

Gaucher Disease Scholarship Program

2009 Recipient Announced

Gaucher Connection congratulates **Meghan White**, of Ottawa, Ontario, recipient of the 2009 Gaucher Disease Scholarship Program. Here is her winning personal essay:



The biggest lesson I have learned living with Gaucher Disease is that it is extremely important to be open and upfront about your disease. I would encourage kids to speak freely about their condition and remind them that they are not their disease. In other words having Gaucher Disease is only a small part of who you are. As a child, I wanted to blend in. I was always worried that someone would find out I had a disease and judge me harshly because I was different. As an adult I realize that we are all different and that our uniqueness should be celebrated.

I did not have many opportunities to interact with other patients my age when I was a child though I was fortunate enough to have a sibling who also shared a similar experience, so I did not feel totally alone. Many children are not as fortunate and so I would encourage them to talk about their experience as much as possible. I would suggest that they speak to their parents or some another adult that they trust and ask them to help them meet other kids who are in a similar situation. Sometimes having Gaucher Disease made me feel isolated and different. I hated not being able to participate in contact sports or gym class and it really helped that my parents encouraged me to participate in as many safe activities as possible. I participated in soccer, T-ball, dance, swimming lessons and many other activities. I had a very happy and active childhood despite the bi-weekly trips to the Children's Hospital for enzyme replacement (ERT) infusions, in fact these outings were kind of fun. We always had lunch at a favourite restaurant and then went shopping after treatment for a little something from the Sick Kids gift shop. Having an IV was not much fun but I would try not focus on the scary part. Every two or so years our family would get together with other patients at the National Gaucher Foundation national meetings and once a year my sister and I would attend a week long camp session for children living with chronic illness. Through these wonderful gatherings I was able to connect with other kids. I was able to share my story and came to realize that my sister and I were not alone and that there were other children who had much in common with us. These interactions allowed me to be more comfortable with my disease and more accepting of my circumstances and helped me come to terms with my condition.

There are many other wonderful tools available to Gaucher patients today that were not available when I was a child. For example, the Gaucher Connection Program offers the chance to connect with other patients online through a buddy program. I would encourage patients to take advantage of this great opportunity and to reach out to others. Transitioning through adolescence had its challenging moments but I had lots of wonderful support and again I encourage young adults to reach out, particularly at this time because soon they will become responsible for their own health and they need to put a support network in place. As a child always wanting to deny my disease I would sometimes ignore the pain caused by Gaucher Disease and keep my symptoms to myself. As I matured I realized that this is not the ideal way to deal with my health and I began to carefully monitor my body and the way it reacted to certain situations. With these observations, I was able to learn what I needed to do in order to maintain a healthy lifestyle and maximize my health. Now when I experience any type of pain, I immediately pay attention and inform my parents and together we deal with it. I have always kept track of my symptoms in a journal and I list what particular symptoms I am experiencing as well as the dates they occur. Keeping track of these events makes it easier to identify any patterns that emerge. Many people would be surprised to hear that as a person with a chronic medical condition I consider myself to be incredibly healthy. In fact, I know I often feel healthier than many of my friends. I would encourage young people to take good care of themselves. I am extremely fortunate to receive ERT and this treatment is vital to maintaining my good health. In addition to my infusions I stay physically active and I eat a very healthy diet to make sure that I get as much rest as possible though as a teenager, this is not always a priority. I have learned to listen to my body.

Gaucher has not stopped me from doing anything in my life. I have travelled extensively and I am currently travelling across Canada volunteering in remote communities. I have a wonderful support network in place and I rely on this to be able to lead the lifestyle that I do. My health care providers have always been eager and willing to support me in anyway that they can. I think young people should take full advantage of all the resources available to them, stay involved, live life to the fullest and know that they are not alone.