

Learning a lesson in tolerance

Young boy writes book about his sister's rare syndrome to help educate others

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In 2009, Manotick resident Tommy Glatzmayer decided at age six he wanted to write a book about his sister.

Melanie, two years older, had a lot to deal with in life. She had a rare medical condition called Cornelia de Lange Syndrome (CdLS). She had one of only 100 known cases in Canada and 2,000 in the United States. Because of it, she had many developmental delays, hearing problems, vision problems, eating difficulties, speech delays and other challenges. The syndrome is named after Dr. Cornelia de Lange who first described it in 1933. CdLS is a congenital syndrome, meaning it is present at birth. The gene that causes it was discovered in 2004.

Tommy wanted to teach his friends about his sister's condition while still entertaining them, so with the help of his mother, he wrote "Melanie and Tommy Have Two Pet Rats and One Syndrome." One day, shortly after the book was completed, he came home crying because his peers in Grade 1 were making fun of his sister, so his mom Nathalie Wen-

dling decided they should self-publish the book and get it out there.

The next year, Tommy was presenting his book by reading it aloud to schools by himself with his sister by his side and their two pet rats. Everybody loved its message of courage, strength, love, and acceptance. Presentation after presentation, school after school, Tommy and Melanie got a little more comfortable on stage.

Now at 13, Tommy is a seasoned public speaker, having done this along with 15-year-old Melanie more than 80 times at venues from coast to coast, including stops in the United States. The book is a best seller, with more than 7,000 copies sold by 2013.

The brother and sister team spoke to the student body at Highview Public School recently, sharing their story and the tale behind the book and its message of tolerance. They also played a video showcasing the two rats which are their dearest pets, and demonstrated how smart the rodents are by racing them through an enclosed ramp, much to the delight of the crowd assembled in the school's gym.

Tommy said his sister has so far undergone 14 different procedures and operations. By the age of six, Melanie could only speak 20 words. With hard work, she is now able to speak 1,000, but her brother augments her vocabulary with sign language.



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Tommy and Melanie Glatzmayer demonstrate their prowess on the bongos during a special presentation held at Pembroke's Highview Public School. Melanie has a rare medical condition called Cornelia de Lange Syndrome. There are 100 known cases in Canada and 2,000 in USA. Tommy, with the help of his mother, wrote a self-published book entitled "Melanie and Tommy have two pet rats and one Syndrome," about his sister in an effort to educate people, and the pair have done 70 presentations so far at schools across Canada and parts of the US

"My sister and I are a lot alike," he said. For instance, they both love drawing and both love the Montreal Canadians.

By Grade 6, in 2014, Tommy and Melanie had performed and dis-

tributed books in all 10 provinces of Canada. In 2015, Tommy lead his first hand drum circle for students with disabilities and without.

Tommy's project has generated funds through private spon-

sorship and donations. The funds have helped them present in more than 80 schools, hospitals, fundraisers, and conferences in Canada and USA, distribute over 10,000 books to schools, hospitals, conferences and families, create a website to find Cornelia de Lange Syndrome families and supply more than 35 hand drums for drum circles at their school and in their community.

The brother and sister team have so far had more than 100 interviews with magazines, newspapers, radio and TV, spoke at several fundraisers like Children's Miracle Network, held book signings in Ottawa, Toronto, New Brunswick, New Jersey and California, were guest speakers for conferences in Toronto, Chicago and Ottawa, and the Kiwanis 100th Anniversary and DILA conference at Ottawa University. They have appeared on TV shows like Accessibility in Action in Toronto and Focus in Montreal, and were presented with numerous awards. They were also invited to meet with then Prime Minister Stephen Harper.

For Tommy, the important part of all this recognition and fame is the fact everyone stopped teasing Melanie, which was his reason for doing the book in the first place. He said it is important to accept anyone who seems different.

"If you see someone different, smile and say "Hi," he said. stephen.uhler@sunmedia.ca