

Honorable Rob Vagramov Mayor 100 Newport Drive, Port Moody, BC V3H 5C3

August 19th, 2020

Request for Proclamation

Dear Mayor

On behalf of the Rett Syndrome Society of British Columbia (R.S.S.B.C.), and the one diagnosed individuals living in the city of Port Moody, 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.

R.S.S.B.C. 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 R.S.S.B.C. to continue public awareness and advocacy, provide parent/family support, fund research projects, and learning opportunities.

If you need anything further, please don't hesitate to contact me by email: christineaw@rettbc.ca or phone at 604-468-4705.

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

Sincerely,

Christinea Walker Presient Rett Syndrome Society of BC



It is the Rett Syndrome Society of British Columbia's desire to have the following proclamation considered.

PROCLAMATION

October as Rett Syndrome Awareness Month

WHEREAS Rett Syndrome is a 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 Canada;

AND WHEREAS as there is no Canadian Rett Syndrome Association, the Rett Syndrome Society of BC (R.S.S.B.C.) has members from all across BC and Alberta and welcome all those across Canada.

NOW THEREFORE, I, _____, Mayor of the _____, **DO HEREBY PROCLAIM October 2020** as **RETT SYNDROME AWARENESS MONTH** in the _____. 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 _____