



A Lifeline for Patients  
Living with Gaucher Disease



June 2014

## Welcome to Gaucher Connection eNews

### Hello

Thank you for signing up for Gaucher Connection eNews, the monthly newsletter designed to help keep you up-to-date and on track with Gaucher disease treatment and management.

As a mother of three, Sarah\* has plenty to keep her busy. These days, her top priority is ensuring that Gaucher doesn't make being a teenager any tougher for her son. In this issue, we talk with her about how moving on from childhood is affecting her son, how she's adapting to the new concerns in his life, and the importance of support and communication. We also revisit the MyNormal.ca website, a great resource for parents and patients to connect and share about their experiences with Gaucher.

### Moving on from Childhood

"With teenagers, you never know what to expect. One day they're cheerful kids without a care in the world. Then, almost overnight, they're suddenly self-conscious about things that never mattered before. Gaucher doesn't make things any easier. Having a rare genetic disease isn't exactly the best way to blend in."

### Adapting to New Concerns

"My son Joshua\* turned 13 last year, and almost immediately new concerns appeared. Like with his treatment. He's been having enzyme replacement therapy infusions for years, and in the past missing a few hours of school for them was never a big deal. We'd bring his schoolbooks along and I'd help him with his homework. Occasionally I'd even let him take a break and watch TV instead."

"But now he feels awkward about leaving school early for treatment as he worries the kids look at him funny. Plus, he wants to try out for the school play, which would mean rehearsals during his usual infusion times. So we're working on switching his schedule to early morning appointments for less disruption. Although I'm not looking forward to getting a teenager out of bed at that hour!"

### Support and Communication

"Keeping his treatment low profile should help Joshua feel less different. But I also make sure to offer lots of positive reinforcement. Like when he complains about being small for his age, I remind him that as long as he sticks to treatment, his teenage growth spurt should be just around the corner. After all, his father's over 6 feet tall!"

"It can be hard to get a teenager to talk but that doesn't stop me from trying! I ask Joshua lots of questions to encourage him to talk to me, his dad, and his health care team. So we feel we have a pretty good idea of how he's doing. Sure, he struggles from time to time with typical teenage issues. But more than anything I'm just so proud of the kid he's become—with or without Gaucher."

### Take Action

If you're facing new Gaucher-related challenges with your teenager, don't worry—changes in attitude and behaviour are normal at this age. Talk to your child's health care team about strategies for dealing with them.

Another great way to get tips and fresh perspectives is by connecting with other parents. Patient organizations can help put you in touch.

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

### Connection and Support

The MyNormal.ca website offers a place for children and adults to share their own stories and experiences about living with a rare condition. Visit our website to read the article "Redefining Normal" and find out more about how MyNormal.ca came to be, how it's evolving, and how parents and teens can be a part of it.

Read the full article posted on the Gaucher Connection website. [Go >>](#)

\* The characters represented in these emails are not real people, but their stories are inspired by those of actual Gaucher patients.

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