



**GAUCHER**  
connection

A Lifeline for Patients  
Living with Gaucher Disease



September 2010

## Welcome to Gaucher Connection eNews

### Hello!

The commitments of a treatment like <sup>Pr</sup>Cerezyme® can pose many challenges to children and their families. Here are some strategies for easing the experience.

### Establishing a Routine

Setting into a treatment routine can be difficult enough, between juggling family members' schedules, coordinating with schools, arranging travel, and more. Your child may be resistant if treatment feels disruptive to their school or social life. These suggestions may help make it easier for everyone:

- Try to keep infusions at the same day and time to establish a predictable pattern
- Talk to your child about school and other activities they want to participate in, and try to arrange their treatment schedule accordingly so they don't feel they've missed out on their favourite pastimes
- Work with your child's school to adapt their program to their treatments and get additional support as needed—just be patient as changes can take time to arrange
- Plan treats as part of their regular treatment routine, like going out for breakfast on the way to a morning infusion
- If your child has siblings that are left at home during infusion times, talk to parents of other Gaucher patients about exchanging childcare during these times

### Tips for Treatment Time

Sitting through infusions can be frustrating for kids who want to be doing other things. Help make the time more enjoyable for everyone! Here are some ideas to get you started:

- Bring favourite toys, games, and activities to provide comfort and entertainment
- Ask your child if they'd like to invite other family members or friends to visit
- Help your child with schoolwork so they don't feel like they're falling behind
- Read books, listen to music, or watch movies together
- Invent unique games to play specifically at the infusion centre, so your child can look forward to special time for the two of you together

Infusions can be an opportunity to enjoy fun one-on-one time with your child. But if they're a teenager, consider that they may actually prefer having that time to themselves. Encourage that independence—and empower your child to take responsibility for their treatment and health.

Other emails in this series offer additional practical advice on fitting treatment schedules into family and life changes, as well as providing emotional support to children dealing with Gaucher.

### Take Action

#### Link with other patients or caregivers!

The National Gaucher Foundation of Canada (NGF), together with Genzyme Canada Inc., have created Gaucher Link to increase your or your child's access to the NGF, its support and community programs.

Through the Gaucher Link program, you'll have the opportunity to attend face-to-face educational meetings and learn from other members of the Gaucher community.

[Learn more >>](#)

### Patient spotlight: Michael

- 40-year-old architect
- Living with Gaucher
- Works hard running his own firm
- Works with his doctor to manage his care



Read how Michael partners with his doctor to make his Gaucher treatments easier. [Go >>](#)

Membership in the Gaucher Connection Program you signed up for includes these complimentary eNewsletters. If you do not wish to receive emails and updates from Gaucher Connection in the future, please [unsubscribe](#).

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.

Review our [Privacy Policy](#).