



GAUCHER
connection

A Lifeline for Patients
Living with Gaucher Disease



February 2012

Welcome to Gaucher Connection eNews

Hello!

In this issue we provide coverage of The National Gaucher Foundation of Canada's 2011 Congress. In October 2011, a group of Canadians with Gaucher disease gathered in Ottawa to learn about their disease and to build a sense of community.

Bringing The Community Together

The meeting, organized by the National Gaucher Foundation of Canada, was designed to disseminate the most up-to-date information on disease management and to bring the Canadian Gaucher disease community together, according to foundation president Christine White. Based on the feedback received, it was a success on both counts.

"It's pretty isolating at times to have a rare disease," says Ms. White, "so one of our objectives was to make people feel like they have the support of people who understand their circumstances."

Meeting Agenda Achieves Objectives

To achieve this objective, the meeting agenda included community-building sessions, such as an art workshop and a voice therapy session, as well as a welcome reception for attendees. The meeting also provided information on disease management, monitoring and treatment, as well as tools to manage pain, information on how to gather accurate information from the internet and discussion on how to gain the most from life.

"One of the reasons I think the educational component of the patient meeting is so important is that it enables patients to go back to their health care provider armed with the very latest information on disease management," says Ms. White. "This is really empowering for patients. Gaucher is so rare that a lot of clinicians do not have an in-depth knowledge of Gaucher disease."

Impressive Attendance

In all, 130 people attended the meeting with more than 100 of the attendees being a patient, a parent or a caregiver. Given that there are fewer than 200 people with Gaucher disease in all of Canada, this is an impressive number of participants. Thanks to an effort to accommodate French speakers with simultaneous translation services and French-language workshops, the 2011 meeting also boosted its representation of Quebec-based attendees.

"We were thrilled that we had quite a few participants from Quebec," says Ms. White. "I think in the past they felt under-represented...or not as included. ... When I actually spent some one-on-one time with patients from Quebec, they were really grateful to be there. It really re-enforced our decision to do that and made us aware of a need to further that cause."

Future Plans

Future plans for the National Gaucher Foundation of Canada include a series of regional meetings starting in 2012 as part of an effort to develop local patient groups.

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

Patient spotlight: Linda

- Mother & Grandmother
- Living with Gaucher & Rheumatoid Arthritis
- Pushing Her Luck
- Thankful for the opportunity to grow old



Read how Linda manages her Gaucher at the same time as another chronic illness, and feels grateful for the opportunity to grow old while being as active as she can be. [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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