



A Lifeline for Patients
Living with Gaucher Disease



February 2014

Welcome to Gaucher Connection eNews

Hello

Thank you for signing up for Gaucher Connection eNews, the monthly newsletter designed to help keep you up-to-date and on track with Gaucher disease treatment and management. In this issue we look at a brand new website that reaches out to children with rare diseases.

MyNormal.ca

The MyNormal.ca website offers a place for children and adults to share their own stories and experiences about living with a rare condition. Launched in February 2013 at the LSD World Congress, the website was created by Emma Rooney, who was diagnosed with Gaucher disease at age 3, and the National Gaucher Foundation of Canada, with the help of a Genzyme Patient Advocacy Leadership Award.

The site features the digital story Emma's Garden: Growing with Gaucher, a video written and narrated by Emma and illustrated by her younger sister Megan Rooney that describes Emma's own childhood experiences with Gaucher disease, as well as an online gallery for other people to share their experiences of growing up with rare conditions.

Sharing with a purpose

In deciding to tell her story, Emma had to determine how to transform individual memories and episodes into a cohesive narrative that would reach children and adults alike. As Emma put it, "It's not just about the drama of being diagnosed with a rare condition...How do you tell the subtle pieces that are so important to express about what becomes 'normal' living? For me it was also really important to show that getting treatment wasn't the only factor in making me well."

Looking back on the whole process, Emma considers the opportunity to work with her sister and opening up discussion with her family to be some of the best parts of the project. Having an end product she was able to share with the global rare disease community was also rewarding. She says she has received numerous e-mails from people telling her how the website touched them and made them reflect on the experience of dealing with illness in their own family.

An Evolving Process

The MyNormal.ca website is constantly evolving. Emma hopes to increase the number of other people's stories displayed on the website, but admits that it is challenging to get people to share their own stories. She says many people do not necessarily think their own story is worth telling, but says, "for the Gaucher community, it's really important to share these stories, because the experiences of people with Gaucher are very different."

In addition, many people are not certain how to go about telling their own story. To help overcome this barrier, a story-telling workshop is being planned for the next Gaucher Canada conference, which will be followed up with information on the topic for the website.

"My hope is that this project will grow into something more than just a place for me to share the video that we've made," says Emma. "I really created the MyNormal project with the intention that people would be inspired to share their stories."

Take Action

The above is an excerpt taken from the article "Redefining Normal", which is currently available in its full format on the Gaucher Connection website. Visit to read the complete article and find out more about how MyNormal.ca came to be, how it's evolving, and how you can be a part of it.

[Read the full article posted on the Gaucher Connection website. Go >>](#)

Did You Know?

MyNormal.ca welcomes all types of contributions to the website - videos, art work, photographs, and pieces of writing, whether short or long, in any language.

Patient spotlight: Cody

- 9-year-old boy
- Benefits from earlier generations
- Part of a supportive community



[Read Cody's story about how he's grown up in the Gaucher Community. Go >>](#)

Patient Stories are examples based on aggregate medical data. The characters represented are not actual Gaucher patients. Their stories are inspired by those of real Gaucher patients.

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