

# Remarkable Celiacs Part 4: **Ellen Bayens**

# Resilience and **Optimism**

by Janet Dalziel

We all know that a diagnosis of celiac disease changes your life in many ways. How you accommodate those changes and rebuild once your health returns varies tremendously from person to person.

On learning that she had celiac disease, Ellen threw herself into working with the Victoria Chapter of the CCA and was an integral part of the committee that organized the annual conference. Taking a break from her day job, she worked with the exhibitors and learned they needed a way to connect with their customers. At this point, she had the brilliant idea to open the trade show to the public for the very first time. That little idea brought in hundreds of interested people, raised both money and awareness, made the exhibitors ecstatic and quickly became the norm at every conference since.

In another creative flash of brilliance, Ellen connected with as many local restaurants as possible, checking out their ability to offer gluten-free meals during the conference and creating a hand-out map that highlighted all those willing to do so. Many

of us used those maps and enjoyed relaxing meals because Ellen had already done all the legwork. The legacy of that first effort lives on because Ellen decided that this was such a useful tool, she would offer to create similar maps for other chapters in other cities. Soon, The Celiac Scene was born.

If you haven't visited Ellen's site, [www.theceliacscene.com](http://www.theceliacscene.com), to find celiac-friendly restaurants in your town or while traveling, then rush right now to check it out. Free to both users and the restaurants listed, this service connects those of us who need gluten-free food with those establishments that can safely offer it. Ellen has strict rules about which restaurants can be listed on her site. She relies on recommendations from members of celiac associations in the US and Canada and then personally contacts each one to check their understanding of the GF diet and cross-contamination issues and to assess their commitment to their celiac customers. A restaurant cannot pay to be listed.



Launching a business is not an easy task. Ellen has yet to make a living from this site and estimates her salary at about 8.7 cents an hour. Revenue does come from businesses that pay to advertise on her site but a restaurant cannot post an ad in order to be listed and, in fact, most do not. But, in her typical fashion, she concentrates on the positive aspects of how much she has learned, "I didn't know a spreadsheet from a bed sheet when I started" and hired experts from whom she learned how to do her own web and graphic design.

Ellen has been able to continue pursuing her dreams partly because of the perseverance and optimism she inherited from her beloved mother. Her mother, who died one year ago, taught her by example to find the good in life. Of Dutch heritage but born in Sumatra, she was interred for four years in a Japanese prisoner-of-war camp. Here she saw that the Japanese guards were suffering as much as the prisoners and that they were often kind. Other prisoners suffered and even died as a result of the inadequate diet whereas she thrived because it was gluten free. No one could have known then that she had celiac disease.

In Holland, after the war, when everyone finally had enough food to eat, she lost weight and was so thin that people stared. After immigrating to Canada, Ellen's mother suffered for years from a growing list of health challenges: hyperthyroidism, diabetes, atherosclerosis, a mis-diagnosis of perimenopausal depression. It took a near-fatal accumulation of fluid in her chest and legs as a result of heart congestion and unbalanced electrolytes before her celiac disease was found. Even so, the diagnosis was only considered by her GP when she brought in an article about celiac disease published in the Edmonton Journal. Ellen dragged her Mother to the meetings of the CCA's Edmonton Chapter and they learned as much as was known about CD in 1988.

Fast forward to 2005 and Ellen's own doctor is investigating her chronically elevated liver enzymes. Ellen's lifestyle became the focus of investigation: How much alcohol did she drink? One or two glasses per year. Was she injecting intravenous drugs? Ellen was a stable, stay at home mom with two young children. Could the protein powder she was consuming be laced with steroids? Tubs of protein powder were dutifully presented for inspection.

Ellen finally underwent a liver biopsy in an effort to find the cause of the problem. The specialist who performed the procedure inadvertently perforated her liver and penetrated her small intestine, retrieving samples of classically flattened villi. A diagnosis was made and all aspersions on Ellen's lifestyle were withdrawn.

What Ellen has done with that life-changing diagnosis is to reach out and make our lives better. She is very grateful for the support of her colleagues in the Victoria Chapter and has enjoyed helping new members there learn to cope.

As a result of working so closely with the hospitality industry and celiac customers in creating her site, Ellen has learned a lot about both. Here are some of her tips for increasing your confidence and getting a safe and delicious meal.

- Understand that people in the restaurant industry really do want to be able to welcome us and meet our needs.
- Realize that gluten sensitivity or celiac disease can make us anxious and emotional about eating out.
- Remember that it's not "their fault" that you have celiac disease.
- Work together for a safe meal; problems are usually the result of a breakdown in communication.
- Act as an ambassador for all celiacs by showing courtesy and appreciation for good food and service.