



## 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. While clinical tests are critical for monitoring Gaucher disease, there's also plenty that people can do themselves to participate more actively in managing their health. Also in this issue, we check in with Joseph to find out how he stays on top of his Gaucher—and his daughter's.

### 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. Here are some tips and strategies for contributing to your overall health management:

### 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 you have

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 notes of any directions or advice
- Schedule future appointments

### Ongoing Organization

Here are a few ways to stay organized in between appointments:

- Keep a "Gaucher notebook" for quickly jotting down symptoms, questions, or other thoughts any time they arise
- Use tools like My Calendar, My Health Diary or My Test Tracker available under My Health Tools on the Gaucher Connection website, or a planner to keep track of appointments and test results
- Keep your trackers, notebook, test results, and any 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. So be sure to share anything that might be important. Ask questions. Discuss your test results in detail. Talk to your health care team about how you can best work together to manage your Gaucher—so you can focus more on your life. You'll find additional tips and strategies for making this easier in other emails in this series.

### Take Action

For easy reference, print out the checklists in this email to keep handy with your other paperwork.

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

### Patient spotlight: Joseph

- 37-year-old Accountant
- Father of Amy, newly diagnosed
- Trusts his treatment for himself, and his daughter



Read Joseph's story about [how keeping track helps him stay on top](#). [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.