



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.

Therapeutic goals offer a framework for measuring improvements in your health. But most people with Gaucher also have personal goals that they want treatment to help them achieve. In this issue, we look at tracking personal progress, and setting goals for real life. We also check in with Elizabeth to hear about the personal goals she's been able to achieve by staying on top of her treatment for Gaucher.

Personal Progress

Setting therapeutic goals with your health care team is an important part of tracking your progress on enzyme replacement therapy. Good test results are a great reminder that your infusions are working—and a great motivator for sticking to your treatment!

But take a moment once in a while to step back from the numbers and figures and reflect on your success—and your hopes—in a more personal way. While it's always good to hear that your spleen has reduced another 10%, or your hemoglobin has stayed steady at 12 g/dL for the last year, what does that really mean for your life?

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. The table below can be a helpful starting point. Writing down these personal goals can be an inspiring reminder of what treatment can help you achieve.

| Therapeutic Goals | Personal Goals |
|--|---|
| <ul style="list-style-type: none"> • Reduce or eliminate bone pain • Prevent bone crisis | <ul style="list-style-type: none"> • Join a local soccer team • Take a family hiking vacation • ----- • ----- |
| <ul style="list-style-type: none"> • Increase hemoglobin to prevent anemia • Increase blood platelets to minimize bleeding and bruising problems | <ul style="list-style-type: none"> • Get through the day without napping • Take on a challenging new work schedule • Stop worrying about sudden nosebleeds • ----- • ----- |
| Reduce and maintain: <ul style="list-style-type: none"> • Liver to 1-1.5 times normal size • Spleen to 2-8 times normal size | <ul style="list-style-type: none"> • Shop for new clothing, with no alterations needed • Have the appetite to enjoy a nice meal with friends • ----- • ----- |

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

Take Action

Print out this email and fill in the table with some upcoming personal goals of your own. Then bring them to share with your health care team and discuss alongside your therapeutic goals—so together you can make sure you get the most out of your treatment.

Posting this list at home can help keep you motivated to maintain your infusion schedule consistently. And remember, too, that your personal goals will change over time. So keep a few copies of this worksheet to periodically reevaluate and update as you look ahead to your next success.

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

Reflect on Your Success

What's the most important improvement treatment has made in your life?

- More energy to keep up with daily activities
- Less pain so I can participate in sports and other physical activities
- Improvements to how I look so I feel better about myself
- Feeling better overall so I can enjoy time with family and friends

Patient spotlight: Elizabeth

- 23-year-old schoolteacher
- Living with Gaucher
- Mastered a tough course load at university
- Maintained full control of her treatment success



[Read Elizabeth's story about how she uses personal goals to help her monitor her Gaucher treatment success. 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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Genzyme Canada - Canadian Office, 2700 Matheson Blvd. East, West Tower, Suite 800, Mississauga, Ontario L4W 4V9, Canada