



Welcome to Gaucher Connection eNews

Hello!

Telling new people about a medical condition like Gaucher isn't always easy-but it's important in many situations. Deciding who to tell about your Gaucher (and when to tell them) is a personal decision that only you can make. It can be helpful to think ahead about the most important conversations, so you're better prepared when the time comes to have them. Here are a few strategies for approaching and handling the subject:

Talking to a Partner

If you're in a relationship that's starting to get serious, your partner may wonder what Gaucher means for your future together. Reassure them that as long as you stick to your treatment routine, you can manage your condition and health. Ask for their support in keeping your treatment commitments.

If you're considering having children together, you'll need to discuss the disease's genetic aspect, including:

- How the disease is passed on genetically
- What being a carrier means, and how your partner could be tested
- What the risks are, and what to do if you have an affected child

Talking these issues over with your health care providers or a genetic counselor can make the discussions easier and help you and your partner plan with confidence.

Talking to Colleagues and Teachers

While you might prefer to keep personal matters like your health private, sometimes it's important to inform your managers, colleagues, or teachers about your condition. It prepares them in case any scheduling issues arise, and ensures you won't feel pressured to skip an infusion due to work or school responsibilities.

Be prepared with simple, straightforward explanations about the disease and its impact. You may want to emphasize that:

- Your treatment will help you to manage your condition so Gaucher does not define you
- You need to stick to a regular schedule for the treatment to keep working
- Missing treatments may cause some symptoms to reappear and interfere with work or school

Good Health Speaks for Itself

When you're consistent with your treatment, Gaucher disease does not need to define you. The best way to demonstrate this to others is not only by telling them, but by showing them too. By sticking to your treatment schedule you'll maintain the good health you need to be there for all the people who need you.

Take Action

If you and your partner are planning to have children, ask your health care providers to discuss all the issues from genetic concerns to strategies for keeping up your own good health as you transition to the responsibilities of parenthood. A genetic counselor can help you better understand the risks of passing Gaucher disease on, and provide guidance and support as you make your decisions.

Learn more about the **Inheritance of Gaucher disease at the Gaucher Connection website.** [Go >>](#)

Patient spotlight: Elizabeth

- 23-year-old schoolteacher
- Living with Gaucher
- Chose to start treatment right after diagnosis
- Knows that early treatment was the right choice for her



Read how Elizabeth regained her confidence through regular Gaucher treatments. [Go >>](#)