



GAUCHER
connection

A Lifeline for Patients
Living with Gaucher Disease



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Welcome to Gaucher Connection eNews

Hello !

RegistryNXT! is the name of the newly updated Genzyme-sponsored lysosomal storage disorder registry system. This web-based platform allows for high-quality data collection and the ability to transfer and store data, incorporating a reporting system that allows registered sites and patients to view the data in near real time. In this issue we hear from a Genzyme RegistryNXT! program manager who answers questions about why a new registry system was needed, it's features and benefits and how you can join the registry.

Why A New System?

The registry was started as a paper-based system 20 years ago. With a life-long disorder like Gaucher disease, a great deal of information on any one patient can accumulate in 20 years and the registry has steadily been adding new patients since its inception. The registry moved to an electronic system nine years ago to help deal with this incredible amount of data, but the electronic technology platform had become outdated. Genzyme was faced with the question of whether to just replace the technology or to innovate, improving the registry system so it could better benefit researchers, physicians, nurses and patients.

New Features

Typically, a registry is a way to collect and organize data for research, to better understand treatment and what happens to patients in the real world. However, involvement in the registry is voluntary and collecting data requires interest on the part of physicians, nurses and patients. Data entry is a time-consuming process and patients can get lost to follow-up, making it difficult to know where the gaps in the data are. To help overcome this challenge, Genzyme wanted to design the registry system so that it would give something back to the Gaucher community, as well as to researchers.

With RegistryNXT!, nurses or physicians who take the time to enter patient information in the registry can immediately see near real-time reports on that patient. A dashboard is provided for each site so that members of the care team can view, download and share patient data in the form of customizable reports and tables. The care team can also decide to share some or all of this information with the patient through a secure portal. Privacy is protected by identifying patients by numbers rather than by name.

Patient Benefits

RegistryNXT! allows physicians to share data with patients, and add their own comments to help explain what the charts and tables mean. For the first time, with their physician's approval, patients will be able to view their own registry information. For instance, patients may be able to see a graph showing how their hemoglobin levels have changed over the past 15 years, or a report detailing the results of their most recent blood tests. Patients will also benefit indirectly from the research generated by the registry, which should help improve care for all patients.

How to Join

Patients who are not certain whether they are already part of the registry should talk to their physician, who can also obtain access to the RegistryNXT! Reports. Patients who are invited to join by their physician will receive an email from the registry system with a link to set up their own secure password-protected access to RegistryNXT! This allows patients to view the information and reports their physician decides to share with them.

Find Out More

More information on RegistryNXT! can be found at GaucherRegistry.com. [Go >>](#)

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

Patient spotlight: Pierre

- 30-year-old assistant manager
- Living with Gaucher
- Travels to remote areas
- Avid Photographer



Read how Pierre manages his Gaucher around his twin passions of technology and photography. [Go >>](#)

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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.

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