



**GAUCHER**  
connection

A Lifeline for Patients  
Living with Gaucher Disease



August 2013

## 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. You know how important your regular enzyme infusions are to keeping your skeleton strong. In this issue we look at healthy habits that will help your bones get the most out of your treatment, so you can get the most out of life. Plus, we check in with Patrick to find out how he maintains a "bone-friendly" lifestyle with steady treatments to keep his Gaucher-affected bones strong.

### Supporting Bone Growth<sup>1-3</sup>

A healthy skeleton develops through a process called **remodeling**, which builds and maintains bone tissue. Remodeling requires **calcium**, the mineral that makes bones hard and strong, as well as vitamin D to help absorb the calcium.

You can help support this process by:

- Maintaining a **consistent treatment** schedule to prevent Gaucher cells from interfering with remodeling
- Eating **foods high in calcium** and vitamin D
- **Not smoking** cigarettes and **avoiding excessive alcohol**, which both interfere with the body's ability to absorb calcium
- Getting **regular exercise**, which makes bones work and grow

### Exercise Precautions

It's critical that you talk to your health care providers before making any lifestyle changes—especially exercise, since Gaucher can increase your risk of fractures. Steady enzyme replacement therapy may strengthen bones, but this process can take some time—up to several years.<sup>4</sup> Until your doctor feels your bones are safely strong enough, you may need to stick to lower-impact activities like swimming or cycling.

### Medical Care

One of the most important things you can do for your skeleton is to see your doctor for **regular check-ups**. Three different tests—x-rays, MRIs, and DEXA—together provide a complete picture of your bone health and progress toward your treatment goals. If you're not achieving those goals, it may be necessary to adjust your infusion dose to specifically target bone problems.<sup>5</sup>

Until your doctor determines your optimal dose, he or she may prescribe painkillers<sup>6</sup> or recommend other strategies for managing bone symptoms. Over time, however, regular enzyme infusions eliminate pain in most people—often within the first year.<sup>7</sup> Most importantly, early treatment can prevent the most serious bone problems from ever developing.

So eat well, stay safely active, and stick to your treatment schedule! See other emails in this series for more information on Gaucher disease and bone health.

### Take Action

Before you make ANY changes to your diet, physical activity, or other habits, it's crucial you discuss them first with your health care team.

You might want to bring a copy of this email to review at your next appointment. Together, you and your health care providers can discuss your treatment goals and the kinds of healthy habits that can bring you closer to them.

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

### Did You Know?

**10%** of an adult's bone mass is replaced each year during **remodeling**

### Patient spotlight: Patrick

- 43-year-old Journalist
- Frequent Traveler
- Chose treatment with proven success



Read Patrick's story about [how he maintains bone health on the go](#). [Go >>](#)

<sup>1</sup> Centers for Disease Control and Prevention website:  
[http://www.cdc.gov/nccdphp/dnpa/nutrition/nutrition\\_for\\_everyone/basics/calcium.htm](http://www.cdc.gov/nccdphp/dnpa/nutrition/nutrition_for_everyone/basics/calcium.htm)

<sup>2</sup> National Institute of Child Health and Human Development website:  
[http://www.nichd.nih.gov/health/topics/bone\\_health.cfm](http://www.nichd.nih.gov/health/topics/bone_health.cfm)

<sup>3</sup> National Institute of Arthritis and Musculoskeletal and Skin Diseases website:  
[http://www.niams.nih.gov/Health\\_Info/Bone/Bone\\_Health/default.asp](http://www.niams.nih.gov/Health_Info/Bone/Bone_Health/default.asp)  
[http://www.niams.nih.gov/Health\\_Info/Bone/Bone\\_Health/Exercise/default.asp](http://www.niams.nih.gov/Health_Info/Bone/Bone_Health/Exercise/default.asp)

<sup>4</sup> Wenstrup RJ, Kacena KA, Kaplan P, Pastores GM, Prakash-Cheng A, et al. Effect of enzyme replacement

therapy with imiglucerase on BMD in type 1 Gaucher disease. J Bone Miner Res 2007;21:119-126.

<sup>5</sup> De Fost M, Hollak CE, Groener JE, Aerts JM, Maas M, et al. Superior effects of high-dose enzyme replacement therapy in type 1 Gaucher disease on bone marrow involvement and chitotriosidase levels : a 2-center retrospective analysis. Blood 2006;108:830-5.

<sup>6</sup> Genzyme Clinical Monograph: "Skeletal Pathology of Gaucher Disease and Its Management." 2007; page 20.

<sup>7</sup> Charrow J, Dulisse B, Grabowski GA, Weinreb NJ. The effect of enzyme replacement therapy on bone crisis and bone pain in patients with type 1 Gaucher disease. Clin Genet 2007;71:205-211.

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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.

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