



GAUCHER
connection

A Lifeline for Patients
Living with Gaucher Disease



August 2012

Welcome to Gaucher Connection eNews

Hello!

While clinical tests are critical for monitoring Gaucher disease, there's also plenty people can do to actively participate in managing their health. In this issue we explore how being involved, organized and partnered with healthcare providers in between appointments can provide more effective health management.

Getting Involved in Monitoring

Staying on top of your condition means getting regular infusions as well as tests to measure your blood counts, liver and spleen size, and bone health. But numbers and figures don't tell the whole story—your personal input is just as important.

Monitoring your status helps you better manage your health—and gives your healthcare team a better picture on which to base ongoing treatment decisions.

Before and After Appointments

Prepare for upcoming health care provider visits by:

- Reviewing test results and notes from past visits
- Creating a list of recent symptoms or health issues
- Writing down any questions or concerns for discussion

After each appointment, take a moment to:

- Ask when test results will be back, and note the date for follow up
- Ask for copies of recent test results or notes
- Enter your latest test results in your personal records
- Make a note of any recommendations from your health care team
- Schedule future appointments

Ongoing Organization

Ways to stay organized in between health care visits include:

- Keeping a "Gaucher notebook" for jotting down symptoms, questions, or thoughts when they arise
- Using tools like [My Health Diary](#), [My Test Tracker](#), or [My Calendar](#) to track appointments and test results
- Keeping your trackers, notebook, test results, and other paperwork together in one folder to bring to appointments

Partnering with Healthcare Providers

Establishing a true partnership with your healthcare team goes a long way to helping you work together more successfully. Be sure to share anything that might be important. Ask questions. Discuss your test results in detail. Ask how you can best work together to manage your Gaucher—so you can focus more on your life.

Take Action

Take advantage of these helpful "My Health Tools" to help you keep track of appointments, test results, and other related information:

- [My Calendar](#)
- [My Health Diary](#)
- [My Test Tracker](#)

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

Patient spotlight: Michael

- 40-year-old architect
- Living with Gaucher
- Fluent in three languages
- Open about his Gaucher



Read how Michael keeps the conversation about his Gaucher open and easy. [Go >>](#)

Membership in the Gaucher Connection Program you signed up for includes these complimentary eNewsletters. If you do not wish to receive emails and updates from Gaucher Connection in the future, please [unsubscribe](#).

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.

Review our [Privacy Policy](#).