing and supporting O.R.S.A. as we strive to build "healthy tomorrows" for all Canadians living with Rett syndrome.

Sincerely,

Steve Miguel
Marketing Committee
Ontario Rett Syndrome Association



Ontario
Rett Syndrome
Association
Building Healthy Tomorrows



It is the Ontario Rett Syndrome Association's desire to have the following proclamation considered.

PROCLAMATION

October as Rett Syndrome Awareness Month

WHEREAS Rett Syndrome is a rare neurological condition that is rarely seen in males but is seen almost exclusively in females and is believed to occur in 1:10,000 female births. Parents believe they have a healthy child and the symptoms do not appear until a regression between six to eighteen months of age;

AND WHEREAS throughout their lives these courageous children will need total care and constant support from their family; they will combat many medical challenges. They may have seizures, osteoporosis, scoliosis, breath holding, hyperventilation, nutritional problems and so much more. Apraxia, which is the inability to motor plan, is one of the most challenging aspects of Rett Syndrome along with loss of speech;

AND WHEREAS in 1999 it was discovered that Rett Syndrome is primarily caused by a sporadic mutation in the MECP2 gene on the X chromosome, and since this discovery there are many research projects taking place across Ontario and Canada;

AND WHEREAS as there is no Canadian Rett Syndrome Association, the Ontario Rett Syndrome Association (O.R.S.A.) has members from many provinces across Canada and through donations and fundraising efforts. O.R.S.A. finances the Canadian Rett Syndrome Registry, has funded over \$500,000 in Canadian Rett syndrome research projects, and financially supports the 3 Rett Clinics in Ontario, with one in Ottawa, Toronto and London. The Rett Syndrome clinics provide direct critical support to the families and their child on care and management issues.

NOW THEREFORE, I, [REDACTED], Mayor of the [REDACTED], **DO HEREBY PROCLAIM October 2020 as RETT SYNDROME AWARENESS MONTH** in the [REDACTED]. I urge all citizens to make an effort this month to learn more Rett Syndrome, fight stigma, light Canada purple and wear a purple ribbon to show support.

Dated [REDACTED]