



Welcome to Gaucher Connection eNews

Hello!

Steady treatment is the number one way to keep Gaucher-affected bones strong – especially when supported by a healthy, “bone-friendly” lifestyle. You already know how important regular enzyme infusions are to keeping your skeleton strong. In this issue we talk about healthy habits that will help your bones get the most out of your treatment, so you can get the most out of life.

Supporting Bone Growth^{1,2,3}

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**, both of which interfere with the 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.⁴ 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.⁵

Until your doctor determines your optimal dose, they may prescribe painkillers⁶ or recommend other strategies for managing bone symptoms. Over time, however, regular enzyme infusions eliminate pain in most people—often within the first year.⁷ Most importantly—started early—treatment can prevent the most serious bone problems from ever developing.

So eat well, stay safely active, and stick to your treatment schedule!

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. Together, you can discuss your treatment goals and what kind of healthy habits can bring you closer.

Learn more about Gaucher Disease and testing for bone health at the Gaucher Connection website. [Go >>](#)

Did You Know?

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

Patient spotlight: Michael

- 40-year-old architect
- Living with Gaucher
- Travels globally
- Accesses treatment locally



Read how planning helps Michael maintain his treatments while travelling. [Go >>](#)

¹ Centers for Disease Control and Prevention website:
http://www.cdc.gov/nccdphp/dnpa/nutrition/nutrition_for_everyone/basics/calcium.htm

² National Institute of Child Health and Human Development website:
http://www.nichd.nih.gov/health/topics/bone_health.cfm

³ 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/Exercise/default.asp

⁴ 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.

⁵ 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.

⁶ Genzyme Clinical Monograph: “Skeletal Pathology of Gaucher Disease and Its Management.” 2007; page 20.

⁷ 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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