



GAUCHER
connection

A Lifeline for Patients
Living with Gaucher Disease



July 2010

Welcome to Gaucher Connection eNews

Hello!

We strive to keep you up-to-date about Gaucher disease treatments and more. In addition to these E-newsletters, we would like to bring your attention to the Gaucher Connection (*printed*) newsletter.

The Gaucher Connection newsletter is filled with information, tools, resources and inspirational stories from Canadians living with Gaucher disease.

The printed newsletter is produced twice a year. You can find it at your local Canadian Gaucher treatments centre or alternatively download your printable version at GaucherConnection.ca.

Below highlights what's in the latest issue:

The Gaucher Registry: What can it do for you? An interview with Margaret Mackrell

The Gaucher Registry is an important tool and resource that help healthcare providers and patients alike with valuable information, including:

- Important information used to educate about the reasons and benefits of regular and ongoing ^{PM}Cerezyme® therapy
- Important data to help you and your healthcare provider decide about treatment timing and registry charts based on registered patient treatment history and statistics
- Valuable information about Gaucher disease that can help researchers and patients in learning about the disease and treatment

Learn more about what the [Gaucher Registry](#) can do for you by reading the latest issue.

Answering Questions

This is a forum to provide helpful tips on issues people with Gaucher disease face in many aspects of their lives, including:

- How—and if—you should tell people you have Gaucher disease
- How to create straightforward discussions
- Ways to explain what the basics of Gaucher disease
- A forum where you can ask your own questions

Read this issue's [questions and answers](#) now.

Profile: Running with it!



Karen MacDonald Carey has been winning the race with Gaucher disease for years—a disease that also affects her sister, Gale. But she got to run a whole new track when she was selected to be one of a handful of people to be a 2010 Winter Olympics torchbearer.

"I did not expect to be as moved as I was when they lit the torch. I was looking at the torch, and when it lit on fire and I looked up at it I just burst into tears... I felt like part of me was running for all those people who can't run. I loved every second of it."

"I know that sometimes the Gaucher may slow me down, but I also know that for me it can be as simple as remembering to put one foot in front of the other and eventually I will cross the finish line."

Read the rest of [Karen's](#) inspirational story by downloading the newsletter.

Helpful Gaucher Tools at your fingertips

The Gaucher Connection Programs has a variety of useful tools to help you manage your Gaucher disease, including:

- **My Test Tracker** – track the progress of your test results
- **My Calendar** – record dates, times and locations of your appointments
- **My Health Diary** – record your health status, symptoms and changes

Find more ways your Gaucher tools can help you. [Go >>](#)

Download and print your Gaucher Connection newsletter

Now that you've had a preview of the latest Gaucher Connection newsletter get all of the information, resources and tools to help you, your family and your healthcare provider manage your Gaucher disease.

Download and print the Gaucher Connection newsletter now. [Go >>](#)



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