



GAUCHER
connection

A Lifeline for Patients
Living with Gaucher Disease



March 2012

Welcome to Gaucher Connection eNews

Hello!

In this issue we talk about the importance of tracking your symptoms in case adjustments to your therapy are required. Although only your doctor can prescribe a change in treatments, you can ensure you get what you need by keeping your health team informed.

Changes Over Time

With treatment, the symptoms of Gaucher disease may all but disappear, but that doesn't mean the disease has gone away. Over time, changes in your body or in your disease can lead to new symptoms or the re-emergence of old symptoms. Early management of these symptoms can be an important part of making sure they do not become more serious. Maintenance of your health may require changes to your therapy.

Assessing Your Needs

While only your doctor can decide if adjustments to your treatment are needed, it is your job to keep your health care team informed. Symptoms like fatigue, loss of appetite, easy bruising or pain in your bones and joints could be the first signs of changes in your disease. It may be easy to dismiss these symptoms as being due to other causes – especially if you have been symptom free for a while – but only your doctor can assess whether they are truly important.

Available Resources

To make sure your health care team has all of the information they need to maintain your health, pay attention to the signs and symptoms that might be related to Gaucher disease and make a habit of talking to your health care team about them.

Symptom	Reporting Frequency		Notes
	How Often?	How Long?	
Bone Pain			
Fatigue			
Appetite			
Weight			
Easy Bruising			
Joint Pain			
Other			

It may help you to use a symptom tracking form like [this one](#) to ensure you remember how you are feeling when your next appointment may not be for weeks or months.

You can also call your health care team at any time between appointments for any concerns you may have.

Keeping Track

Visit the My Health Tools section of the Gaucher Connection website to access resources to help you track your Gaucher symptoms. My Health Diary is an easy way for you to note any changes to help you remember important information during your next visit with your health care team.

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 never feels unlucky. [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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