

# My Celiac Journey

by *Melanie Waye, CA, NSTU Financial Officer*

“You have celiac disease.” The confirmation came from my doctor over the phone. I burst into tears. How could I have a disease that I had never heard of? It was the summer of 2005 and I was off studying for my CA exam. I had been having problems for over a year—extreme fatigue, anemia, cramps, bloating and chronic diarrhea. I remember being so tired that some days I would go home and nap at lunch or at supper time—or both before I would go back to work for the afternoon/evening. My normal active lifestyle became a struggle. During an annual 5 km fun run, I had to walk and struggled to maintain my breath. These are not exactly the type of symptoms that you want to live with, especially while working long hours and studying for your accounting designation. My doctor had been unsuccessfully treating my anemia with iron injections but until this point could not identify what was wrong with me. Finally, my doctor ordered a colonoscopy. The diagnosis was in part a huge relief. I finally knew what was wrong with me. Now, I could start the proper treatment and hopefully begin to feel better.

I did some research and found out what was going on in my body. Celiac is an autoimmune disorder. When gluten is consumed, the immune system forms antibodies to gluten, which attack the intestinal lining causing inflammation and damage to the villi, which lines the small intestine. Villi normally absorb the nutrients from food. Gluten was damaging my intestines and making it difficult for me to absorb my nutrients, especially fat, calcium, iron and folate. No wonder I didn't feel well.

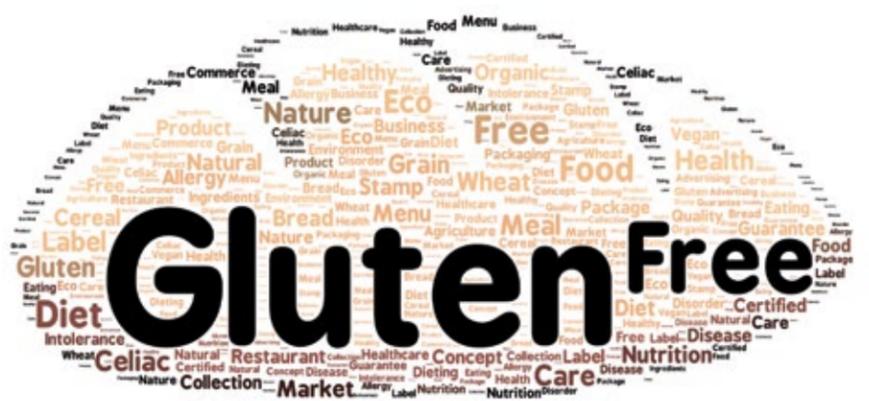
The doctor instructed me to follow a gluten-free diet, which is currently the only treatment. What the heck was gluten? I had no idea. As I would come to find out, gluten is a protein found in wheat, rye, triticale and barley. Gluten is commonly what binds bread and other baked goods together. It is frequently found in many processed and packaged foods. I guess this was why the toast and

sandwich diet that I had been consuming for my upset digestive system wasn't working. I immediately panicked. What was I going to eat? All I could think of was what I couldn't eat—my grandma's sugar cookies, my nanny's butterscotch pie, a McDonald's cheeseburger, my favourite cereals, BREAD! After the initial shock wore off I figured out that there was still a lot that I could eat; meat, eggs, rice, corn, all fruits and veggies, not to mention gluten-free products.

I met with a gastroenterologist who provided some more information on my disease and gave me some information on reading labels. It was surprising how many foods contained gluten. There was a lot of label reading in those first few months and a lot of foods that I had to bid a farewell. It was an adjustment. Luckily I had a good support system, my boyfriend at the time (now my husband) had celiac in his family so it was not new to him. He has since discovered that he has a gluten sensitivity (has symptoms when he eats gluten but does not have celiac) so our house is gluten free, which makes life a lot easier. Being the first known case of celiac in my family, I had to educate everyone on eating gluten free. For the longest time, they struggled to feed me but now they can cook gluten free for me or have gluten-free options available at family suppers.

After beginning my gluten-free diet my health started improving. My digestive system settled down and I slowly got my energy back. I still took iron pills for a while and received B12 shots until my levels reached the normal ranges. I was really lucky to be diagnosed considerably quickly. Today, it is estimated that celiac disease affects 1 per cent of Canadians and Americans, with less than 10 per cent having been diagnosed.

Being gluten-free has changed considerably in the past ten years. When I was first diagnosed it was challenging to find gluten-free products and very difficult to eat out. So much has changed. Gluten-free is the fastest growing food intolerance



category in the market. According to Health Canada, celiac is recognized as one of the most common chronic diseases world-wide. These days you can pretty much find a gluten-free substitute for any food item. Grocery stores have whole sections of gluten-free products and restaurants have gluten-free items or even separate menus that are gluten-free. This has made life easier. I remember years ago being excited just to find gluten-free products—now there are options and a lot of them.

Besides availability of products, food labelling has also advanced. As of 2012, Canadian food allergen labelling regulations require that specific priority food allergens and gluten sources be declared on the label of prepackaged foods sold in Canada. This has saved me time at the grocery store. Instead of reading through all the ingredients and remembering the names of all the

ingredients that are gluten, I just look for “gluten-free”.

Today, living gluten free is second nature for me. Do I still miss gluten? Sure, once in a while. On holidays I miss my grandmother's baking—especially when the cinnamon buns are being passed around or when the sugar cookies are coming out of the oven. On a hot day I miss eating licorice at the beach. And I miss my favourite desserts that my mom makes for family suppers. But I don't feel like I am missing out. Life is pretty good for this gluten free girl.

**May is Celiac Awareness Month.** If you would like more information visit the **Canadian Celiac Association of Nova Scotia** at [www.celiacns.ca](http://www.celiacns.ca) or **Health Canada** at [www.bc-sc.gc.ca](http://www.bc-sc.gc.ca).

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