

Newsletter of the NL Chapter of the CCA

DISCLAIMER AND EXCLUSION OF LIABILITY:

The contents of this publication, provided in good faith for information purposes only and using the most current information available, should not be used as a substitute for the advice of a qualified health professional. The Professional Advisory Board of the Canadian Celiac Association (the "CCA") has not reviewed this publication. Use of the information in this publication is at your own risk. The CCA does not endorse any product referenced in this publication. To the fullest extent permitted by law, the CCA, its local Chapters and all persons involved in compiling this publication disclaim any responsibility for, and make no representations or warranties regarding the information provided in this publication. In no event will the CCA, its Chapters or those persons involved in compiling this publication be liable for any damages of any kind resulting from the use of the information in this publication. Please review the CCA's disclaimer policy on its website at <http://www.celiac.ca>.

CCA National Conference (St. John's) Summary

A four-page supplement summarizing the presentations at this year's National Conference begins at page 5.

President's Message

A belated Happy Thanksgiving to all! I am very grateful for a number of things this year, but especially the success of the National Celiac Conference this summer! I am especially thankful for:

- The help and support from the conference planning committee.
- The leap of faith that National took to let a small Chapter host the National Conference, along with their financial backing so it could happen.
- The support of my family and friends as I was away from home for meetings and conference calls necessary for the conference to succeed.
- The realization of a full Chapter executive team.

By the time you read this newsletter Thanksgiving will be long over, but for future reference have a look at this website for some non-traditional stuffing ideas. <file:///Users/LisaDooley/Documents/recipes/Tasty%20gluten%20ofree%20stuffing%20recipes.webarchive>

Our Chapter appears to be very strong and continues to offer various activities for our local members (see the *Upcoming Events* panel, p4). As always, we welcome your feedback as to what topics you want at our local meetings.

I am just back from a trip to Happy Valley-Goose Bay, where I was delighted to be able to order a gluten-free supper of cod tongues with home made fries, salad and vegetables at *Bentley's and Maxwell's* restaurant. If you are going to travel to Labrador, check out their website here for more gluten-free options: http://www.maxwellsandbentleys.ca/bentley_s_restaurant

Finally, a big thank you to Mr. Ray Druken, one of the vendors from our Gluten-Free fair at the National Conference, who has compiled a list of all *Bonte* gluten-free products that can be found provincially in Dominion and Sobeys stores. The list should be on our Chapter website soon.

Wishing you and your families a great Fall,

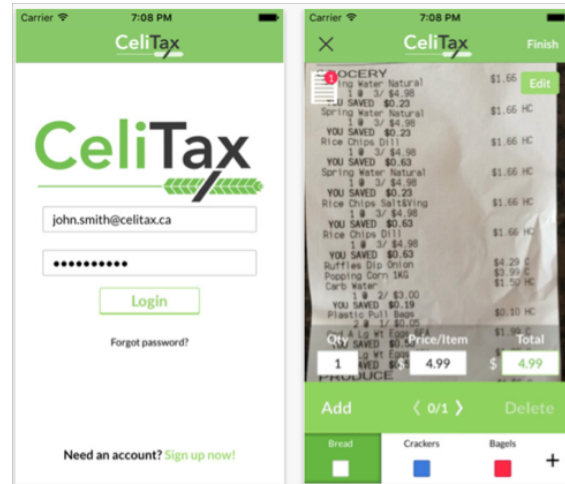
Lisa Dooley, President
glutenfreenuggets@outlook.com

Ontario Man Creates App to Track Gluten-Free Purchases for Tax Credits

Burlington-based chartered accountant Justin Gravelle, has developed a mobile app that lets those with celiac disease keep track of receipts for gluten-free (GF) products for a tax credit. The 24 year old's girlfriend, Rachel, was diagnosed with celiac disease during their college days. When she began her GF diet she wanted to take advantage of the GF tax credit, but keeping track of all purchases throughout the year was not easy. So to help her, and others, track their everyday GF purchases Gravelle developed and released the CeliTax app for iOS, with an Android version coming soon. The app digitizes receipts and stores them, allowing users to review or download them at any time.

Sue Newell, operations manager for the Canadian Celiac Association, agreed that the tax credit can be frustrating for people coping with celiac disease.

GF items are typically three to four times more expensive than regular items with gluten.



Individuals with celiac disease are entitled to the incremental cost difference between GF and non-gluten free products but tracking things can be a hassle.

The app is available as a free download in the App Store, <https://itunes.apple.com/ca/app/celitax/id1043703929?mt=8>

Adapted from Hamilton/Burlington Summer/Fall 2016 Newsletter

Insects for Gluten-Free Flour?

Many of the alternative flours used for gluten-free (GF) baking lack the nutrients of wheat flour, which in Canada is fortified with vitamins and minerals. For a long time the CCA has suggested that celiacs take a daily multivitamin. Fortunately, our flour choices are broadening. Teff, soy, lentil and quinoa are just some of the readily available GF flours that pack a nutritional punch.

But in many countries around the world the consumption of insects is commonplace, and accepted as a regular part of a healthy diet. Jarrod Goldin, president of Entomo Farms, is working to change the North American aversion to consuming insects.

“If you want your relationship with food to be one where the food you eat enhances your life, enhances your

wellness and helps you live longer, then you should consider insects. And at the same time they help the planet,” he says.

Bugs have all nine essential amino acids and 30 times more B12 than does beef. They also emit fewer greenhouse gases and less ammonia than cattle or pigs, and need significantly less land and water than cattle rearing. They're also GF.

Entomo Farms houses approximately 90 million crickets at any given time. When ready, they are put to sleep, frozen, and afterward are left whole or ground into a very fine powder, or flour, which can be used in a variety of foods, like energy bars, chips, cookies, pasta, bread and smoothies, greatly enhancing the nutritional value of these foods. Roasted crickets or mealworms can be sprinkled on salad like croutons.

Adapted from article in Calgary Celiac News September 2016 original source: The Associated Press

CCA Restaurant Program

The Allergen Control Group is working with CCA and Fondation québécoise de la maladie coéliquie (FQMC) to create the Gluten-Free Food Program. It is scheduled for a “soft roll-out” with certain pilot locations as of July 1, 2016.

The program has 2 components:

- GF Smart (food service training for individuals – a two-hour online course)
- GF Verified (for restaurant establishments), including documented process and annual third party verifications.

The course is accredited for Nutrition Management Society members. Registering for this program will demonstrate a restaurant’s commitment to specific protocols and verifications.

Being gluten-free is about managing risk. Restaurants are higher risk than cooking at home, but this program can help to narrow that gap.

The specific requirements of the program will vary by restaurant, depending on its type. The current course is an overview. The CCA may look at adding specific modules for seniors’ homes, caterers, etc., for a more targeted experience.

Once the program gets underway, a GF Verified List of restaurants will be provided via the CCA website. CCA members can be ambassadors for this program. We all want to be able to dine in safety, so advertise the program and ask your favourite local restaurant to register. Bring them the information they need and support restaurants



These images are copyright and cannot be used without the explicit permission of The Gluten-Free Food Program Inc.

that have made the investment in this program by eating there.

The CCA will be working on awareness as well. We are hoping to get the program into the industry via trade associations and other key contacts. Work is already underway.

This program is just the latest initiative of the CCA and helps us get closer to its mission, which includes improving the quality of life for all Canadians with a “gluten problem”.

Edited and adapted from an article in the Kitchener Waterloo Chapter Newsletter August 2016

Notice about GF Cheerios

The Canadian Celiac Association (CCA) recommends that people with celiac disease or gluten sensitivity DO NOT consume the gluten-free labeled *Cheerios* products at this time because of concerns about the potential levels of gluten in boxes of these cereals. For the full CCA statement go to http://www.celiac.ca/b/wp-content/uploads/2016/08/CCA_Statement_on_Cheerios.pdf

Upcoming Events

Membership meeting: November 8, 7-9 pm Old Cafeteria conference room Miller Centre.

Sobey's Cooking Class(es) (Possible): dates to be determined.

Christmas Dinner: December 16th at *Hungry Heart* café. An email of the menu & prices will be sent out during the last week of November.

The Last Word

Whether at home or away, eating safely is a constant concern for those of us with celiac disease, and for those with non-celiac gluten sensitivity. At home we have a large degree of control over what we eat and can easily check the labels of anything we buy. Eating at a friend's house one has somewhat less control and it still surprises me that my hosts don't take offence when I ask to read the label on something they are offering.

We feel we have least control when eating at a restaurant, and the advice to "get to know" your favourite local eating establishments is sound. The biggest problem is when travelling, so the imminent launch of the CCA's restaurant program (see p2) is welcome news, provided one is travelling within Canada. Within a few years we should be able to feel confident that the restaurant displaying one of the "Smart" or "Verified" stickers is safe for us.

But travelling outside of Canada can still be worrying, although my experience in Europe has been very positive, and even in Nepal I was pleased to find that in one of the tourist areas in Kathmandu the local supermarket had a small selection of gluten-free (GF) products. But how long it will be before a restaurant GF program is world wide is anybody's guess, and my guess, for what it is worth, is that it will be very many years.

Travelling in another country is challenging enough. Travelling in one where English is little understood is even more worrying. Fortunately there are websites from which one can download travel cards in a variety of languages for presentation to restaurant staff. (See *Gluten-free Globetrotter*, p6). I can personally attest to their usefulness, although don't be surprised if further clarification is needed.

I was in Italy this summer, and as I had read somewhere that Italy has one of the highest prevalences of celiac disease in Europe I didn't anticipate a huge problem. Nonetheless, I carried an Italian restaurant card. I know very little Italian but could tell that it stated that I had gluten sensitivity, etc. The first waitress to whom I presented the card studied it for what seemed an age before asking me, "Celiac?". I confirmed that, yes, I had celiac disease, and understanding dawned. It may have been just the area I was in, but "celiac" seemed to be better understood than "gluten sensitivity."

With the CCA Restaurant Program on its way, and with a choice of restaurant cards in so many languages, we're all going to be able to eat out with more confidence, almost wherever in the world we are. Bon Appetite.

Mervyn Dean, Newsletter editor

CCA National Conference 2016 Summary Supplement

(Adapted from Hamilton/Burlington Summer/Fall newsletter, and document from Mark Johnson & Judy Campbell)

During June 24-26, 2016, nearly 200 people from across the country converged on St. John's for *Waves of Change...Oceans of Possibility*, the first CCA National Conference to be held in Newfoundland and Labrador. By all accounts, it was very successful.

Dr. Daniel Leffler (Celiac Centre at Beth Israel Deaconess Medical Centre, Boston) said that we are seeing more celiac disease now than in the past for two reasons – the methods of diagnosis are better, and there are more people with celiac disease. However, even better awareness is needed as there are still many not diagnosed.

Although celiac disease is better understood than other auto-immune diseases (it is not an allergy, or an intolerance – it is an autoimmune disease and needs to be treated as such) there are a lot of misunderstandings. The three top myths are that celiac disease is rare, not a serious condition, and the gluten-free diet (GFD) is a perfect treatment. Celiac disease is NOT a food allergy but a multi-system immune disorder, taking an average of ten years to diagnose. Currently, in North America, most people on a GFD are not celiac, and most people who are celiac are undiagnosed and eating gluten.

Non-celiac gluten sensitivity (NCGS) has received significant interest only in the past 5 years, and various theories have been tested. Some patients may be reacting to Fermentable Oligo-, Di- and Mono-saccharides, and Polyols (FODMAPS), or to amylase trypsin inhibitors (ATI's), a protein in modern wheat, rather than to gluten. For these people, the gluten-free diet is an imperfect treatment. What is the difference?

Celiac disease is a chronic intestinal immune-mediated enteropathy precipitated by exposure to dietary gluten in genetically predisposed individuals.

Non-celiac gluten sensitivity (NCGS) relates to one or more of a variety of immunological, morphological or symptomatic manifestations that are precipitated by ingestion of gluten in people in whom celiac disease has been excluded.

The gluten-free diet is viewed as one of the most difficult, apart from the ESRD (kidney failure) diet. A GFD is not always the end of the story. 10-30% of celiac patients have persistent symptoms despite doing everything “right” and not everyone's intestine heals completely. For those who are older, there is only a 50% chance of healing completely. In children, the figure is around 80%. For adults who do heal completely, the process can take 2-3 years.

A number of therapies are being studied to improve the lives of those with celiac disease – those that work somewhat like lactaid to keep gluten out of the mucosa; immune-suppressants; and immune therapies, to help reverse and restore immune tolerance.



Expert Panel: Dr. Jenni Zelin; Dr. Jeff Critch; Dr. Anne Lee; Dr. Daniel Leffler

Photo: Nancy Dawson

Dr. Jeff Critch (Pediatric Gastroenterologist, Memorial University) said that diagnosis in children starts with a high index of suspicion - for example, one of the commonest causes of short stature in children is celiac disease - followed by a blood test. If the tTG level is elevated and the child has the HLA-DQ2/DQ8 genes a biopsy may not be needed. Treatment is not just the GFD. Monitor growth & adherence to diet, assess the psychosocial and financial impact, screen family members and, as the child grows, teach them how to manage their illness.

Dr. Anne Lee (Nutritional Services Manager, Dr. Schär USA) told delegates that there are many naturally gluten-free (GF) foods, such as fruits and vegetables, meat and fish, etc., but overall the GFD tends to be heavy on rice, and has poor overall nutritional quality. Even when the gut heals, there may still be nutritional deficiencies. GFDs tend to be lacking particularly in calcium, iron and magnesium and many GF products contain more sugar, salt and fat than their regular counterparts.

People needing a GFD should diversify their diet to include more nutritious grains, such as soy, millet, quinoa, amaranth, and also consider taking supplements, as the GF diet is not always nutritionally adequate. Calcium/magnesium, iron, fatty acids, fat-soluble vitamins (A, D, & E), and B complex are often low. A multi-vitamin can address these deficiencies, but should be age and gender specific.

To improve the diet, foods with more fibre should be added, but best to do so slowly.

Dr. Donald Duerksen (Associate Professor of Medicine, University of Manitoba) explained that celiac patients have a 1.37 increased risk of major fracture because of decreased bone mineral density (BMD). This is for two reasons: malabsorption resulting in lack of necessary nutrients for healthy bones, such as calcium



Dr Anne Lee speaking to the Conference Delegates

(Photo: Nancy Dawson)

and vitamin D; and inflammation caused by celiac disease that has a negative effect on bone health. The good news is that many with celiac disease will see an improvement in BMD scores as early as one year after maintaining a GFD. Celiacs should ensure adequate amounts of calcium and vitamin D, and discuss the need for medication with their doctor.

Dr Jenni Zelin (Family doctor, Charlottetown, PEI) brought delegates celiac disease from the perspective of a family physician. When a family physician sees a patient who has what seems to be classical celiac disease symptoms, it could also be a wheat allergy, IBS, a FODMAP intolerance, lactose intolerance, or stress-related physical ailments. It is important to understand that the doctor wants to find out exactly what it is the problem - so don't walk in telling the doctor it's celiac and refuse to listen to any other possibilities!

She strongly recommends bringing the new CCA document, *Follow-up Management of Patients with Celiac Disease*, to your family doctor. It is a two-page document - a fast read - and can be downloaded easily from the CCA website (www.celiac.ca).

Erin Smith, The Gluten-Free Globetrotter ([facebook.com/GlutenFreeGlobetrotter](https://www.facebook.com/GlutenFreeGlobetrotter), gfglobetrotter@gmail.com) gave many useful travel tips and suggested the following GF travel resources:

- CeliacTravel.com (have travel cards in many languages for you to bring to restaurants)
- SelectWisely.com (have travel cards as well, but at a cost)
- Bob and Ruth Travel Club
- Jovial Food Culinary Getaways (Italy) Villa
- Bien Cuit GF at Savoir Faire Chalet (France)
- OpenTable will make your reservations with allergy considerations
- Finding GF App
- Yelp
- TripAdvisor (good for finding where to eat and where not to)

She also provided several tips such as keeping handy snacks like roasted chickpeas, travelling with ziplock bags, and using hotel room coffee pots for boiling water to make hot cereal.

Erin gave a shout-out to Arenas del Mar in Costa Rica, which reportedly is very celiac friendly and makes for a great winter getaway.

Dr Elena Verdù (Associate Professor, Division of Gastroenterology, Dpt of Medicine, McMaster University) spoke about celiac disease research. We can be thankful that more is known about the mechanisms of celiac disease than any other autoimmune or chronic gastrointestinal disorder (including IBS/IBD).

In terms of potential treatments, Dr. Verdù warned that their aim is to use them in addition to – not in replacement of – the GFD. Once finalized, all treatments could possibly be given together at the time of a celiac diagnosis because damage can take up to five years to resolve on the diet. Treatments could prevent adverse consequences of accidental contamination and reduce the anxiety of potential contamination.

To give a run-down of many of the potential treatments:

- Polymer treatment to sequester gliadin. Bioline Rx has gone through phase 1 studies with mice (CCA funding helped to support this Canadian research).
- Oral proteases (enzymes) studies not successful so far due to problems keeping enzymes active in the intestine, but there remains potential – more research is required.
- Optimizing microbiota (gut bacteria) with probiotics to produce enzymes to breakdown gluten, or a combination of pseudomonas and lactobacillus.
- Larazotide acetate to decrease tight junction leakability (decrease space between the cells). This is going into phase 3 clinical trials so should be available soon, if efficacy is shown in this last trial.
- Anti-IL-15 cytokine (key player of innate immune response).
- Vaccine Nexvax2 in phase 1 trials, involves re-educating the immune system, similar to peanut allergy research and treatments

In terms of diet, she highly recommends fermented foods – good for many reasons. She warned the audience about products such as “Gluten Cutter”, purported to digest gluten. These are simply amylase, which breaks down starch and not protein such as gluten. These products are “ridiculous”, she said. As we know, you have to be careful even with naturally GF grains. They are frequently contaminated, with the most contaminated being millet, buckwheat, sorghum, and soy. Stick to brands with gluten-free markings.

David Graham (Executive Director of Brigadoon Village, Camping Canada) spoke to the conference about Camp Silly-Yak, an exciting GF camping experience for children in the Maritimes. The main purposes of Camp Silly-Yak are to show children they are not alone, to give them things they can't get anywhere else (pasta, pizza, cake, cookies, etc.) and to show them how to cook things themselves. To learn more, please visit <http://brigadoonvillage.org/camps/summer-camps/celiac-camp>.

Sue Newell (Operations Manager, Canadian Celiac Association) brought us news on the latest CCA projects.

1) The Gluten Free Certification Program (GFCP) continues to expand. It is a comprehensive food safety management system that certifies food production facilities (not products). Once a company has achieved the required status and standards, they can use the Gluten-Free Certification Logo. Facilities are audited on an annual basis. The program is becoming an international model for a GF food safety standard. A huge accomplishment for the CCA.

2) The CCA is working on a program to ensure safe, GF grains, looking at putting procedures in place to assess reduction in contamination throughout the grain handling process. \$500,000 from the Government of Canada to support this project was announced at the conference. A stakeholder session was scheduled to take place in September in Toronto.

Grains are often allowed to have 2,000 - 5,000 parts per million gluten but celiacs need <20 ppm for safe, GF food, so a new system is required. Testing for gluten is very different in cooked versus uncooked products, solid versus liquid, wheat versus barley. The new sampling and test protocols will be setting a world standard.

3) The Allergen Control Group is working with CCA and Fondation québécoise de la maladie coéliquie (FQMC) to create the Gluten-Free Food Program (see p3).

Stacey Andrews' (Registered Dietitian, Sobey's) presentation was a good orientation session for any newly-diagnosed celiac and a sound refresher for the rest of us.

Are you changing a recipe? Do so one ingredient at a time, so you can keep track of what worked and what did not. Make sure



One of the Gluten-Free Market Displays

Photo: Nancy Dawson

you measure properly – use level amounts, not heaping. Mix dry ingredients very well. Add liquid ingredients at room temperature, or slightly warmed – not cold. Do not overmix when combining wet and dry ingredients. To get better results, chill your dough/batter for about 30 minutes before baking and ensure your pan is in the middle of the oven to promote even baking. If you're not serving your creation right away, wrap the product well while it is still warm and store it in the freezer – this will help preserve the moisture.

Try mixing three or more flours to get the best results, keeping in mind the properties of the different flours:

- Whole grain flour (crumbly texture)
- Bean flour (strong flavour)
- Nut flour (requires more liquid or fat)
- Starch flour (helps with cohesion)

Consider non-traditional baking ingredients such as dates, beans, legumes, ground flax and chia.