

Manitoba PC Caucus



NEWS RELEASE

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For Immediate Release

MLA thanks Manitoba family for bringing attention to Rett syndrome

The Guimonds have helped Manitobans affected by rare neurological condition: Martin

Shannon Martin, MLA for Morris, today marked Rett Syndrome Awareness Month by thanking a family from his constituency for its efforts to assist Manitobans affected by this rare neurological disorder. In a private member's statement, Martin lauded Lionel and Trish Guimond for the volunteer work they have done since their seven-year-old daughter Ema was diagnosed with Rett syndrome in 2013.

"The Guimonds initially faced many challenges finding the support and resources they needed. But rather than focus on what was broken, they were determined to arm themselves with information and improve things not only for Ema, but for other Manitoba families," said Martin. "The volunteer work they have done and continue to do will benefit so many families today and tomorrow."

During Martin's statement, the Guimonds and representatives of the Red River Valley School Division sat in the legislature's gallery. They, along with many members of the Legislative Assembly, wore purple ribbons that celebrate efforts to help those living with Rett syndrome and their families.

Rett syndrome affects one in 10,000 infant girls. The condition is characterized by a loss of speech and repetitive hand use, epileptic seizures, osteoporosis and scoliosis. Many with Rett syndrome live long into adulthood, though most need a variety of health-care services.

Trish Guimond travelled across Canada to gather vital information on the disorder, before re-establishing the Manitoba chapter of the Rett Syndrome Association. With the help of doctors, therapists, educational professionals and the Children's Hospital Foundation, the Guimond family launched an awareness campaign. They also created Eyes on Ema, an organization that raises funds for resources for the girls and their families.

To mark October as Rett Syndrome Awareness Month across Canada, the north side of the Manitoba Legislature is being illuminated in purple with the Rett Syndrome Association's logo through Oct. 31.

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