



GAUCHER
connection

A Lifeline for Patients
Living with Gaucher Disease



March 2010

Welcome to Gaucher Connection eNews

Hello!

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. In this issue find out what you can do to stay on top of your Gaucher symptoms.

Get 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 symptoms or health issues recently experienced
- Writing down any questions or concerns you want to discuss

After each appointment, take a moment to:

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

Ongoing Organization

In between health care visits, there are a number of easy ways to help you stay organized:

- Keep a **Gaucher** diary for keeping track of symptoms, questions, or other thoughts you have, whenever they arise. You can use a paper notebook, or an online tool like [My Health Diary](#)
- Use tools available at the Gaucher Connection website like [My Test Tracker](#), and [My Calendar](#), or a regular paper calendar or 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

Spotlight: Partner 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 and ask questions. 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.

Get tips and strategies to make it easier for you to talk to your medical team. [Go >>](#)

Spotlight: PrCerezyme® Supply



Genzyme has provided an update on the supply of PrCerezyme® for the months of March and April 2010.

Click here to access the latest update. [Go >>](#)