

## CORRI & ANDREW KAWESKI AND TROOP

Our journey with Morquio begins back in September 1995 when our older two children, Damien, born in 1992, and Natasha, born in 1994, were diagnosed with Morquio. This diagnosis came after three months of doctor visits, X-rays, and blood tests with the definitive test taking one month. Since then our family life has had ups, downs, and plateaus.

My husband, Andrew, and I went on to have two more daughters, Samantha, born in 1996, and Alexa, born in 1998, who are not affected but we presume they are carriers. They can have DNA testing done when they are old enough to understand the issues better. With four children ranging in age from nine years to three years our house is never quiet.

With the arrival of Morquio in our family and house, some of our dreams for our older two disappeared, many were kept but modified and some new ones added. In the spring-summer of 2000, we chose to extensively modify our home to better meet Damien's and Natasha's needs: lower light switches, lever door handles which are lower on the doors, two wheelchair accessible bathrooms with one of these also being "short-stature" friendly, long windows so Damien and Natasha can see outside easily, two hand-rails on the stairs and a wheelchair elevator. At the time, the elevator seemed like an excess but when Damien was in a body cast and horizontal for six weeks due to hip surgery in January 2000, the elevator was a true lifesaver. Our kitchen, although untouched during renovation, has a bar fridge for the kids and a low work table so they can all get snacks, breakfast or lunch with minimal help. We still have numerous stools around for reaching things or sitting on.

School has been a wonderful experience so far. Our school is one level with only two sets of stairs which Damien and Natasha rarely use. The school has done an excellent job of modifying classrooms, the computer lab and washrooms to accommodate Damien's and Natasha's short stature. Four of the six bathrooms have been renovated to meet their needs: lower, smaller sink and taps, lower handles on doors, lowered toilet paper and paper towel. The occupational therapist who oversees a number of children in our school district has not only been involved in all the school renovations but had desks modified so Damien and Natasha can sit properly and safely while they work. For the time being, these desks are lower than their peers and always located close to the teachers' main teaching spot. We have talked about raising the desk height but then this raises issues of independently getting into their desks. Damien and Natasha don't seem to have a problem with the desk height right now so they will stay that way until some problem or issue develops.

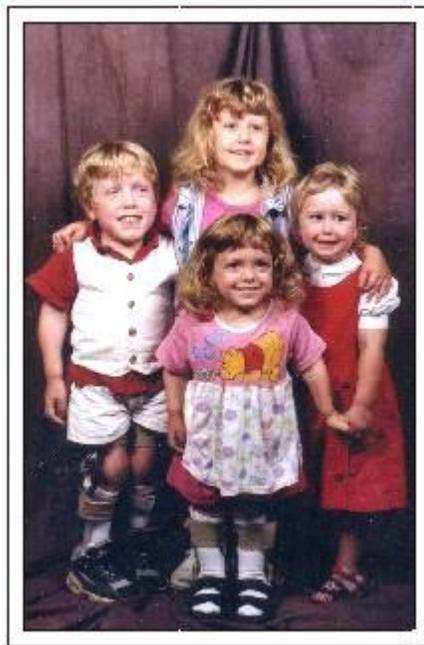
Due to Morquio Damien and Natasha have had a number of orthopedic surgeries. In March 1998, Damien had lower leg surgery to straighten knock-knees. In Jan 2000, he had hip surgery to straighten the femur bone and to bend it so it went in the hip socket properly. This surgery put him in a body cast for six weeks. In May 2000, he had his tonsils and adenoids removed due to minor sleep apnea and breathing problems. Damien will have lower leg surgery again in October 2002 as he has grown slightly, the storage continues and the knock-knees are bad again.

Natasha had lower leg surgery in October 1999 for the same reason as Damien. In June 2000, she was hit with a major streptococcus infection in the top of her right femur bone- nine days in hospital, two surgeries and IV therapy three times/day for five weeks. Thank goodness we owned our own manual

wheelchair by September 1999 as it was very well used between October 1999 and July 2000. For the moment, there are no surgeries planned for Natasha. We are trying to determine the reason for her fingers tingling every so often and what possible therapies are successful to prevent the tingling.

As for Samantha and Alexa, they keep up with all this and are typical sisters. They probably know more about orthopedic surgery than most children their age and are use to people with different needs. Samantha is a great deal taller than Damien and Natasha. Alexa is taller than Natasha and almost taller than Damien. We talk frankly about height issues and how everyone in our family has strengths and weaknesses and how younger can help older, smaller can help taller and anyone can help anyone.

Our life seems to be on a plateau at the moment which is great. We just purchased, through Andrew's extended medical, two power wheelchairs which Damien and Natasha will use primarily for transportation needs to and from school and on field trips, not constant daily use. I have been pulling them to school in a wagon which is truly uncool for nine and seven year olds, never mind for my back and shoulders. We are hoping these power chairs will provide added independence and mobility for them both. We purchased a 1992 extended van with a built-in wheelchair lift in November 2001 knowing these power chairs were coming along. Nothing like driving a "beast" down the road.



Damien 9 years old,  
Natasha 7 years old,  
Samantha 4 3/4 years old,  
Alexa 2 3/4 years old

In and amongst all this, we are not only members of the Morquio Support Network, but are actively involved in the Canadian MPS Society. We also try, not always successfully or quickly, to stay in touch with others living and journeying with Morquio. With that I shall close this long letter. We enjoy writing letters and emails to others so feel free to drop us all a line.

Written by: Corri Kaweski

Email: [Corri\\_Kaweski@telus.net](mailto:Corri_Kaweski@telus.net)