



A Lifeline for Patients
Living with Gaucher Disease



February 2011

Welcome to Gaucher Connection eNews

Hello!

We're pleased to announce that the National Gaucher Foundation of Canada will hold its national meeting for patients, caregivers, family members and healthcare professionals in Ottawa in the fall of 2011.

Goals of the National Meeting

This meeting is intended to provide Gaucher patients with new disease and treatment information. Christine White, president of the National Gaucher Foundation says this educational meeting "brings people together from across the country to discuss the latest developments on Gaucher disease and to give them the opportunity to meet other patients and to network."

The meeting is especially important because Gaucher disease is quite rare, which means there is limited opportunity for those living with the disease to meet others in similar situations. Meeting others with the disease helps people to know that they are not alone; and it also allows those touched by the disease to exchange ideas and share advice.

"I think education is one of the key components," says Ms. White. "There are so many new developments that people are not necessarily aware of. It's really key to get them together so you can discuss and let them know what opportunities are available for their treatment."

Who Can Attend

The meeting is intended for anyone with Gaucher disease as well as those living or working with Gaucher patients. Although the agenda for 2011 meeting has not yet been determined, past meetings have included workshops and information on children with Gaucher disease, for adult patients, parents, siblings in different age groups, and healthcare professionals.

The National Gaucher Foundation sponsors the cost of travel for patients who wish to attend the event, as well as a caregiver in cases where a patient needs assistance. The meeting is supported by funds provided by Genzyme Canada and other companies involved in the treatment of Gaucher disease.

Stay Tuned

Although the meeting dates have not been set, Ms. White suggested the meeting may take place in October, depending on availabilities. More information on the meeting will be made available through Gaucher disease treatment centres, through the National Gaucher Foundation's website (www.gauchercanada.ca) and through e-mail invitations to those listed in the National Gaucher Foundation's database.

Learn more about **Managing Gaucher at the Gaucher Connection website**. [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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