

Proclamation

Office of the Mayor

Rett Syndrome Awareness Month October 2023

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 the Canadian Rett Syndrome Registry, fund over \$678,000 in Canadian Rett syndrome research, and fund and support Rett clinics in Ontario. Currently, the Rett syndrome clinics provide direct critical support to families and their loved one regarding care and management issues.

THEREFORE, BE IT RESOLVED THAT the Corporation of the Town of Pelham does hereby proclaim October 2020 as Rett Syndrome Awareness Month.

DATED AT the Town of Pelham this 24th day of March, 2023.

Mayor Marvin Junkin Town of Pelham