



## Welcome to Gaucher Connection eNews

### Hello !

Balancing family, friends and work or school on top of the demands of managing a chronic condition like Gaucher disease can make it difficult to find the time and energy to pursue a healthy lifestyle – but the physical and emotional benefits make it well worthwhile. In this issue we discuss healthy habits you can cultivate to ensure you're living well and staying well.

### Get Treatment and Stay Informed

According to Colleen McNeil, Nurse Clinician for Lysosomal Storage Disorders at the Alberta Children's Hospital in Calgary, the most important things to do for your health are to listen to your Gaucher specialist physician and attend follow-up appointments and tests, including enzyme replacement infusions, MRI and X-ray bone scans, and routine work appointments. It's also important to be fully educated on Gaucher disease, and there are many ways to do so, including attending local or national patient meetings, reading up on research that is being done, and talking to other people with Gaucher disease. Not only does this allow people to make informed decisions about their health care, it means they can help educate family members and even other clinicians involved in their care about Gaucher disease, and become advocates for their own health.

### A Healthy Lifestyle

Of course, healthy living is not just about managing one condition. A healthy lifestyle should incorporate a balanced diet, regular physical activity and a commitment to being tobacco-free.<sup>1</sup> Transitioning to a healthy lifestyle can seem daunting, but Ms. McNeil offers some practical advice on how to make changes you can live with.

"So many people start an exercise program... but they don't last. Part of the reason that may happen is they simply don't enjoy what the routine is," Ms. McNeil explains. She suggests incorporating activities you actually enjoy into your routine, "mixing things up" to add variety and prevent boredom. For instance, if walking is your regular exercise, consider adding an activity that focuses on your arms, such as a racquet sport. Whatever physical activity you choose to do, it's important to take small steps to begin with, modify the exercise to fit your level of fitness and set realistic expectations and timelines. Be realistic about your limitations - someone with more severe bone disease, for example, might want to concentrate on lower impact activities like swimming, walking or yoga.

Variety is also the key to preventing a healthy diet from being a boring one. Ms. McNeil suggests trying new recipes from newspapers, the internet or other sources. Keep eating fun by incorporating mini-challenges like making sure to eat a red, yellow and green food every day – this will help you include an appropriate amount of fruits and vegetables in your diet. People with Gaucher disease should also make a special effort to eat foods that are high in vitamin D and calcium, nutrients that are important for bone health. Dairy products, like milk and yogurt, contain plenty of calcium and are also fortified with vitamin D, so you should aim to consume two to three servings of dairy every day.<sup>2</sup> Vitamin D can also be obtained from many kinds of fish, including salmon and tuna, and from exposure to sunlight.<sup>3</sup> It is not uncommon to need to take a vitamin D supplement, particularly during the winter.<sup>3</sup>

### Stay Smoke Free

One thing that remains the same regardless of season is the importance of staying smoke-free. "Smoking isn't healthy for anybody," says Ms. McNeil and adds it can be particularly harmful for Gaucher patients, as some rare patients can experience pulmonary involvement as part of the disease.<sup>4</sup> Additionally, smoking can make exercise difficult because it affects the lungs and this can have a negative impact on bone health.<sup>5</sup> For those people who are smoking, she emphasizes there are many resources available to help them quit and suggests joining a support group as a good first step.

Ms. McNeil's final piece of advice for the Gaucher patient looking for a healthy lifestyle is to not neglect their emotional health. She advises people to include social time in their regular schedule, avoid worrying too much about things they cannot change and, above all, to get enough sleep. "I think all that plays an important role with regards to healthy living," she concludes.

### Find Out More

There are many steps you can take to help manage your Gaucher and the effects it has on your life, including maintaining a healthy lifestyle and ensuring regular treatment. We offer a wide variety of resources to assist you with staying connected and knowledgeable about living with Gaucher.

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

### Patient spotlight: Pierre

- 30-year-old assistant manager
- Living with Gaucher
- Travels to remote areas
- Avid Photographer



Read how Pierre manages his Gaucher around his twin passions of technology and photography. [Go >>](#)

<sup>1</sup> Health Canada. Healthy Living. Available at: <http://www.hc-sc.gc.ca/hi-vs/index-eng.php>. Accessed: June 7, 2011.

<sup>2</sup> Health Canada. Vitamin D and Calcium: Updated Dietary Reference Intakes. Available at: <http://www.hc-sc.gc.ca/fn-an/nutrition/vitamin/vita-d-eng.php>. Accessed: June 7, 2011.

<sup>3</sup> Hanley DA et al. Vitamin D in adult health and disease: a review and guideline statement from Osteoporosis Canada (summary). CMAJ 2010; 182(12):1315-9.

<sup>4</sup> de Fost M et al. Gaucher disease: from fundamental research to effective therapeutic interventions. Neth J Med 2003; 61(1):3-8.

<sup>5</sup> National Institutes of Health. Smoking and Bone Health. Available at: [http://www.niams.nih.gov/Health\\_Info/Bone/Osteoporosis/Conditions\\_Behaviors/bone\\_smoking.asp](http://www.niams.nih.gov/Health_Info/Bone/Osteoporosis/Conditions_Behaviors/bone_smoking.asp). Accessed: June 7, 2011.

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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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