
Spotlight on Ellen Bayens of The Celiac Scene

Let's Celebrate Celiac Advocates from Coast to Coast

By Lisa Rigney

I connected with Ellen Bayens of The Celiac Scene within a couple of weeks of starting my role with the Chapter in January this year. I was seeking permission to use one of Ellen's articles in my first newsletter. I quickly learned that Ellen is exceptionally helpful, very encouraging and an amazing resource on all things gluten free. I am not the only Chapter who looks to her as a great resource. She has also been featured in Gluten Free Living, Allergic Living and Delight Gluten Free magazines.

Ellen was born in Calgary and moved to Edmonton when she was 5 years old, she now lives in British Columbia. Her mom joined the Edmonton Chapter when she was first diagnosed over 30 years ago. Ellen accompanied her Mom to her first meeting and remembers the happiness of finding Kinnikinnick. Ellen herself was diagnosed in 2003, 25 years after her Mom's diagnosis. She understands the challenges of the gluten free diet and shines a light on how it can become the gateway to good health.

Ellen has educated thousands of newly diagnosed celiacs and their families, helping them to navigate the challenges of the gluten free diet. Since her diagnosis, Ellen has volunteered with the Victoria Chapter, eventually serving as Vice President and helping to organize the National CCA Conference in 2008. She continues to make herself available to anyone who needs support.

The Celiac Scene launched in 2009. Ellen worked with Chapter volunteers across Canada for 5 years, keeping the maps to their trusted restaurants up to date until the GF diet took off. A national resource just became too large to handle so Ellen down-sized and went local and in 2014 the Scene became a Vancouver Island resource! She publishes a monthly online newsletter that speaks to the local scene but also offers news of interests to all celiacs. theceliacscene.com/

Ellen created a Facebook group <https://www.facebook.com/groups/CeliacParents/> when she felt that parents needed a safe place to 'care and share.' Now over 1900 families strong, members ask for and offer support to others whose children have just been diagnosed, school questions, family predicaments and everything in between.

Ellen does a lot of public speaking - from Gluten Free Expo in Vancouver to the Gluten Free Gala in Victoria, on radio, schools, the local Dental Hygienist Association, and anyone who would like information on celiac disease. She makes herself available to local restaurants who want to learn more about feeding celiacs safely.

Ellen is a regular contributor to Sue Jennett's A Canadian Celiac Podcast and each month they discuss articles and information Ellen has brought to Sue's attention. These two ladies have joined forces and recently launched Celiac Kids Stuff stickers, wristbands and magnets. Both women have a keen interest in the unique issues of children diagnosed with celiac disease and identified resources that might make a celiac child's life easier. They saw a gap in the market and from those discussions, Celiac Kid Stuff was born. Ellen and Sue are excited to bring these helpful aids to children, parents and caregivers alike. Check out <http://celiackidstuff.com/>

She will also be part of the CCA's November 13-14, 2021 Online Conference in regard to dining out. Click this link for more information <https://www.celiac.ca/news-events/national-conference/>

ELLEN'S BACK STORY:

Is it just your Mom and you who have been diagnosed with CD? I don't use the word "just" lightly!

"We did not know at the time that the disease was genetically mediated so I did not realize that I was at risk. My adult children both have tested positive for the genetic predisposition for the disease, but so far, the pre screening

blood tests have been negative. They are aware that they need to be retested every 3-5 years, or sooner should they experience any new health concerns”.

Would I be correct in saying that you struggled for a long time before diagnosis?

“Yes! I went to my GP when I was 18 to ask about the severe albeit intermittent pain I would experience below my right rib cage ie in the liver area. I would sometimes double over in pain. He ordered a ‘barium swallow,’ but the results were inconclusive because the barium did not progress beyond my stomach. The GP attributed the pain to stress, and a potentially developing ulcer. He did no further testing. He said I should undertake some relaxation techniques to reduce stress. The pain continued on and off but I never knew what triggered it.

25 years later, I changed GPs and she ordered a full work up. While I felt very well, I knew that if I ate bread or pasta, I would have gas and bloating. I thought that was the female condition! I also struggled with depression, worse so after my children were born.

Test results indicated that my liver enzymes were elevated. They remained elevated for 2 years. Out of an abundance of concern, my GP ultimately ordered a liver biopsy.

During the procedure, the radiologist perforated my liver and entered my small intestine. Samples of villi were withdrawn through my liver, which could have led to very serious consequences. Fortunately, all was well.

The news got better! The pathologist who viewed the samples microscopically, identified the cells that were withdrawn from the small intestine as flattened villi. I had my diagnosis, without having to undergo an endoscopy! My GP had never asked for my family history, so she seemed exasperated that I had not told her that my mom had CD. I did not know I was at risk to develop it.

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Switching to the GF diet was easy! I knew exactly how to eat, given what I learned from my mom. We became even closer! My liver enzymes normalized and the gas and bloating, which I thought was “normal” all but disappeared.

Did you find the diet difficult initially or was it a bit “easier” because of your Mom?

“Easy peasy! I went to my local store, bought some GF bread, and new peanut butter. From there I cooked from scratch from whole food and slowly worked through my cupboards to remove gluten-containing foods.”

“I went alone on my first big trip to the Superstore, so that I could take my time and find GF facsimiles of all the foods I loved. It took 3 hours but I came away with the GF version of my new life. I’ve never looked back and my children know that if they develop it, they will be more than fine.”

“They both worked at the Deli in Save on Foods and became the store’s experts on CD and helping customers find GF foods!”

How long did it take for you to think it was a gateway to good health?

“I felt better in a matter of weeks and was so grateful that the gas, bloating and constipation that I thought was normal vanished. My new normal! I was very into body building and became fitter than ever! My depression/brain fog has generally abated.”

Ellen is keen to support anyone living in or traveling to Vancouver Island with restaurant suggestions, great shopping and gluten free events! Follow her across social media [@theceliacscene](https://twitter.com/theceliacscene)

Thanks to Ellen for taking the time to answer these questions and sharing her story and for being such a great celiac advocate from coast to coast.

Extra reading:

Click this link for further information about dining out <https://www.celiac.ca/living-gluten-free/dining-out/>

Does a low FODMAP diet benefit someone with Celiac Disease?

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While many patients with Celiac disease will experience symptom improvements while following a strict gluten-free diet, a portion will continue to experience GI symptoms. This can likely be attributed to the fact that Celiac disease and IBS share a wide range of symptoms, including abdominal discomfort and bloating. People newly diagnosed with Celiac should work closely alongside a dietician to ensure that small amounts of gluten aren’t sneaking into their gluten-free diet. The FODMAP diet has gained traction over the last 5 years, with benefits becoming more and more clear as research progresses. Studies have shown that a low FODMAP diet can be beneficial to those with Celiac disease who experience IBS-like symptoms (Beyond

Celiac, 2018; Roncorino et al., 2018). It is worth noting that continuing symptoms may also be associated with factors unrelated to food, such as stress or emotions.

WHAT IS CELIAC DISEASE?

Celiac Disease is an autoimmune disorder that occurs in genetically predisposed people (an immediate family member having the disease lends to a 1 in 10 chance for others in the family developing it as well). Since the cause of Celiac is not yet fully understood, it is important to seek testing if symptoms are present. Worldwide the disease affects 1 in 100 people, so it’s more prevalent than you would think.