



A Lifeline for Patients
Living with Gaucher Disease



July 2009

Welcome to Gaucher Connection eNews

Hello

Thank you for reading Gaucher Connection eNews, the monthly newsletter designed to help keep you up-to-date and on track with Gaucher disease treatment and management.

Explaining Gaucher disease to people you know

Sharing the facts about Gaucher with others puts the disease and its impact on you into perspective. If you need hints or advice on telling friends, colleagues, family members and other people you know about Gaucher disease, keep reading. In this issue you'll find out what to say, when to say it and how to answer common questions people often have.

Communicating the facts

When you first tell others about your Gaucher disease, they're likely to have questions, and you may need to play the role of educator. Although you know a lot about the disease, remember that many people have never even heard of it. So be prepared to start with the basics. Explain the science behind Gaucher, how it can affect you, and most importantly, how you're successfully managing it.

Some people may be surprised to hear you have this condition—because they see you as healthy, not sick! So emphasize that you are healthy, and that maintaining your regular treatment schedule helps you to better manage your health. Below are some of the common questions people may ask you about Gaucher disease. Get ready to talk to others about Gaucher by clicking a question and reading up on an appropriate answer:

[What is Gaucher disease?](#)

[How do you get it?](#)

[What kind of symptoms does it cause?](#)

[How do you manage it?](#)

Check out the latest on Gaucher Connection

2009 Scholarship Recipient Announced! This year's recipient of the Gaucher Disease Scholarship Program is **Meghan White of Ottawa, Ontario**. [Read the winning personal essay](#)

Coming Soon to the Media Library!

New video topics regarding insurance coverage options, costs for people with Gaucher disease and the process applicants must go through to get approved. Check back soon!

Patient spotlight: Elizabeth

- 23-year-old schoolteacher
- Living with Gaucher
- Mastered a tough course load at university
- Maintained full control of her treatment success



Read Elizabeth's story about helping friends understand. [Go >>](#)

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