



Welcome to Gaucher Connection eNews

Hello!

Cody, a nine-year-old boy from Calgary, sees Gaucher disease as something that makes him unique. "In my school I think I am the only one that has it," he says. His mother, Anita, reinforces the point by telling the story of how Cody showed his infusion port to the rest of his kindergarten class for show-and-tell. She explains she has always encouraged him to view his condition as just another part of him, not something to be ashamed of, or to hide.

Cody: Growing Up With Gaucher

For the most part, Cody does perceive his condition this way – as something with both good parts (playing video games while he gets his treatment) and bad parts (the "pokes") – just like school (gym is his favorite class, music his least favorite) or anything else in his busy life.

In addition to school, Cody plays soccer and golf, helps take care of the family pets, reads voraciously (an avid reader since the age of three, the Pokémon series is his favorite), plays video games whenever he can, and is given his infusion at home by his mother, a trained caregiver, on a biweekly basis. Last summer he looked forward to attending a mock-government day camp (his choice) and visiting Las Vegas with his grandmother to see the Cirque du Soleil. With such a packed schedule, Cody may not have much time for existential angst, but Anita confides that he is starting to realize that having Gaucher, and getting treatment, will be a life-long occurrence for him – and that his mother will not necessarily continue to give him his infusions as he gets older.



Benefiting From Earlier Generations

Cody has been receiving infusions for most of his life. He was diagnosed with Gaucher disease when he was 18 months old and started treatment shortly after. It was only later, after becoming involved with the National Gaucher Foundation of Canada (NGF), that Anita realized how exceptional this was and how different his experience was in terms of timely diagnosis and treatment when compared to earlier generations of people with Gaucher disease. She explains that learning Mark Freedman's story and meeting individuals who campaigned for treatment to come to Canada really touched her as she realized that when Cody was diagnosed and needed treatment, he could start it right away because of the efforts of others.

A Supportive Community

Anita cites the support and services available through the NGF, as well as through the Alberta Children's Hospital and Genzyme, as key to helping Cody and his family deal with the various challenges associated with growing up with Gaucher disease. "It's like a family," she explains. For instance, when Cody developed needle anxiety, he was able to take part in a six-session program at the hospital designed to help children become more comfortable with needles. Cody has also benefited from the opportunity to meet other individuals with Gaucher disease at three past NGF national patient meetings and is looking forward to attending the next one.

Looking further into the future, Cody is not certain what he wants to do when he grows up. Being a veterinarian, a scientist or an engineer could be neat, but professional golfing and Pokémon training are also high on his list of potential careers. Anita tells him he can be whatever he wants to be (except an unemployed drummer). Whatever the future holds for Cody, Anita is thankful he is growing up as part of the Canadian Gaucher community and hopes he will become part of the next group of individuals to fight for changes that will benefit future generations.

Take Action

The Gaucher community is filled with people, like Cody, who have their own inspiring and interesting experiences. You'll find more stories like Cody's featured in our newsletters on the Gaucher Connection website. We invite you to visit, read, and think about what you'd like to share with your community. In a future edition, we'll talk about how you, or someone you know, could be featured in an upcoming issue.

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