



A Lifeline for Patients
Living with Gaucher Disease



January 2011

Welcome to Gaucher Connection eNews

Hello!

A busy travel schedule may have interfered with or stopped you from receiving your regular infusion treatment on schedule. In this issue we discuss how it's now possible for you to maintain your treatment schedule either while traveling or living abroad.

Have Gaucher, Will Travel

The itinerary is set, the bags are packed and the taxi is waiting out front. The experience and excitement of a life-changing travel adventure lie ahead, and your time away looks like the very definition of freedom. Of course, there's just one catch: you have to be back in time for your next infusion. Or, maybe not.

In many cases, it's now possible to arrange for an infusion in your destination country with just a little planning and some co-operation. Just tell your infusion centre nurse where and when you'll be traveling. They'll provide your information to Genzyme Canada, who will in turn contact their international representatives to find a centre and arrange for your infusion(s). While it may not be possible to make arrangements for very remote areas, Genzyme will attempt to accommodate patients no matter where in the world they are going, and will do their best to find an infusion location. Your nurse will act as intermediary, providing you with details of the arrangements made on your behalf and answering any questions you may have.

For some, it may be tempting to skip or delay a treatment - but it's not a good idea. It's important to have a constant level of the enzyme in the body, and having your infusion however often it's prescribed ensures that a constant level is maintained. Patients considering skipping or delaying an infusion should discuss this with their health care team or physician.

A New Process

Making arrangements for traveling patients is a relatively new process and some of the protocols for doing so are still being developed. This means that nurses in some metabolic clinics may not have gone through the process before and may be unaware of the steps needed to help patients make arrangements for infusions away from home. While materials to assist in this process are currently being developed, you don't need to wait for them to be finished before asking your nurse to make arrangements on your behalf. Simply ask the staff at your clinic to contact their Genzyme representative and the information needed will be made available.

Take Action

Take some time to think about how you can get the most out of your treatment. Are you planning travel that could interfere with your treatment schedule? Talk to the nursing staff at your clinic about making the necessary arrangements so you can stay on schedule with your treatment.

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

Patient spotlight: Tim

- 30-year-old executive
- Living with Gaucher
- Loves being active, both physically and intellectually
- Doesn't let his diagnosis slow him down

Read how Tim makes his life work for him with regular Gaucher treatments. [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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