



**GAUCHER**  
connection

A Lifeline for Patients  
Living with Gaucher Disease



September 2009

## Welcome to Gaucher Connection eNews

### Hello!

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

### Personal Goals

Therapeutic goals offer a framework for measuring health improvements. Good test results are a great reminder that your infusions are helping and a motivator for sticking to your treatment! But most people with Gaucher also have personal goals that they want treatment to allow them achieve. This issue will help you step back from the numbers and figures and reflect on your success and hopes in a more personal way.

### Goals for Real Life

Staying consistent with your treatment keeps your body healthy—which means you can lead the full and active life you want. So think about how those therapeutic treatment goals translate into the things you want out of everyday life. For example:

Therapeutic Goals	Personal Goals
<ul style="list-style-type: none"><li>Reduce or eliminate bone pain</li></ul>	<ul style="list-style-type: none"><li>Join a soccer team</li></ul>
<ul style="list-style-type: none"><li>Increase hemoglobin to prevent anemia</li></ul>	<ul style="list-style-type: none"><li>Get through the day without napping</li></ul>
<ul style="list-style-type: none"><li>Reduce and maintain liver and spleen size</li></ul>	<ul style="list-style-type: none"><li>Shop for new clothing, with no alterations needed</li></ul>

What are your personal goals? Writing them down and sharing them with your healthcare team can help ensure you get the most out of your treatment. Posting your goal list at home can also help keep you motivated to maintain your infusion schedule consistently. Your personal goals may change over time, so take advantage of the [My Diary](#) tool on the Gaucher Connection site to keep track of and update your goals.

### Managing Gaucher disease tip

**Remember:** all treatment goals come with timeframes based on your particular symptoms and conditions—so be sure to talk to your health care team about a realistic timeframe for achieving your personal goals too.

You can set realistic timeframes using [My Calendar](#), part of My Health Tools on Gaucher Connection.

### Patient spotlight: Sarah

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



Read Sarah's story about new interests and new concerns.  
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