



GAUCHER
connection

A Lifeline for Patients
Living with Gaucher Disease



December 2009

Welcome to Gaucher Connection eNews

Hello!

Much of what we know today about how Gaucher disease affects people—and how treatment affects the disease—comes from analyzing data in the Gaucher Registry. When you're successfully managing your Gaucher with Cerezyme, you're benefiting from years of research and the contributions of many health care providers and patients who made it possible. You can join this legacy yourself by participating in the Gaucher Registry and helping expand knowledge and understanding of the disease.

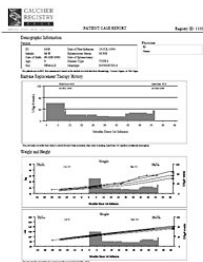
About the Registry

The Gaucher Registry is a clinical database established in 1991 to collect information on people with Gaucher disease worldwide, so medical professionals can better understand Gaucher and how to treat it. Because the disease is rare, it can be difficult for individual researchers to find enough patients to study on their own. The Registry provides medical researchers with access to a large and comprehensive pool of patient data. Almost 5,000 patients in 60 countries participate—and those numbers are growing. Gaucher experts from around the world form the International Collaborative Gaucher Group (ICGG) and use the Registry data to develop all the standard treatment goals and disease management guidelines you're probably familiar with.

How to Get Involved

If you're interested in furthering the Gaucher Registry's goals, you can volunteer to participate. You must have your doctor enroll you. He or she will then regularly update details about your health, treatment goals, and test results. Your privacy is always protected, because your identity is kept anonymous to anyone except your own doctor. But other doctors can review your anonymous data to learn more about the disease and gain new insights.

The Benefits



Beyond the satisfaction of contributing to a larger goal, you'll gain other benefits by participating in the Registry. It offers a systematic way to record and track your treatment goals and progress over time. Your data is summarized into Patient Case Reports (PCRs), presenting your information in easy-to-review formats such as tables and graphs, which your doctor can print to go over with you, and then produce copies for you to keep.

So take advantage of these useful tools for tracking your progress—and celebrate your success by giving something back to the Gaucher community. It's an easy and valuable way to make a difference.

Curious about what a Patient Case Report looks like?
[Download a sample PCR here \(PDF, English\) >>](#)

Take Action

To learn more about the registry and its benefits, visit the Gaucher Registry website. [Go >>](#)

The Registry isn't the only way for those affected by Gaucher to share their success. Patient organizations offer the chance to reach out to others and support the larger Gaucher community. Learn more at the National Gaucher Foundation of Canada website. [Go >>](#)

New on Site!



The second issue of our printed newsletter is now available for download.

Read about the benefits of the Gaucher Registry, Q&A on how to obtain insurance with Gaucher, a new patient profile and more. [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](#).