My Weekend at the Canadian Celiac Association (CCA) Conference

By Paul Clarke

I am 69 and have been a Celiac since the fall of 2002. My younger brother has been a Celiac for 12 years and our mother had Celiac but actually didn’t know it. This is my second celiac conference and I also attended a one-day seminar hosted by the K-W chapter in the winter of 2003.

GF101

The conference opened on Friday with a new concept called “GF 101”. This was a stand alone one-day seminar targeted at those who are new to Celiac Disease (CD) or wanted a refresher on how to deal with it. Of the 125 attendees, 4 had CD for more than 20 years while one quarter of the attendees were diagnosed within the past year.

The first part of the morning was GF Diet presented by Shelley Case, an authority on celiac disease and the gluten-free diet. Shelley covered a broad range of topics in her presentation. The prevalence of CD is in the order of 1 in 133 world wide, with a 1 in 22 chance of having CD if you have 1st degree relative with CD and a 1 in 39 chance from a 2nd degree relative. Her message was to make sure your relatives are aware that CD is hereditary.

Shelley reviewed the known sources of gluten and in particular, the issue of whether oats are safe or not. There is much work going on to provide a standard for oat producers to achieve in order to market pure oats. Oats are a good source of fiber.

Shelley discussed the nutritional value of several safe grains that can be used in a GF diet: amaranth (a weed), buckwheat (a fruit from the rhubarb family), flax (according to Shelley, a great roto-rooter and a source of Omega 3 nutrients when ground with a coffee grinder), Indian ricegrass (known as Montina™), mesquite (lots of fiber from the pods), quinoa (a fruit from the lambs quarter family), sorghum and teff (from Ethiopia, used in making wraps). This was a fast-paced but very interesting session.
Alexandra Anca, a dietitian who worked on our new Pocket Dictionary, talked about the current labelling laws in both the USA and Canada. There is a food code (CODEX Alimentarius) which was adopted in 2008 but is not binding on countries. Every country sets its own safe level of gluten. Although many countries allow 20 parts per million to be called gluten-free, Canada does not.

Alexandra also touched on things that could contain gluten like seasonings, modified food starch, hydrolyzed food protein, barley malt and malt vinegar. This was an interesting session with an abundance of info and tips.

Who ever said that a hotel couldn’t cook GF for the masses? We were treated to a GF buffet that was sooooooo good. Thanks to the Waterloo Inn and their chef.

Donna Washburn and Heather Butt are working on their fourth GF cook book and they excel in getting out the message about cooking GF. It was interesting to hear new tips and tricks from the last time I listened to them in Toronto. Things like:

- It’s not bread dough, it’s cake batter. Go ahead and mix the devil out of it.
- Let it stand 30 minutes and give it a longer baking time.
- Bake goods to an internal temperature of 200 degrees F.

This all made sense after experiencing bread making in a bread machine.

There is a lot of importance about organizing your GF cooking area, especially if you are ultra sensitive to gluten. Donna and Heather did a demonstration on how to prepare your ingredients with tips like, sifting those bulk bags of flours as soon as you bring them home, refrigerating quinoa and amaranth flour, and filling a measuring spoon and levelling it off. Their best tip was about how not to try and clean up spilled xanthan gum – it’s like mixing oil and water. It’s nice to know we celiacs have resource people like Donna and Heather looking out for our needs.

The final speaker, Bob Levy, is the Bob in Bob & Ruth’s GF Dining & Travel Club. They arrange holiday trips to all points of the world, both on land and sea. His message was quite simple - take charge of your diet while travelling. It’s a very personal diet. Take control of your eating by asking about the cooking facility. When you arrive at a restaurant, tell the receptionist that you have a “medically required diet”. He suggests that you ask to talk to the chef or general manager about the menu, don’t bother asking the server. You need the help of the chef in order to get a GF meal.

GF 101 reminded me a lot of the seminar that I attended back in 2003. A lot of information packed into one day that a family could attend, without having to plan accommodation etc. The audio-visual aspect was excellent and the room was quite comfortable. Thank you CCA for doing this.

**Saturday**

The CCA National Conference opened Saturday morning with over 400 attendees. The room grew to 3 times its size from Friday with 2 large projection screens. The 7 speakers on Saturday each presented a topic which was in their field and they were all interesting.

- Dr. Markku Mäki, a gastroenterologist from Finland presented “Diagnosis of Celiac Disease, Yesterday, Today and Tomorrow”
- Dr. Jenni Zelin, a family doctor from PEI presented “Celiac Disease in a Family Practice”
- Dr. Elena Verdu from McMaster University presented “Use of animal models for the preclinical testing of experimental therapies in gluten sensitivity”
- Marion Zarkadas, a Dietitian member of the CCA Professional Advisory Board presented “Living with a GF Diet – A Study in Progress”
- Dr. Mohsin Rashid, a pediatric gastroenterologist from Dalhousie University, presented “Learning from Patients with CD”
- Dr. Farid Mahmud, a pediatric endocrinologist from Toronto presented “Celiac Disease in Type 1 Diabetes: An Endocrinologist’s Perspective”
- Dr. Jocelyn Silvester, a pediatric resident from Winnipeg presented “Long-term follow-up of patients with Celiac Disease by Canadian Gastroenterologists”
As you can see, the topic range was quite varied. Some of the highlights that I found are as follows.

Dr. Mäki talked about CD in his homeland where 0.6% of the total population of Finland has been clinically diagnosed with CD and educating the medical field, he has seen a 25% increase in clinical diagnosis. He feels that by making use of genetics and blood testing, the increase could jump to 90%. Dr. Mäki was a very interesting speaker who definitely loved his work.

Dr. Zelin, who is a celiac, keeps celiac disease in mind when she sees patients. Since the PEI health system pays for a TTG blood test, she can use this without a burden on her patients. Her message was that the family doctors must sort out all the problems of a patient. Celiac Disease may not be the highest on the list of possible diagnoses.

Following these two speakers, Dr. Zelin, Dr. Mäki and Dr. Connie Switzer (chair of the CCA Professional Advisory Board) formed a panel. Jim McCarthy coordinated written questions from the floor and here are a few highlights:

- There are no guidelines for family doctors to follow in diagnosing families where 1 or more are already celiac.
- An interesting comment from Dr. Switzer was that Canada has 12 different health care systems and every province and territory does its own thing.
- The consumer must be aware of what is true and what is “snake oil”.
- The final message from the panel: be aware and be alert with regards to what you eat. The GF diet is OK.

Marion Zarkadas outlined the many hurdles that had to be crossed in order to get the latest survey out. Things like financing, approvals by Health Canada, translation into French, pre-test protocol, printing & mailing and entering data. 10,737 surveys were mailed and there was a 72% response rate. The survey will provide new data which will help increase awareness with the medical professionals, food service and manufacturing industries. It will also provide data for Canadian legislation on gluten labeling.

Dr. Mohsin Rashid said he considers himself a student of CD but is not a Celiac. His presentation was all about what can be learned from patients who are Celiacs. He talked about improving the awareness of CD with the Health Profession and thoughts on how to target them. The family doctor is the gateway to the health system and that gate needs to be opened. His teaching technique get the message out was to send case histories to student doctors with a follow up quiz.

Dr. Rashid closed with a quote from William Osler. “If you listen carefully to the patient, they will tell you their problem”.

Sunday

On the Sunday morning, Dr. Connie Switzer, chair of the CCA Professional Advisory Board gave an update on the board’s activities and especially the 13th International Celiac Symposium in Amsterdam. Dr. Switzer also touched on the research going on and the educational initiatives that the PAB are involved with. She also talked about the management of CD and that the GF Diet is the cornerstone. There are new tests being worked on and drug development to supplement GF Diet.

Jim McCarthy, our Executive Director, gave a presentation on the CCA Certification program for the GF symbol and “PAVENA” which would identify pure and uncontaminated oats. Jim spoke on the process of registering the trademark for the logo and how the logo will be used. Liz Kovacs, with the QMI certification body, described the requirements for a supplier, producer, or manufacturer to be allowed to use the logos. They must go through a very long and costly certification process. This process is similar to the ISO type certification that my company went through a few years ago. Questions from the audience raised the concern that cost is going to chase away small suppliers.

continued on page 6
When a chapter commits to host a conference two years in advance, you never know what is going to happen in those years. Despite an economic downturn, the H1N1 virus, and last minute cancellations from speakers and sponsors, the CCA 2009 conference was a success. The speakers, the exhibitors, Chef Lori, and the hotel staff all delivered more than we could have expected. More than 45 dietitians attended a training session with Shelley Case. Our chapter provided more volunteers than we had jobs for and our new GF 101 workshop was full to bursting. Thanks to the Victoria conference example, we were able to reach out to the community and give them a chance to connect with the CCA by visiting vendors and by handing them a shopping bag that included information about local and national activities.

We could not have funded the conference without the help of our generous sponsors:

**Gold:** 2G Pharma, Freybe Meats, El Peto Products, and Riceworks  
**Silver:** Pamela’s Products  
**Bronze:** Glutino, Kinnikinnick  
**GF 101:** Leslie Orser, A Celiac is Coming

Our vendors were generous with their samples and their donations to the conference. They handled the influx of almost 600 members of the general public with smiles and answers to every question. Links to all the vendors can be found at www.kwceliac.org/conference2009.html
We said we there to learn ... Panelists Peter Kokkovas (Judy’s Magic Mixes), Elisabeth Riesen (El Peto Products), Jerry Bigam (Kinnikinick Foods) and Shelley Case (CCA Professional Advisory Board) gave us an excellent economics lesson about why gluten-free food costs so much.

and to work ... Chapter delegates vote on a motion at the CCA Annual General Meeting on Saturday afternoon.

but we were really there for the food! Delegates finish another hors d’oeuvres platter at the Friday evening reception.

We can’t wait to meet again in Winnipeg. June 4-6, 2010.

Thank you to Joan Tuckey of Edmonton for the conference photographs. For more images of the conference, please visit: http://tinyurl.com/JT-CCAPictures
The final activity on Sunday was an excellent panel discussion with representatives from Judy's Magic Mixes, El Peto, Kinnikinnick along with Shelley Case. Jim McCarthy again fielded questions and entertained comments from the floor.

Some of the points that were given by both the panel and attendees were:

- Gluten-free ingredients cost 4 - 10 times more than “regular” ingredients.
- Transportation is a big part of the cost of gluten-free food.
- Consider buying products from a GF property, not just a GF line
- Manufacturers must spend time teaching employees about gluten free and allergens
- Customers want more than just gluten free, including dairy free, nut free, egg free, soy free.
- The cost of packaging and listing nutritional facts has risen a lot, as has the cost of testing products and ingredients for gluten.
- Legislation changes that require new labels are a big expense.

Mid-west Regional Director Barb de Haan summed up the GF food discussion perfectly:

A box of gluten-free cookies - $4.95  
A loaf of gluten-free bread - $6.95  
A gluten-free pie - $8.00

Healthy enough to work, play, travel.  
No sick days. 
No hospitalizations. 
No weekly doctor’s visits. 
No medications. 
Priceless

Gluten-free food may appear to be expensive, but it is cost effective when you realize what you get in exchange—peace of mind, health and thus quality of life.

---

**Make your plans for next year**

The Manitoba Chapter is very pleased to have been selected as the host for the 2010 National Conference for the Canadian Celiac Association.

The conference will be held June 4-6, 2010 at the Victoria Inn, 1808 Wellington Avenue in Winnipeg.

The keynote speaker will be Dr. Joe Murray of the Mayo Clinic. The full schedule and conference information will be available on the chapter website (www.celiac.mb.ca) and registration information will be included in the November edition of Celiac News.

For more information, check the Manitoba chapter web site:

[www.celiac.mb.ca](http://www.celiac.mb.ca)