



A Lifeline for Patients
Living with Gaucher Disease



June 2011

Welcome to Gaucher Connection eNews

Hello!

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...

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 infusions for years, and in the past missing a few hours of school for them was never a big deal. We'd bring his school books 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-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."

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

Take Action

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

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

Patient spotlight: Sarah

- 36-year-old pastry chef
- Teenage son has Gaucher
- Manages a busy schedule
- Raises a regular kid



Read how Sarah stays supportive with her teenage son about his Gaucher. [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.](#)