

VICTORIA CELIAC NEWS



Serving Vancouver Island and the Gulf Islands

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Join the executive and help shape the future of our Chapter
Jobs of all shapes and sizes are available:

- President
- Vice President
- Event Planner

- Monthly Restaurant Visit Co-ordinator
- Monthly Advisor at Market on Millstream
- Chapter events tea/coffee maker

The choice is yours -- all of these exciting possibilities are available. We need your help.

Contact: Christine Rushforth at crushforth@shaw.ca for job descriptions and encouragement.

CELIAC SUPPORT MEETING

Lifestyle Markets,
2950 Douglas St., Victoria
Tuesday, February 10, March 10,
6:30 to 8:00.
Meet in front of the deli case.
Contact: Anne Sherber 250-920-6444

SHOPPING TOURS

MARKET ON MILLSTREAM,
125-2401C Millstream Rd.
Wednesday, February 25, March 25,
6:30 to 8:00
Meet in the coffee area
Contact: Erin or Kathryn in the
Self Care aisle.

A NEW YEAR OF CHAPTER EVENTS

Saturday, March 21, 2009 at 2:00 p.m., St. Aiden's Church Hall, Victoria.
Victoria Chapter AGM and Bread Making demonstration by cookbook author Cathy Lauer, Cathy's Gluten Free Creations Ltd. Opportunity to buy Cathy's Gourmet Gluten Free Baking cookbooks and baking mixes. Brush up your bread-making skills.

Saturday, March 21, 2009 Nanaimo Support Group Encore Presentation of the TGIF Dr. Fasano and Shelley Case presentations on DVD recordings. See page 7.

Saturday, March 28, 2009 14th Annual Family Health and Wellness Fair. See page 7.

May 29-31 National Conference in Waterloo, Ontario. See page 6.

IN THE WORKS

Saturday, June 20, 2009 -- Trip to Salt Spring Saturday market and Laughing Daughters GF Bakery stall. Remember the glorious day we enjoyed last year?

August -- Annual Picnic, host to be sweet-talked and date to be confirmed.

From the President's Desk

This is my 10th year as newsletter editor. I took over from Mike Rose in 1999 at a time when Mike was wearing all the chapter hats -- president, newsletter editor and events organizer. Mike passed on the torch of president to Carol Newhouse that year and passed the responsibility of the newsletter to me. Mike went on to greater things as Regional Director.

With six newsletters a year, I often think I'm going to be short of articles and it will be a dreary issue, but then I get wonderful, well-written contributions from members that entertain and inform readers. Keep them coming!

It has been an exciting 10 years in a job I love and I will keep on doing it until someone wrenches the computer away from my grasp.

Having said that, it is time for me to pass on the responsibility of the president's job to fresh blood. So at the AGM on March 21 I will be stepping aside for a new president to pick up the gavel and lead our chapter. I've been in the president's role for 3 years now and it has been an honour to represent you at meetings and conferences and get to know you on a more personal basis. The executive team has been a tower of strength and the whole chapter showed its mettle during the conference. What a team we are!

The job of vice president will also become vacant. Heather Sutherland has done an excellent job as vice president but feels she is ready to step aside to devote more of her energies towards producing a 2010 calendar. The 2008/2009 calendar was such a resounding success that she is fired up to repeat her achievement.

TGIF donation to national

I forgot to tell you in the last issue that, as is customary, we had sent a cheque for half our conference profits to the national office for their use in running our organization. The cheque for \$8,765 was gratefully received and the acknowledgment from Executive Director Jim McCarthy said: "You, your conference team, and all the volunteers with the Victoria Chapter, should be proud of the resounding success of the conference".

National President Janet Dalziel also sent a gracious card. She said: "I hope the Victoria organizers and volunteers are proud to know that many of the innovations from TGIF will be retained for further conferences. On behalf of the national board of directors, I salute your drive for excellence and thank you for all your efforts. It was an enormous investment of time and energy and the result was spectacular."

Is gluten free the flavour of the month?

One of the less desirable aspects of the growing awareness about the gluten free diet is the proliferation of misinformation floating around in the news and "sound bites" about gluten free as the new cure-all diet.

A recent **CBS** broadcast described gluten free as "the latest diet craze" that was creating a "feeding frenzy" amongst GF producers. Telling us that even Oprah was on a gluten free diet to lose weight and making statements confusing a gluten allergy with celiac disease, these news clips are not making it any easier for those of us with celiac disease. We are not eating gluten free because it is the latest "fad diet" or a "lifestyle choice" but because it is a medically necessary treatment.

There are more examples of less than accurate news items. I expect you have seen them too.

Fortunately, authoritative experts are also getting coverage. A December issue of **Chatelaine** featured an article by Shelley Case under their *Ask an Expert* section.

And, Dr. Fasano's clear explanation of the difference between gluten allergy and celiac disease was covered in the **Baltimore Examiner** -- see this article on page 13.

Legitimate research sometimes needs an explanation too and Dr Connie Switzer provided us with her response to new research at the University of Edmonton about celiac disease and eggs. See page 21.

And sometimes things just get too confusing altogether. Beth Armour sorts out the **ppm** conundrum see page 11.

But, if all you really want to do is settle down with a nice cup of tea and a sandwich then read Margaret McKenzie's article about making the perfect gluten free sandwich -- see page 5.

Christine

Our online version of this newsletter on our website www.victoriaceliac.org is password protected.
CCA members and advertisers have been emailed the password.

AN EXPERIENCE TO REMEMBER

It has been a fantastic experience for me involving myself in the activities of the Victoria chapter for the last two years. My first project was, of course, the Celiac Lifestyle Calendar, which took a whopping eight months and a whole lot of help from our great Advertising and Sponsorship Co-ordinator, Ellen Bayens. It was an incredible learning experience and I never expected that I could be a part of such a satisfying contribution. When we launched our calendar at Lifestyles Markets during October Awareness Month, 2007, it was extremely well received. Our second calendar project is currently on my drawing board....look for it in September 2009!

I have great memories of planning events, going to our Annual Picnics, sojourning over to Saltspring Island this past summer to feast at the Laughing Daughters' Bakery, and attending the executive meetings. For the Christmas Potluck in November 2007, I brought my Pringle Bells choir to give a musical recital to you all, and we just loved the privilege. Last May, at the Victoria TGIF Conference, I earned the illustrious title of Bag Lady as I organized 30+ volunteers to stuff 500+ delegate bags. I recall someone asking me "Heather, what do we do?" and replying "I don't know, I haven't thought about it..." I also recall all the great help the volunteers gave to get the job done. Thanks, everybody!

It's time now for me to stand down as vice-president. I shall remain an active member of the Association.

Heather Sutherland

Editor, the Celiac Recipe Calendar 2010 (until I can come up with a better name!)

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BREADS * BUNS * BAGELS * MUFFINS * DONUTS * PIZZA CRUSTS * WAFFLES * COOKIES * MIXES

SHELLEY CASE DVDS PROVIDE USEFUL INFORMATION

Our Chapter meeting on Saturday, January 24 was attended by a small but attentive group who clustered around the TV to watch the two Shelley Case DVDs.

Members said they learned a lot:

Just a quick note to say how much I learned from the meeting on Saturday. I find it so worthwhile to attend these meetings and the evening meetings put on by the Celiac Association. I would have been lost without the help and encouragement I have received through the association and talking to other members. Thanks again for all that you do.

Bev Turkington

GF Chicken Sausages

During the tea/coffee break we enjoyed gluten free chicken sausages from **Island Farmhouse Poultry**. They were a treat!

We really appreciated Sales and Marketing Manager, Marlene McLean, making it to our meeting at very short notice and loaded with trays of hot sausages for us to try.

Marlene says their facility at Cowichan Bay is completely gluten free and all their sausages are gluten free too. You can buy these sausages at Country Grocer. Look in the freezer section. They are very delicious!

www.farmhousepoultry.ca

Has your CCA membership lapsed?

Don't miss out on the considerable benefits of membership.

Invest in your own health, you're worth it!

If you are not sure of your membership status call the CCA National office to check or renew by phone at 1-800-363-7296.

Nutritious Cookies

We enjoyed some nutritious cookies during our tea break at the meeting. I was asked to reprint the recipe in the newsletter, so here it is:

Crunchy Flaxseed Cookies

from The Best Gluten-Free Family Cookbook, Donna Washburn and Heather Butt (page 129)

Preheat oven to 350°F. Lightly grease baking sheets

- 1/3 cup sorghum flour
- 1/4 cup whole bean flour
- 1/4 cup tapioca starch
- 1/4 cup ground flaxseed
- 2/3 cup cracked flaxseed (I put whole flaxseed through the blender until it was the right consistency)
- 1 tsp baking soda
- 1 tsp xanthan gum
- 1 tsp salt
- 1/2 cup butter or shortening softened
- 1/2 cup packed brown sugar
- 1/3 cup granulated sugar
- 1 egg
- 1/2 tsp vanilla
- 2/3 cup of buckwheat flakes (you may have trouble getting these)

In a medium bowl, combine sorghum flour, whole bean flour, tapioca starch, ground flaxseed, cracked flaxseed, baking soda, xanthan gum and salt. Mix well and set aside.

In a large bowl, using an electric mixer, cream the butter, brown sugar and granulated sugar until combined. Add egg, vanilla and cream until light and fluffy. Slowly beat in the dry ingredients until combined. Stir in buckwheat flakes. Roll into 1 inch balls. Place 2 inches apart on prepared baking sheets and flatten with a fork or the bottom of a drinking glass.

Bake in preheated oven for 10-15 minutes or until set. Remove from baking sheets to cooling rack immediately.

Donna and Heather's recipes are always a hit. I have all three of their cookbooks and use them frequently.

Christine

BUILDING A HEALTHIER SANDWICH -- Margaret McKenzie, RD

Yes you read that right. I said SANDWICH! Just because we cannot tolerate wheat and some other grains that commonly make up those things others like to eat for lunches doesn't mean we can't still enjoy our version of a sandwich. They are delicious, nutritious, scrumptious and great for the brown bagger.

Your first step of course is to find yourself a good purchased or homemade gluten free bread that will hold together long enough to make and eat a sandwich. I make my own "buns" in 3 inch rings and then just slice once through the middle on the horizontal and I have a great surface for sandwiches. I tried one this week and had forgotten how good a well made sandwich can be.

Start with whole grain – this is true for all bread choices – gluten free or not. If you are still attached to white rice bread – get over it. You may as well eat sawdust – both for flavour and health. Your best choice would be gluten free bread made with a brown rice and bean or soy flour mix. There is some fiber and good nutrients in these flours but there is nothing left in most white gluten free flours like rice, tapioca and potato starches. Fiber rich breads keep you feeling full longer, stabilize blood sugars and help maintain your energy for your days work. You could try corn tortillas for a wrap if you're really brave.

Spread wisely: A healthy spread is key to making a delicious, nutritious sandwich. Choose lower fat condiments such as relish, ketchup, mustard, low fat mayo, or barbeque sauce. Add zip with tzatziki hummus,

bean dip, guacamole, chutney, salsa or your favourite low fat salad dressing.

Add lean protein: Fill your sandwich with a lean source of protein such as canned salmon or tuna, shrimp, poultry, lean beef, beans or veggie burgers. Try to avoid deli meats. They can be quite lean but they are usually loaded with salt. If you want to try them ask for the amount of sodium in each and choose the least. Try nut butters such as almond butter, peanut butter and tahini. Go easy on cheese but if you want that look for cheese with less than 20% MF.(milk fat). Try strong flavoured cheese such as Asiago or Swiss so you just need a bit to punch up the flavour of the whole sandwich.

Load up on veggies: Boost the nutritional value of any sandwich with the freshness and crunch of vegetables. Add the classics such as lettuce, tomato and onion or try some new ideas like red pepper, shredded carrot, sliced cucumber or zucchini, sprouts, spinach or apple and radish slices.

Then sit back and enjoy a real sandwich again. Here is an easy gluten free flour mix to use in your next bread recipe.

1 part low fat soy or bean flour; 1 part brown rice flour; 1/3 part tapioca starch.

Sift together and use as an all purpose gluten free flour. It is healthy and works in most recipes. Happy gluten free eating! *Margaret McKenzie*

SIDNEY HEALTH FAIR

Our presence at the **Sidney Health Fair** on January 11 - 12 was a formidable one with a crack team of volunteers from the Victoria chapter of the CCA! We set up at the Mary Winspear Centre in Sidney, armed with plenty of celiac disease leaflets. **Kathleen Shoemaker, Lorna Rizzie, Heather Sutherland, Sandra Fraser, Sheila Howlett, Shirley Bond** and our guest from the **Osteoporosis Society, Margaret Woodlock**, all showed up in force. Throughout the weekend, we talked to people, handed out leaflets, gave out tasting samples of gluten-free products to children and adults alike, and practically threw recipe calendars everyone's way as though we were Sowing Seed! Our booth was extremely well received and we heard no end of stories that started out with "I know somebody who has a bunch of symptoms he can't figure out..." or "My mother-in-law's friend just found out she is celiac..." so it only confirmed our belief that there is a real need for the Victoria chapter's continued presence at local Health Fairs.

There were also a lot of people who said "I'm sort of allergic to gluten some of the time but not always" which gave us an opportunity to teach them that it's not possible to be only a little celiac.... You either are, or you aren't.

Continued on page 7.....

CCA National Conference Coming Up

It's time to make your travel plans for the 2009 CCA Annual Conference, May 29-31 in Waterloo, Ontario.


The conference program is jam-packed. The problem of identifying people with celiac disease will be one of the main topics, addressed by Keynote Speaker Dr. Markku Mäki, developer of the Biocard Home Test for Celiac Disease, and by gastroenterologist Dr. Houda Ergaiey and family physician Dr. Jenni Zelin, who both face this challenge in their everyday practices in Canada. Other speakers will comment on ongoing medical care for people with celiac disease and on the issues of manufacturing GF food.

The program also includes reports on CCA-sponsored research projects from J.A. Campbell Research Award and J.A. Campbell Young Investigator winners. Marion Zarkadas of the CCA Professional Advisory Board will bring us some preliminary results from the Living with a Gluten-Free Diet Survey distributed to all CCA members.

A new feature of the conference this year is an optional Gluten-Free 101 seminar offered on Friday before the main conference begins. This seminar was created for people who are fairly new to the GF diet, but it would also be a useful refresher for people who were diagnosed with celiac disease a few years ago. We have an expert panel of speakers for this event: Shelley Case explaining the GF diet; Alexandra Anca, principle researcher on the Pocket Dictionary, talking about reading product labels; cookbook authors Donna Washburn and Heather Butt making GF baking easier; and Bob Levy of Bob & Ruth's GF Dining & Travel Club offering tips on eating safely in restaurants. This GF 101 conference is not included in the full conference registration – look for the GF 101 option on the registration form if you want to attend. For a lot of people, the conference weekend is just too short. How about a vacation to Niagara Falls including pre-arranged GF meals? Check out the Niagara Falls Getaway Bob & Ruth's GF Dining & Travel Club is offering immediately following our conference. If you would prefer to stick around Kitchener-Waterloo, consider a tour of the village of St. Jacob's, the Stratford Shakespearean Festival, or a drive around the traditional Mennonite areas of the county.

For more information about the conference program and hotel, the Niagara Getaway, and other activities in the Kitchener-Waterloo area, check the conference website at www.kwceliac.org. You can register online or download a printable registration form.


Sue Newell



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NANAIMO Support Group Encore Presentation of The Gluten Intolerance Festival from the 2008 National Conference

Couldn't get to the National Conference in Victoria, May, 2008?

Here's your chance to view two of the keynote speakers

Dr Alessio Fasano, the international authority "Guru" on Celiac Disease

Shelley Case, Registered Dietitian and leading nutrition expert in North American

on a DVD presentation.

Saturday, March 21st, 2009

Nanoose Place, 2925 Northwest Bay Rd, 1.8km from Petro Canada Service Station, Nanoose Bay, B.C.

- 9:30 a.m. Welcome while enjoying coffee and treat
- 9:45 a.m. Dr Fasano's Part One Presentation and Question Period
- **12:00 Lunch**
- 1:00 p.m. Dr Fasano's Part Two Presentation & Question Period
- 2:00 p.m. Snack Break/Chance to view displays
- 2:30 p.m. Shelly Case
- 4:00 p.m. Wrap up

Registration: Includes snacks, coffee, lunch

\$10.00 for CCA Members

\$15.00 for Non-Members

Send to: no later than March 13th, 2009

Pat Audley
3077 Dolphin Dr

14th Annual Family Health & Wellness Fair

Saturday, March 28, 2009 10:00-3:30
Parksville Community Centre
1342 Jensen Ave, Parksville, B.C.

We will have a table set up
Looking for Volunteers to man!
Call Anne or Pat A

Continued from page 5...

People were grateful to receive the information and the calendars and everyone loved the idea of sampling gluten-free goodies. I myself went around to all the booths, introducing the CCA and giving calendars and information. I met a lot of professionals who knew about us, and those who didn't, they were happy to become acquainted. The feedback from my "crack team" was that it was an event that was well worthwhile, fun, and positive. So to you, team, I say thanks, it wouldn't have happened without you. **Heather Sutherland**

Pure oats can be part of a heart-healthy gluten-free diet.



Most people with Celiac Disease can safely eat oats if they are uncontaminated with wheat, barley, rye and other closely related grains.


At Cream Hill Estates we are committed to improving the lives of people on gluten-free diets by producing and distributing guaranteed pure oats as rolled oats, oat flour and whole-oat kernels (groats).

Visit us online to learn more about our products and view a complete list of stores that sell them at:
creamhillestates.com




The Pure Oats Company™
 Email us: info@creamhillestates.com
 or call toll free: 1-866-727-3628

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GREAT TIPS FOR USING COMMERCIAL PRODUCTS

El Peto Frozen Pie Shells

3 per box, \$6.99 at Lifestyles

What could be easier? We made lemon meringue, pumpkin and banana cream pies. Great if you don't have time to make crusts. These are not deep-dish, so the pies are fairly shallow.

Glutino Cinnamon Raisin Bagels

5 bagels per bag, \$6.99 at Superstore. Also available at Lifestyles and some Safeways.

Un sliced, so you need to defrost prior to slicing and toasting.

Good with butter and cream cheese. They are identical in texture and taste to the Glutino Cinnamon bread, so while they look like a wheat bagel they do not have the same chewy texture as wheat ones.

Food For Life Brown Rice Tortillas

6 per bag, \$3.29 at Superstore, also available at Planet Organic (in fridge with other tortillas) and Lifestyle Markets (frozen).

These are very good. To make a quesadilla, put 1 on

non-stick skillet on med-low, add grated cheese, thinly sliced chicken breast or other filling, top with a second tortilla. Flip and cook for total of 3-5 minutes until slightly crispy. Cut into wedges with serrated knife. Wrap in wax paper for lunches. For enchiladas, defrost in microwave or on counter covered with damp towel. Roll around filling and top with sauce according to your favourite recipe. They can get flaky if they dry out, so work quickly with them.

My 13 year old daughter has CD, her twin sister does not. So we frequently look for GF substitutes of popular fast foods. Here are 2 favourites that taste like the original.

Orange Julius (GF)

In a blender or processor, mix: 6 oz. frozen orange juice concentrate, 1 c milk, 1 c water, ¼ c icing sugar, ¼ tsp vanilla extract. Add up to 8 ice cubes, one at a time, until frothy. Can add ¼ c powdered milk.

DQ Blizzard (GF)

In processor or by hand in a bowl, mix 3 Reese's Peanut Butter Cups with 2 c DQ Soft Serve Ice Cream. Be quick or it turns to milk shake. Also try M & Ms or Chocolate K-Toos (Kinnikinnick).

Shirley Bond

IS PPM GETTING YOU CONFUSED?

A clear explanation from Beth Armour of Cream Hill Estates -The Pure Oats Company

We are getting closer to a world-wide common definition of gluten-free. Here is a summary of the GF labelling today:

Codex Alimentarius / European Standard

was 200 ppm for gluten-free labelling but as of 2008, gluten free is **now** defined as 20 ppm; they list oats as an ingredient not being allowed to be labelled GF - but have a footnote saying this is to be determined at the national level of each country;

- they allow ingredients that have been specially processed to remove the gluten - e.g. wheat starch, as long as the product it is used in is less than 20 ppm;
- I think there are a lot of changes in GF products in the European market as well because of the lower 20 ppm level - companies having to reformulate.

Australia - has two levels of gluten-free labelling: **gluten-free** - meaning no detectable level* of gluten and no oats or oat products and no cereals containing gluten that have been malted;

- **low gluten** - must be less than 20 ppm;
- it was recommended in 2004 that oats could be called low-gluten if they tested at less than 20 ppm - not clear if this has officially been adopted yet;
- oats can be called wheat-free; they do not allow ingredients which have been specially processed to remove gluten e.g. wheat starch, to be called gluten-free

US - had no guidelines, companies used the previous Codex standard of 200 ppm;

- **since the summer of 2008** FDA notified manufacturers of their intent to define gluten-free as having less than 20 ppm - thus the panic by some manufacturers to reformulate recipes and test their products to ensure what used to be 200 ppm is now 20 ppm [this is why there is so much confusion as some companies have removed products from their GF list until they can get test results at less than 20 ppm];

- oats are part of the proposed regulation to be called gluten-free if testing less than 20 ppm; they likely will allow ingredients that have been specially processed to remove the gluten - e.g. wheat starch, as long as the product it is used in is less than 20 ppm.

UK / Britain has always used the Codex so they also are now having to reformulate products to meet the 20 ppm; oats were allowed to be called GF because of the 200 ppm but now it is my understanding that they are having more difficulty getting consistent test results so may not have GF oats available like they did before. Since they follow the Codex they allow ingredients that have been specially processed to remove the gluten - e.g. wheat starch, as long as the product it is used in is less than 20 ppm. In addition, some foods made using cereals that have been specially processed to remove most of the gluten, but which contain less than 100 ppm of gluten, will be able to make the claim 'very low gluten' on the packaging. These include substitutes of certain staple foods such as bread.

Canada - as you know has defined gluten-free as 20 ppm for a long time, but we are also in revision mode;

- oats will likely remain in the regulation as not being able to be called GF - unless they have the Pavena trademark or follow a specific process for production;
- we **do not** allow ingredients that have been specially processed to remove the gluten - e.g. wheat starch, to be used in a gluten-free product even if it tests less than 20 ppm. Carla Berry - who used to be the head of labelling at CFIA, told us once that "**technically**" gluten-free should be **0 ppm** gluten - but in reality this is not realistic - so they go with 20 ppm.

continued next page.....

0 ppm is not even measurable or detectable. The only way you could claim such would be if the food item is naturally gluten-free and has no possibility of cross-contamination - like fruits or vegetables. (At Cream Hill Estates) we use the most sensitive test available at the moment - R5-7001 Ridascreen ELISA test which has a lower limit of detection at 3 ppm and a lower limit of quantitation at 5 ppm. The lab we currently use uses the limit of quantitation to report results as there is some discrepancy between the 3 ppm and 5 ppm in

some products. Many manufacturers do in-house testing and use a **quick test** which has a lower limit of detection of 10 ppm but has not been validated with many products so the reliability is questionable according to the test lab people at FARRP (Nebraska) and BiaDiagnostic (Vermont).

Beth Armour, CCA member, friend of the Victoria Chapter and dietitian.

DEFINING GLUTEN FREE assessing the level of gluten freedom

Level 1 – Labelled GF and made in a gluten-free facility with foods independently tested and ensured to be free of gluten.

Level 2 – Labelled GF. In Canada this means that a food is not permitted to be labelled, packaged, sold or advertised in a manner likely to create an impression that it is “gluten-free” unless **it does not contain wheat, including spelt and kamut, or oats, barley, rye, triticale or any part thereof.**

Level 3 – Not a gluten-free facility, however, the product has been identified as GF and we have been assured that the lines are cleaned and sanitized between products following strict guidelines in order to greatly reduce risk of cross-contamination

Level 4 – The ingredients appear gluten-free and, upon investigation, the company confirms that the product is gluten-free, based on its ingredients and processing practices.

Thanks to the Toronto Chapter for kind permission to reprint this useful item.

Living with the Gluten-Free Diet Study

Thank you for completing this study so promptly when it dropped through your mailbox.

Janet Dalziel, our National President said: “Good news from Marion Zarkadas. The study questionnaires have been arriving steadily and, at last report, the rate of return was around 62%. Of course, we would like to achieve an even higher response rate. Some people who put their survey aside during the holiday may now think it is too late to send it in. It is not. Please let your members know, through whatever means you have, that their responses are still welcome.”

Information from the last CCA survey on diagnosis and related illnesses helped support changes to medical practice and product labelling legislation. The information gathered was published in three medical journal articles to educate physicians and dietitians across the world.

CCA advisor Marion Zarkadas is the principal investigator on this new study and Health Canada is providing financial and logistical resources to make the study a reality. The Health Canada contribution is a big compliment to the CCA, the quality of research we conduct, and the support of our members for research. Health Canada made extensive use of the results of the diagnosis survey to support the need for improved product labelling legislation.

GLUTEN ALLERGY OR CELIAC DISEASE? DR. FASANO CLARIFIES

Dr. Alessio Fasano is director of the University of Maryland Center for Celiac Research, which is part of the School of Medicine, where he studies a long-misunderstood illness that affects about 3 million Americans. Celiac disease causes gastrointestinal symptoms such as bloating and diarrhea, as well as anemia, joint pain, fatigue and skin disorders. In recent years, research and awareness has grown, as has the popularity of gluten-free foods, the only treatment for celiac disease.

Celiac disease is more than just an allergy to gluten, isn't it an autoimmune disease?

For many years [people] were under the impression it was a food allergy. The understanding of it as an autoimmune disease changes a series of paradigms. It has been revolutionary. From a patient's standpoint, knowing it is an autoimmune disease implies you are not going to grow out of it.

Is treatment a lot different?

Treatment is more than saying, "You have to avoid the food that contains the material that offends you. But if you by any chance are exposed to it, it's not a big deal because you will pay the price on the spot. You will feel bad, and it will go away."

An autoimmune disease will have a cumulative effect over time. You can end up in a very unpleasant situation [with] possible co-morbidities [such as rheumatoid arthritis]. Because it's an autoimmune disease, there is the genetic component, and then there is an environmental component that is the trigger that is mismanaged by the immune system. What is revolutionary is that this is the only autoimmune disease from which we know the trigger. And this has created tremendous turmoil because our [response] is that if you have an autoimmune disease there is nothing you can do about it. But celiac disease suggests otherwise.

Because you know the trigger?

We know the trigger. The treatment of a gluten-free diet allows you to take one of the two elements out of the picture. These people go back to normal. The symptoms go away, and damage in the intestine that is the autoimmune insult goes away.

How do you know it's celiac disease and not an allergy to gluten?

It's a very important question. We see roughly 1,100 people a year, and a fraction have celiac disease. All of them come claiming they are sick from eating and when they go on a gluten-free diet they feel better. As a matter of fact, there is a spectrum. A reaction to gluten on one end, and the worst-case scenario is the autoimmune reaction of celiac disease. But there is a lot in between.

Are there other symptoms that help you know it's celiac disease?

No, because some of the symptoms of allergies overlap with celiac disease. The situation becomes even more complicated when you talk about gluten sensitivity. That's a condition where the vast majority of people [have].

What is that?

It's an immune reaction to gluten, but it's not an allergic base and not an autoimmune base like celiac disease. But definitely there are different machineries involved in that. And there are specific ways to diagnose celiac disease and specific ways to diagnose an allergy. There are not yet ways to diagnose a sensitivity.

Is the treatment more than a gluten-free diet?

For all of them the basic [treatment] is a gluten-free diet. But the rules of engagement are different for where you are on the spectrum. That is why a proper diagnosis is extremely important. Celiac disease is an all-or-none proposition. If you go on a 99.9 percent gluten-free diet, that 0.1 percent is perceived by the immune system as something dangerous there. It can't distinguish between a crumb and an entire bread loaf. It's a different story with gluten sensitivity and allergy. Some people can't tolerate a crumb, and others have a threshold that is such that you can tolerate a piece of pizza.

Why are we hearing more about it and seeing more gluten-free products?

When we started this process the general wisdom about celiac disease was that it was a pediatric condition, it has only [gastrointestinal] symptoms and involves only Caucasians.

That's what we had in mind, and indeed when you look in that direction the disease is rare. The real celiac disease, we see now, is not confined to pediatrics, not confined to GI symptoms, and not confined to Caucasians. What you see now is the entire picture, and [we've] come up with this 1 percent [of the population].

So we just weren't looking at it the right way?

[In 2004, the National Institutes of Health] concluded the disease is indeed a public health problem in the U.S. involving almost 3 million people. And it's even more of a public health problem if you consider that of this 1 percent, a ridiculous fraction is diagnosed.

So we have changed how we approach it because we understand it better?

Yes, and the other major work we had to do once there was the flag on the ground. [There] was a

tremendous effort to educate health-care professionals, to change the paradigm. It was a tremendous effort. Celiac disease was put on the map, and we started this awareness campaign.

Are people still self-diagnosing and cutting out gluten?

Absolutely. But the hazard is ... once you go on a gluten-free diet, the tools we use for the diagnosis are not available anymore. The tests will test negative once you go on a gluten-free diet. You lose the ability to make a diagnosis. It's like you say, "I am peeing a little too much, and I am light-headed, so let me take 20 units of insulin and see if I have diabetes." For celiac disease, a gluten-free diet is like insulin for diabetics.

Baltimore Examiner, January 16, 2009



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MEMBERS' LETTERS AND EMAILS

RESTAURANTS READERS HAVE TRIED AND ENJOYED

Longwood Brew Pub 5775 Turner Rd., Nanaimo, ph: 250-729-8225.

The location for our annual Christmas Dinner. Once again the restaurant provided an awesome meal. The website for those interested in visiting this fine dining establishment is www.longwoodbrewpub.com

Anne Radix

Ilios Restaurant in Nanaimo at 215 Terminal Ave across from the White Spot, ph: 250-754-1122.

Serves Gluten Free meals as well as delivers Gluten Free Pizzas. Can be noisy in there as it is all glass around you.

We wish everyone in Victoria a Happy New Year. You have all been very helpful to us this year as my husband was diagnosed in February and we were very welcomed at your meeting and the conference was very helpful as well.

Glenda and Brian Barker

Anne Radix says, **Ilios Restaurant** even advertises **Gluten Free Pizza** on their signage. 60% of menu can be offered Gluten Free!

Amrikkos Grill, Parksville. East Indian Cuisine 487 Island Hwy E, Parksville 250 951-0682.

Although they have two other locations in Nanaimo, my friend is the manager of the Parksville one and is familiar with Celiac Disease. They will actually be offering a Gluten Free menu as soon as it is finalized.

Anne Radix

The Landing West Coast Grill located at the Pacific Shores Resort & Spa, 1600 Stroulger Rd., Nanoose, ph: (250) 468 - 2400.

There are many items on their menu which are already Gluten Free without any adjustment - these are marked with a little picture of a fish skeleton. I always let them know that I am a Celiac and that eating Gluten Free is not a choice, but a necessity. If there is any ingredient that is suspect, they will work around that. I have never had a problem and the food is excellent.

During our New Year's dinner our waiter informed us that the chef would be happy to make us a Gluten Free Pizza - in fact he delights in this sort of thing - he only needs to be

informed in advance - such as earlier in the day, for dinner. We have yet to try this, but will let you know about it after we do. I don't know of any other place in this area that would accommodate celiacs in this way.

Heather Watson, Parksville, Qualicum Beach

Orale, 1002 Johnson St., Victoria, ph: 250-590-3370.

Mexican Taqueria Style Restaurant

Orale's is a very good Mexican restaurant with lots gluten free choices. Homemade tamales are my favourite with the tacos a close second. Authentic tacos, tostodos and tamales. The mole is not gluten free.

Nancy Adrian

GOOD BREAD

Deep Cove Market, 10940 West Saanich Rd, Sidney, BC V8L6A8 Phone: (250) 656-2547, is now carrying **SILLY YAK** bread from Qualicum. The owner says they have a high demand for celiac friendly products and therefore they are going to create a section for their various products.

Jeff Lumley

BROWN RICE TORTILLAS

I was in Delaware recently visiting my grandkids and daughter and found some really excellent Brown Rice Tortillas at Trader Joe's. We picked some up in Seattle on the way back.

I have tracked down their supplier it is "Food for Life" <http://www.foodforlife.com/gluten-free-wheat-free-breads.html>

They distribute to many places but have no outlet in BC as far as I can see.

These Brown Rice Tortillas are excellent. They are large and soft and bendable and actually taste good. I brought several packets back but it is a long way to drive for a refill.

Mike Rose

YES WE DO!

We do carry these tortillas, they are in our freezer section. They are \$4.29 for a 6 pack. Look for the Food for Life logo.

Carmine

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2 large eggs, separated; 1½ cups **Pamela's Baking & Pancake Mix**; ¾ cup water; 2 Tbsp oil. Whip egg whites until stiff. In a separate bowl combine Pamela's Mix, egg yolks, water, and oil together until there are no lumps. Fold in stiff egg whites and bake immediately in preheated, greased waffle iron. Serve waffles hot off the iron. May need to increase baking time for crispy waffles.

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LOCAL GROCERY STORES PULL OUT ALL THE STOPS TO SERVE CUSTOMERS LOOKING FOR GLUTEN FREE PRODUCTS

THRIFTY FOODS has just completed a listing of more than 200 gluten free products that are available in their stores.

Jessalyn O'Donnell, RD, Nutrition Services at Thrifty Foods says:

"I am proud to say that I have now completed a list of gluten free products carried at Thrifty Foods. This list will be available in all our Thrifty Foods locations in the Vitamins and More departments, Customer Service and Pharmacy.

LIFESTYLE MARKETS, 2950 Douglas St., Victoria www.lifestylemarkets.com

This store has been our faithful supporter for many years and stocks a wide variety of gluten free products gathered together in a dedicated gluten free section.

Pop into a **Celiac Support Meeting** on the second Tuesday of the month, 6:30 to 8:00 p.m., and connect with a CCA member for a coffee and a chat and tour the store to check out the latest gluten free products.

ISLAND NATURAL MARKETS

6560 Metral Drive, Nanaimo.
www.islandnatural.ca

Island Naturals is a strong supporter of the Nanaimo Support Group and our Chapter. They are a great source of gluten free products.

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Do you have a secret desire? Want to help fellow celiacs? Consider offering 2 hours of your time, once a month, to accompany Kathryn or Erin on their tour. Lend an ear or provide CCA information. Receive the richest of rewards for your kindness.

Contact Ellen (ebayens@telus.net) or Christine (crushforth@shaw.ca).

MEDICAL NEWS AND RESEARCH

Type 1 diabetes and coeliac disease linked Scientists identify shared genetic markers

Type 1 (juvenile) diabetes and coeliac disease appear to share a common genetic origin, scientists at the University of Cambridge and Barts and The London School of Medicine and Dentistry, have confirmed.

Their findings, which are reported in this week's edition of the *New England Journal of Medicine*, identified seven chromosome regions which are shared between the two diseases. The research suggests that type 1 diabetes and coeliac disease may be caused by common underlying mechanisms such as autoimmunity-related tissue damage and intolerance to dietary antigens (foreign substances which prompt an immune response).

Type 1 diabetes is an autoimmune disorder which causes the body to attack the beta cells of the pancreas, limiting its ability to produce the insulin necessary to regulate blood sugar levels. Coeliac disease, also an autoimmune disorder, attacks the small intestine and is triggered by the consumption of gluten (a protein found in wheat, barley and rye) and cereals. The development and anatomy of the small intestine and pancreas are closely related, and the gut immune system shares connections with pancreatic lymph nodes, which have been linked to an inflammation of the pancreas and the destruction of beta cells.

In order to assess the genetic similarities and differences between the two inflammatory disorders, the researchers obtained 9339 control samples, 8064 samples from people with type 1 diabetes and 2560 samples from individuals with coeliac disease. They found a total of seven loci (regions of a chromosome) were shared between the two.

The researchers, who were funded by Juvenile Diabetes Research Foundation, the Wellcome Trust and Coeliac UK, believe that these regions of the chromosomes regulate the mechanisms that cause the body's own immune system to attack both the beta cells in the pancreas and the small intestine. Their results suggest that type 1 diabetes and coeliac disease not only share

genetic causes but could have similar environmental triggers as well.

Professor John Todd, from the University of Cambridge, said: "The next step is to understand how these susceptibility genes affect the immune system, and to keep exploring environmental factors that might alter the risk of type 1 diabetes, which results from an incredibly complex interaction between nature and nurture."

Professor David van Heel, from Barts and The London School of Medicine and Dentistry, said: "These findings suggest common mechanisms causing both coeliac and type 1 diabetes - we did not expect to see this very high degree of shared genetic risk factors."

Karen Addington, Chief Executive of JDRF in the UK said: "These studies demonstrate that type 1 diabetes and coeliac disease share far greater genetic overlap than had been appreciated; which helps explain the high prevalence of both conditions occurring simultaneously in an individual and may provide new avenues for understanding the cause and mechanisms of both conditions."

Sarah Sleet, Chief Executive of Coeliac UK said: "This is a real advancement in understanding the underlying mechanisms generating coeliac disease, a much under diagnosed condition which affects 1 in 100 people in the UK today however, only 1 in 8 of those has currently been diagnosed. We hope that these findings will help in increased awareness and diagnostic understanding of both coeliac disease and type 1 diabetes."

Type 1 diabetes and coeliac disease together affect about 1% of the population.

Source: Coeliac UK

EGGS HELP CRACK TREATMENT FOR GLUTEN INTOLERANT

Edmonton Journal, January 7, 2009

(thanks to Lynda Funston and Anne Radix for spotting this article and Dr. Switzer for providing some feedback)

A University of Alberta researcher has found a cost-effective way to produce antibodies against gluten, potentially opening up a whole new world for people with celiac disease.

Celiacs can't tolerate gluten -- a protein found in wheat, barley and rye -- and currently there is no cure.

Hoon Sunwoo, a research associate in the faculty of pharmacy and pharmaceutical sciences, has produced antibodies in chicken eggs that would allow celiacs to eat bread and other foods containing gluten.

After three years of research, his technique will start human clinical trials this fall, if it passes animal safety studies.

"There is no treatment other than a lifetime without gluten," says Sunwoo, an animal scientist specializing in poultry. "It's a tough life, because you want to go out and eat with friends, but you can't."

Gluten prevents crumbling in bread and other baked goods, and is used in many processed and packaged foods. Celiacs must check every food label, because even a small amount of gluten can trigger symptoms that include diarrhea, weight loss and fatigue.

It's estimated that one in 133 Canadians is affected by the disease, which damages the surface of the small intestine so the body can't absorb protein, fat, carbohydrates, vitamins and minerals -- all necessary for good health.

Sunwoo says celiacs would be able to take a pill containing the antibodies that would eliminate the symptoms. He's also developing an egg that will contain a high level of gluten antibodies that may one day be sold commercially.

Chicken eggs, which are loaded with bioactive components, are an ideal vehicle for antibody research, he says.

In September, Sunwoo and his team will work with U of A gastrointestinal specialists on the first phase of human clinical trials on about 20 patients.

He has applied to Health Canada for registration as a specialty food product rather than a drug, which would shorten the time to get it to market.

Response from the agency has been positive, but it won't make a decision until after the animal safety trials, Sunwoo says.

Even as a specialty food product, it would be another three years before it reached the public, providing it successfully completed the trials. Drug trials take about 10 years.

Sunwoo says funding from the Alberta Livestock Industry Development Fund has been his saviour.

Dr. Connie Switzer, chair of the Professional Advisory Board of the Canadian Celiac Association has offered this comment about the story in the Edmonton Journal about celiac and eggs.

"It is an interesting method of developing basically an antibody to the toxic part of gluten. It is a long way from clinical testing yet and has to be tested now in animal model to prove safety and efficacy then it will move into a long series of human tests before coming to clinical care arena. If the early trials show safety and efficacy then, I suspect individuals with Celiac disease will be asked to participate in phase III trials but this is a long way off."

**Connie M. Switzer MD, FRCPC, FRCPC
Clinical Professor of Medicine
University of Alberta, Edmonton, Alberta
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Preheat oven to 325 degrees. Place butter/margarine on 15 1/2 x 10 1/2 jelly roll pan; place in oven to melt butter/margarine for about 7 minutes. Meanwhile, beat egg whites with salt until frothy and very stiff; gradually add sugar, beating to stiff peaks. Gently fold in almonds and cinnamon. Pour almond mixture onto jelly roll pan; toss with melted butter/margarine.

Bake about 30-40 minutes, tossing every 10 mins, 'til almonds are crisp. Store in airtight container up to 2 weeks. I like to add some nutmeg too just for added flavor...careful how much because it's very powerful. Enjoy!

Anne Radix

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Victoria Chapter Address: PO Box 5457 Stn B, Victoria, B.C., V8R 6S4. Hot Line for advice in a hurry is (250) 472-0141.

Victoria Chapter e-mail is victoriaceliacs@canada.com Chapter Reg. Charity #89887-2734 RR0001.

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