

Town of Arnprior Proclamation Rett Syndrome Awareness Month October 2021

Whereas Rett syndrome is a rare genetic neurological disorder that occurs almost exclusively in girls and leads to severe impairments, affecting nearly every aspect of the individual's life. Rett syndrome occurs worldwide in 1 of every 10,000 female births and is even rarer in boys, but not impossible. Rett syndrome is usually recognized in children between 6-18 months of age as they begin to miss developmental milestones or lose abilities they had once gained;

And Whereas throughout their lives these courageous individuals 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 have been able to fund finances the Canadian Rett Syndrome Registry, has funded over \$600,000 in Canadian Rett syndrome research, and support three Rett clinics in Ontario. The Rett syndrome clinics located at the Children's Hospital of Eastern Ontario, Ottawa, Holland Bloorview Kids Rehabilitation Hospital, Toronto and Thames Valley Children's Centre, London, provide direct critical support to the families and their loved one on care and management issues.

Now Therefore, I, Chris Toner, Deputy Mayor of the Town of Arnprior, **Do Hereby Proclaim October 2021** as **Rett Syndrome Awareness Month** in the Town of Arnprior. I urge all citizens to make an effort this month to learn more about Rett Syndrome, fight stigma, light Canada purple and wear a purple ribbon to show support.

Chris Toner, Deputy Mayor Town of Arnprior