

# CanadianCELIAC

**It's our 50th year – forging ahead to a brighter future**

**NEW TRAVEL SECTION!**

*Plus*

**MARK: CCA CHANGE MAKER**

**GLUTEN-FREE TRAVEL IN DISNEY**

**LOW ENERGY? COULD IT BE B12?**

**COMMUNITY RECIPES**

**IT'S TAX SEASON! GET INFORMED**

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# Canadian CELIAC

A MAGAZINE FOR CANADIANS WITH  
CELIAC DISEASE AND GLUTEN SENSITIVITY

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# A magazine for Canadians with celiac disease and gluten sensitivity

## WINTER 2023



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# From the Executive Director

50TH ANNIVERSARY

## START OF A NEW ERA: CELIAC CANADA



I am pleased to kick off our 50th anniversary year with the announcement of the change in name to Celiac Canada/Coeliaque Canada from the Canadian Celiac Association.

Five years ago, the National Board of Directors, after a thorough review, realized that change was needed away from individual memberships. Memberships were in decline but the audience for information about celiac disease and gluten free, such as our Facebook Group, was skyrocketing. In addition, there was a growing tension in deciding what information was to be saved for members only versus meeting our charitable mandate for supporting the public. A vote was tabled and passed at the 2019 Annual General Meeting to ensure all people at risk and with celiac disease in Canada had access to the resources and information they need to empower their health. Other similar organizations such as Diabetes Canada have also made this successful transition.

Now that CCA was to be a 100% charitable organization by the end of 2020, there was no longer a need for the word 'Association' in our name so Celiac Canada (or Coeliaque Canada) was formally adopted. Given the size of the CCA (we'll still be known as CCA), our name transition will take time. We've seen incredible support for us as a charity. We continue to grow, developing new resources, programs and research all thanks to individuals like you!

You will also see a transformation with our Gluten-Free Certification Program (GFCP) trademark to match the new name on your favourite certified products. This transformation will take place over time in your local grocery stores as companies change their labels. Speaking of the GFCP, we asked former CCA President, Anne Wraggett to provide us with the impetus of the program as part of our 50th anniversary stories.

While we have changed our name, we haven't strayed from our founders' vision. We take you back through time before our origin story to show the progression of celiac disease in Canada and then how our founders Kay Ernst and Nora Reck helped drive the first decade of the CCA. Kay and Nora are the inspiration the inspiration for our Volunteer Recognition Program launching with our anniversary. We are going to celebrate individuals, like Mark Johnson our cover story, who dedicate hundreds of hours each year to give back to the community and make a real difference.

Along with our looking back, we know many of you are looking forward to travelling more after the pandemic. So, we've got some fun travel tips and destinations featured to get you excited about venturing out and exploring.

We are truly excited about the year ahead and hope to have your support as we venture into the next 50 years and achieve our vision to have every person with celiac disease diagnosed and empowered. Come along for the ride!

Yours truly,  
Melissa Secord, CAE  
National Executive Director



# FOOD MARKET

MARINATED LEMON AND HERB CHICKEN KABOB

STEAKHOUSE SEASONED BEEF KABOB

BLUEBERRY BLISS CHEEZECAKE

COUNTRY STYLE CHICKEN BREASTS

CLASSIC STUFFED POTATOES

# 34+ GLUTEN-FREE OPTIONS AVAILABLE



Satisfy your comfort food cravings with absolute confidence that they are certified gluten free. With the Canadian Celiac Association as our partner, our range of gluten-free choices is now wider and tastier than ever.

## SAME-DAY DELIVERY



Shop online at [www.mmfoodmarket.com](http://www.mmfoodmarket.com)

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# By the decades

50TH ANNIVERSARY

## Celiac disease in Canada BY THE DECADES

**Weaving a patient's journey through the progression of the disease in the 60's and early 70's**

JOANNE MURRAY

**The Canadian Celiac Association (CCA) was established 50 years ago in December 1972. Over the next three editions of *Canadian Celiac*, I am going to weave a story that includes my history of diagnosis (May 1968) intertwined with the history of the CCA and the general medical knowledge of the time related to celiac disease, keeping in mind there was no CCA in the early years of my diagnosis. I'll cover this history two decades at a time, with this first part covering the 1960s and 1970s. The storytelling may make it easier to understand why the pathway to diagnosis is still so complicated and riddled with inconsistencies and variances in diagnostic practices and why the gluten-free diet standards are fraught with misconceptions and inconsistencies.**

I will begin with my entry into the health care field in 1963 as a student x-ray technologist. Little did I know then that my experiences as a student and later as a newly graduated technologist would be so intimately attached to my understanding of this disease, initially known as Adult Non-Tropical Sprue and later, as celiac disease, and that I would be diagnosed with it and become a part of this community. As much as medical fields were moving forward with research, they were also limited by

lack of the science and technology that had only begun to advance more quickly with the beginning of the space age (and a few other great revolutions and revelations that developed in the 1950s). For example, Saran Wrap<sup>®</sup>, as we know it and rely on it today, was a product developed for use in the space race. There was even pop music written about the wonders of this indispensable product.

Enough of that! Let's get into the wonders of medicine. Part of my

training as an x-ray technologist included assisting with procedures with the use of fluoroscopy, which was real time active imaging using radiation. We were called upon to assist the gastroenterologists with the fluoroscopic scanning of patients as they fed a piece of biopsy equipment down through the open mouth into the dark recesses of the stomach and intestines. There were two basic types of equipment used, either the Watson Capsule or the Crosby-Kuglar Capsule.

*Continued on next page*

# “... more than anything, they had to rely on gut instinct, as celiac disease was only beginning to be recognized – JoAnne Murray

This was long before modern-day endoscopes entered the medical scene. This capsule equipment was cumbersome and invasive. (The term invasive still lingers today despite the safety of the current equipment.) There was rudimentary fibre optic equipment, but it did not have the capability of snipping biopsy samples.

Without equipment that offered full visualization of the pathway into the small intestine, the only means the gastroenterologist had to guide the equipment was the use of fluoroscopy that showed the tip of the equipment as it was fed into the sweet spot in the small intestine, known as the Ligament of Treitz. It often involved several minutes of radiation exposure to accomplish the capsule placement. Once in place, it was critical that it not shift even slightly from its optimal location. At this point, the patient was wheeled back into the gastric lab. The gastroenterologist had one chance only to retrieve a single viable biopsy sample.

The capsule was equipped with a small window, a suction force that sucked a bit of intestinal tissue into the window and a tiny knife that snipped a small tissue sample. This single tissue sample was reviewed by a pathologist to determine the nature of any pathology. If the capsule was removed with no retained tissue (and this did happen on oc-



casation) we could rarely persuade any patient to submit to a repeat procedure. The use of radiation was a significant concern, especially with children and women of childbearing age.

Because of the invasiveness of the capsule biopsy, these proce-

## THE CROSBY – KUGLER CAPSULE

■ The Crosby–Kugler capsule, also called the Crosby capsule, is a device used for obtaining [biopsies](#) of small bowel [mucosa](#), necessary for the diagnosis of various [small bowel](#) diseases. This capsule was originally invented by [Dr. William H Crosby](#) to assist in diagnosing [Coeliac disease](#).

■ The capsule, attached to a long tube, is swallowed. The other end of the tube remains outside the patient’s mouth. When the capsule has reached the desired section of bowel, suction is applied to the tube. This suction triggers a mechanism in the capsule which causes a spring-loaded knife to sweep across an aperture in the capsule, cutting away any mucosa protruding into the aperture. The capsule is then pulled up by the tube, and the biopsied tissue is retrieved from within the capsule chamber.

dures were never performed as a general investigative procedure. They were performed to confirm a clinical diagnosis, in this case, celiac disease. (This biopsy procedure was also used for other diseases common to the stomach and small intestine.)

*Continued on next page*

# “ My weight ... plummeted to a mere 87 pounds when I finally connected with the gastroenterologist ... – JoAnne Murray

Before any gastroenterologist would subject a patient to this biopsy procedure, they had to explore all other means to validate the potential for celiac disease. However, these resources were limited. This was long before the introduction of many of the blood tests that we currently take for granted. There were no screening tests for celiac disease. The physicians relied on the basic blood tests of hemoglobin, electrolytes (potassium, magnesium and chloride) and ESR (sed rate which was the only available marker of inflammation at the time). They did stool tests for fat malabsorption if there was evidence of steatorrhea (an increase in fat excretion in the stools). There had to be strong clinical evidence of classic symptoms, including weight loss, diarrhea, gas and bloating and in children, wasting. And more than anything, they had to rely on gut instinct and previous experience, as celiac disease was only beginning to be recognized as an adult-onset disease rather than the previous belief of its being a childhood disease that would be outgrown.

Fast forward to 1968. I continued my work in the x-ray field and continued participating with the x-ray component of the small intestinal biopsies. And I was experiencing serious health issues. My weight

“  
**I found gluten-free bread ... In great excitement I bought two loaves, only to discover after cutting into one of them that they made better door stops than edible food**



had plummeted to a mere 87 pounds when I finally connected with the gastroenterologist who took my concerns seriously. As it happened, he had an interest in celiac research. He reached a clinical diagnosis of celiac disease very quickly and within days, I was scheduled for a biopsy. Oh, how I dreaded having the procedure done. I was going to have it in my own working environment amidst my colleagues and I was terrified

of behaving badly in their presence, as so many of our patients did. Sedation wasn't an option in those years as the procedure required active participation of the patient. With a huge resolve, I did my best to cooperate and had the procedure done. Because I was in a familiar environment and worked with the physicians involved, they extended me the courtesy of taking a quick look at the tissue sample under the microscope in the gastro lab before it was sent off to the pathologist. That single tissue sample was diagnostic and demonstrated total villous atrophy, a totally conclusive diagnosis of Adult Non-Tropical Sprue. Within days I had met with a dietitian and had a small list of instructions for following a gluten-free diet and was dismayed by how little information was actually offered.

I was exposed to the typical diagnostic pathway of the time, a pathway that had been present for children for almost two decades and would persist for more than a decade longer before diagnostic tests and equipment would gradually improve. It would also be years before Sprue was renamed as celiac disease and was recognized as an autoimmune disease. At the time I was diagnosed, it was recognized that there was  
*Continued on next page*

# “Ice cream was off my list of foods for ... a decade until carrageenan and other ... products replaced wheat flour as a stabilizer

a relationship between celiac disease and Type-1 diabetes, but the relationship was not even marginally understood. I was part of a very small group and there was little focus on this disease. In my first 10 years of diagnosis, I met only two others who were also diagnosed. There were few gluten-free food products. I found gluten-free bread in the Woodward's food department. In great excitement I bought two loaves, only to discover after cutting into one of them that they made better door stops than edible food.

The diet was both a challenge and incredibly simple. Processed foods in abundance were only beginning to make their way onto the grocery store shelves. At the time of my diagnosis, the standards of the gluten-free diet were based on fresh meats, potatoes, fruits, vegetables, rice, legumes, eggs and dairy. It was that simple and, many would say, so boring. There was no requirement for commercially prepared foods to have ingredient labels, though some producers did provide information for basic ingredients but never proprietary ingredients. There were, yet, no next generation food stabilizers, so wheat flour was used as the agent of choice for stabilization and as the thickening agent for almost all foods. Ice cream was off my list of foods for more than a



decade until carrageenan and other similar products replaced wheat flour as a stabilizer.

At the time of my diagnosis, most of the information for the gluten-free diet came from Britain. They were ahead of us in understanding the diet and what could be included in it. It was from these early resources that we landed on the pathway called 'confusion' for some of our gluten-free food practices. The BROW acronym was used at this time as the gluten containing grains were listed as Barley, Rye, Oats and Wheat. It would be almost three decades before oats would be recognized as being free of the proteins harmful to people with celiac disease and that the risk with oats was related to the field contamination of the oats with wheat, barley and rye. It would be more than three decades before triticale would

enter the human food chain and be added to our list of gluten containing grains to be avoided. The two commonly recognized substitutes for wheat flour were rice flour and cornstarch. It would be another couple of decades before the many choices for gluten-free alternative flours would become available, and more importantly, free of gluten contamination.

There were some British practices that made their way to Canada that were ultimately called into question as food science and technology forged ahead. As an example, barley malt extract as a flavouring agent was considered acceptable in England, as was highly refined wheat starch. I continued to eat Kellogg's® Rice Krispie Squares as a favourite treat for 25 years, until I learned that I was consuming very small  
*Continued on next page*

“ It would be another four decades ... before we have a trustworthy food labelling regulation that offered us the means to eat ... with our friends

but potentially harmful amounts of gluten. I could actually find small packages of wheat starch in health food stores until it fell out of favour and disappeared forever in the early 1970s. We knew little about cross contamination in my early years of diagnosis as there was no means to measure small amount of gluten in foods. The Codex standards for gluten free, first established in 1979 and revised in 1998, allowed for a gluten-free claim on foods made from naturally gluten-free ingredients or ingredients rendered gluten free (wheat starch as example) containing no more than 200 parts per million ppm). It would be more than 30 years after my diagnosis before we had reliable testing that could measure amounts as small as 20ppm and later, five ppm of gluten contamination.

“  
**I have nothing  
but gratitude  
for all  
the health and  
food choices  
I have today**

Fast foods were limited to a very few chains, primarily the basic beef patty and French fries from the golden arches locations as example. At the time of my diagnosis, Canada was experiencing an upswing of broad international immigration, with the new members of the Canadian mosaic bringing with them such a huge variety of their traditional foods. It was through these years that the true

complexity of the gluten-free diet became so very apparent. It would be another four decades before we would have a truly trustworthy food labelling regulation that offered us the means to eat like and with our friends and neighbours.

I have nothing but gratitude for all the health and food choices I have today. I owe my kids a huge apology for their very limited childhood experiences with interesting foods, based on my need for gluten free eating. And I hold the greatest appreciation for Drs. Lambros Costopoulos (deceased), Ron Wensel (deceased) and Martin Atkinson for providing the pathway to my diagnosis. ♦

*Stay tuned for some 1980s and 1990s historical storytelling in the next edition of **Canadian Celiac**.*



# CCA: the first decade

50TH ANNIVERSARY

## 1973 - 1983 INFANCY, BEGINNINGS, START UP

JANET DALZIEL AND BEV RUFFO

From the first support meeting in a southwestern Ontario city of Kitchener, a core group of volunteers helped support groups become established as chapters in several areas across Canada; by 1983, at least 16 chapters were registered as “Canadian Celiac Association”, a national charitable organization. The first support group meeting was held at the Kitchener Waterloo Hospital on a stormy winter night in February 1973 with early financial support from the Kauffman Foundation. It was arranged with help from Isobel Burrows, a nurse at the hospital.

### KEY HIGHLIGHTS

#### Food

■ From 1974 – 1978, the CCA “Food Committee” headed up by Murray Schlueter would help import food from the United States. The committee helped navigate the expensive brokerage charges that came with the orders. Thanks to Bob Beausoleil, a customs broker, who helped make this process more efficient and cost effective.

■ Sick Kids Hospital and Weston Bakery developed a bread, made with wheat starch, which was kept

in a freezer in the dispensary at Sick Kids Hospital and sold at cost; along with imported pasta and a bread mix. Outside of Toronto, Weston Bakery required a minimum order of 350 loaves of gluten-free bread. KW chapter volunteers were responsible for picking up the bread and stored and sold it at a member’s home.

#### Organization

■ A national network of chapters was created, and the National Association established, with the assistance of a \$500 donation from Waterloo Rotary Club.

■ An article in Chatelaine magazine spurred the growth of chapters Canada-wide.

■ Print materials, including a national handbook, were created to support and educate members.

■ The first chapter started in 1975 in Hamilton, Ontario and its first meeting was held at McMaster University Medical Centre.

■ First conference held in 1979 in Kitchener/Waterloo.

■ May 1981 – a national organization was officially formed and later incorporated.

*Continued on next page*

# “The lack of resources and information along with the difficulty of accessing gluten-free food in Canada, drove both women to take action ...

## Medical/Scientific

■ Gluten-free diet accepted by medical establishment as necessary treatment for dermatitis herpetiformis.

■ Celiac disease confirmed as a lifelong condition.

## Key People

■ Kay Ernst, Nora Reck, Founders

■ Frances Murphy, President '79- '81

■ Dr. J.A. Campbell

■ Major Mike Henderson

■ Carol Lindsay, President '73- '75

■ Murray Schlueter

## ABOUT OUR FOUNDERS

### Kay Ernst and Nora Reck

In autumn of 1972, an adult with sprue and the mother of a 17-year-old son with celiac disease met by chance. The young son

had written home from Switzer-

land stating that delicious gluten-free food products were available on store shelves and included bread, cookies, cakes, and pastry. Nora

had learned about a Coeliac Spruce Society in England. The lack of

resources and information along with the difficulty of accessing glu-

ten-free food in Canada, drove both women to take action together.

They gathered information and consulted with pediatricians in the

Kitchener-Waterloo area and gastroenterologists in Toronto and pro-

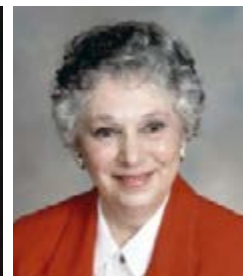
posed the establishment of a celiac society in Canada. Together they

organized the first ever meeting. Shortly thereafter, it was determined

that an organization needed to be formed. ♦



**Kay Ernst**



**Nora Reck**

PHOTOS FROM CCA ARCHIVES



gluten free ...



**Find thousands of gluten-free products using our  
Product Finder Tool  
Celiac.ca**

# Mark's journey into celiac

**Unsung hero Mark Johnson, one of many dedicated volunteers, who has CCA moving forward**



**Mark's journey to Antarctica, 2017**

PHOTO BY MARK JOHNSON

50TH ANNIVERSARY

## CCA change maker and celiac explorer

**Q The CCA is turning 50 this year. You have seen many changes. What are some of your most memorable moments with the CCA?**

**A** I've been involved with the CCA as a volunteer since mid-2006, serving on the boards of directors of both the Ottawa Chap-

ter (2006 to present) and CCA National (2011 to 2018). Chairing or co-chairing several national conferences of the CCA has been a challenging but extremely fulfilling experience. Seeing the conferences go forward, knowing how much work you and your teammates put into the huge array of logistics, is something I cannot

put into words. I'm fortunate to be in a position to offer so much time for volunteering, and for a cause that matters so much to all of us.

Secondly, at the national level, the launch of the Gluten-Free Certification Program (GFCP) was a signature moment for the CCA.

*Continued on next page*

# “ Having been diagnosed back in 2005, I am humbled to now be able to provide advice and guidance to newer celiacs – Mark Johnson

It came with major start-up costs, but also huge benefits down the road. For example, being able to quickly understand, by seeing the logo, that a product is not just gluten free, but prepared with safe ingredients and processes, all of which have been verified by external auditors has been an immeasurable benefit to the gluten-free community in Canada. There were many players involved in launching the GFCP, and we see the results every time we go to the grocery store.

## **Q Where do you see the CCA in the next 50 years?**

**A** To be brutally honest, I'm part of the group that feels that, in an ideal world, the CCA would not need to exist. By that, I mean that we will have a cure for celiac disease, and the need to eat gluten free is no longer a reality. The CCA and other like-minded organizations are funding cutting-edge research into therapies that, while perhaps not curing us of celiac disease, can at least offer some protection, since cross-contamination is a never-ending challenge. While the CCA does critical work on our behalf, and will for many years to come, I hope that someday celiac disease will no longer exist, and with that, the CCA will ultimately have achieved its objectives.

## **Q We love our volunteers and**



## **Mark volunteering as emcee at CCA State of Celiac conference**

## **truly could not exist without them. What drives your commitment to volunteer with the CCA?**

**A** I feel it is rewarding to be able to give back to the community, but doubly so when you yourself (or your family or friends) have a lot of “skin in the game”. In improving diagnosis and quality of life for those in Canada with celiac disease and gluten sensitivity, volunteers are helping both themselves and others. Having been diagnosed back in 2005, I am humbled to now be able to provide advice and guidance to newer celiacs.

I also love the diversity of the

volunteer opportunities that are out there. Such duties as writing and social media - and helping organize national conferences - make sense for me, as they align with my interests. Counselling the gluten free on travel is, of course, also right up my alley! For those who are able to fit it into your lives, please consider volunteering, whether for your local support group or Chapter, or for CCA National. There are diverse opportunities to suit all interests and skills!

## **Q Tell us about the Ottawa Chapter. When did you become president?**

**A** The Ottawa Chapter began in the 1980s, and I joined its board of directors in 2006, a few months after relocating from Kitchener-Waterloo to Ottawa. I have served as Chapter president for four of the past six years. The boundaries of our Chapter area are not exactly fixed, but we cover as far south as Peterborough, as far west as Sudbury, and up to Timmins in Northern Ontario.

## **Q You have celiac disease. What is your diagnosis story?**

**A** Believe it or not, my diagnosis story isn't too exciting or painful. *Continued on next page*

“ Along with volunteering and being a news junkie, travel is one of my top three passions. I’ve been to over 60 countries so far – *Mark Johnson* ”



PHOTO SUPPLIED BY MARK JOHNSON

**Mark keeps going back to Cuba, because he finds they take great care of people with celiac**

I was feeling tired and bloated all the time, with gut pain, and I was losing weight. The doctor ordered a bunch of blood tests, including for celiac disease.

When that came back positive, I went and got the biopsy (in January 2005), and after that, went totally gluten free. I had never heard of celiac disease before my diagnosis, although it turned out that a second cousin also has it, too.

**Q You love to travel; in fact, you have spoken to our community**

**about travel many times. What are your favourite holiday destinations for the GF traveler?**

**A** As I type, I’m with my lovely wife, on our honeymoon, aboard a cruise ship scheduled to arrive in Antarctica in a couple of hours. Yes, I love to travel! Along with volunteering and being a news junkie, travel is one of my top three passions. I’ve been to over 60 countries so far. The place I “keep going back to” is Cuba, where I find they take great care of me as a celiac, and beach therapy is

always in order. No matter where I go, I always seek out celiac-friendly restaurants, but I find that cruise ships (depending on the company) do an amazing job with all food allergen issues. Across the globe, countries that were particularly easy to eat in for me were Norway, Finland, and New Zealand, while countries that were very challenging were South Korea, China, and Russia. There are always options, of course, and depending on the destination, I might take some of my own food along. Preparation is the key to successful travel! ♦

# Gluten-free food safety

50TH ANNIVERSARY

## GLUTEN-FREE CERTIFICATION PROGRAM (GFCP): *behind the trademark*

ANNE WRAGGETT, CCA PAST PRESIDENT

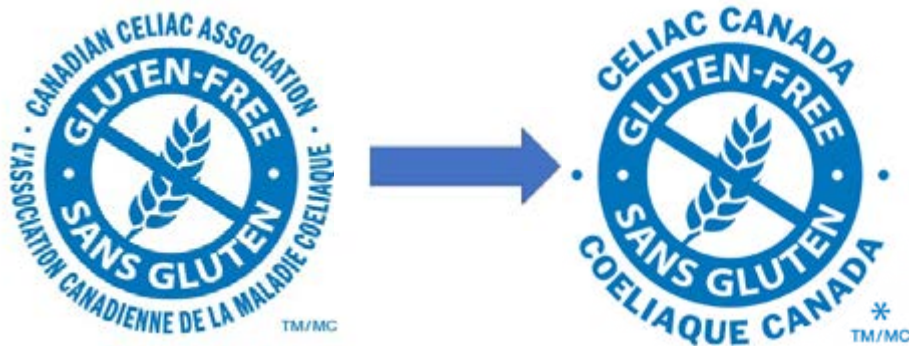
As part of our 50th Anniversary celebrations, we'll be featuring milestones and innovations that you have supported throughout our history. Flashback 11 years ago when we led the development of what has become one of North America's first and still today one of the world's strongest gluten-free food safety programs.

### GFCP: Behind the Trademark

On food packaging we've all seen that little blue symbol of crossed-out grain surrounded by the words, "Canadian Celiac Association Gluten-Free" in English and French. Ever wonder how it came to be on the food package? What it actually means? How it all began?

#### It's a trademark!

The symbol is the CCA's Gluten-Free Food Certification Program (GFCP) trademark. I always like to start by indicating what this program is not. It does not reflect a manufacturer's in-house end-pro-



uct testing. It is not some kind of written verification, "yes our products meet the < 20 ppm standard". It is not an advertising logo that companies buy into. So ...

#### What actually is it?

Unlike many other gluten-free programs, the GFCP is a HAC-

CP-based food safety program. Some of you will be familiar with HACCP or Hazard Analysis Critical Control Point programs. This is the basis of all scientific, food safety programs and is something with which all food manufacturers are familiar.

*Continued on next page*

# “Coming to a grocery shelf near you! You will soon be seeing our new mark to reflect our name change!”

## It is a systematic, preventative approach to food safety (read: gluten safety)

- It is used at all stages of food production including preparation, packaging etc.
- Going far beyond simply inspecting or testing finished products, a HACCP program analyses the hazards, identifies the critical points at which a process can go wrong, – or in our case, a food can become contaminated with gluten.
- Monitors procedures, establishes verification processes, and ensures that there is complete documentation.
- To achieve certification through the GFCP, each manufacturing plant is audited annually by specially trained 3rd party, independent auditors.

## “It is quite fun to watch for new products bearing the GFCP logo ... Currently there are more than 150 certified brands and more than 6,000 products!”

### Why do we need it?

- If we have good labelling laws, why do we need this program? It is simply another layer of safety for us indicating that products are below the 20-ppm threshold for gluten free and is also an indication of the manufacturer’s commitment to a gluten-free product.
- The use of the trademark is licensed to companies that apply and pass their annual audit.
- The CCA receives royalties from the license fees, which are scaled for the full range of manufacturers from large corporations down to Mom-and-Pop operations.

### How did the GFCP get started?

Going back more than a decade, finding gluten-free foods that we could be sure were truly gluten free, was not easy. The CCA began searching for a way to mark safe foods and hired an Executive Director, Jim McCarthy, with a background in standards. Jim began discussions with organizations that administered standards, trademarks, and certificates. A working relationship was established with Paul Valder Corporation (PVC), later the Allergen Control Group (ACG) and in time, ACG was contracted to administer the program while the CCA retained the rights to the trademark and earned royalties. BRCGS purchased ACG and now administers the ongoing program.

### Are there many GFCP products?

It is quite fun to watch for new products bearing the GFCP logo as there are increasing numbers of them! No need to make inquiries of these manufacturers because we know they have passed their audits. Currently there are more than 150 certified brands and more than 6,000 products! ♦

### Check out Gluten-Free Product finder and start shopping.

[Coming to a grocery shelf near you!](#) You will soon be seeing our new mark to reflect our name change!





## CELEBRATING OUR 50 YEAR HISTORY

50 years ago little was known about celiac disease and the gluten free diet.

Fast forward to today and both the disease and diet are firmly on the worldwide map. Thanks to our founders and the work of the charity ever since, almost 40,000 diagnosed people in Canada now live a better way of life thanks to improved recognition and diagnosis of the disease and ongoing improvements to the gluten-free diet.

We have much to celebrate in terms of our achievements and the amazing work of our volunteering community over the past 50 years.

We'll be featuring stories and snippets of the past 50 years in 2023 editions of Canadian Celiac Magazine and on our website as well as social media. We're also gearing up to get more support for our research activities so we'll keep you informed on how you can help us do that.



*Christine Nesbitt, Canadian Olympic Gold Medalist, is raising awareness of celiac disease across Canada*

### Help us celebrate

Help us celebrate our passionate and committed community and our food and health professional networks who have campaigned, fundraised and worked alongside us to make incredible innovations and improvements to living gluten free and making sure celiac disease has become a recognized and treatable condition.



*Local volunteers like Mary Anne Griffin make a huge difference in the community*

### Get in touch with pictures, stories and more

Have you been with us since 1973? Or are you also turning 50 next year? Do you have a story to tell about what it was like living gluten free all those years ago? Please send us stories, photos and anything you think might interest our community and help us really celebrate our history.

Send your photos and stories to:

communications@celiac.ca or 1450 Meyerside Drive, Suite 503, Mississauga, ON L5T 2N5, Canada.

# CCA volunteer recognition

50TH ANNIVERSARY

## RECOGNIZING the spirit of our community

**Our National Volunteer Recognition Program will celebrate and recognize the incredible spirit of our community leaders and volunteers past and present**

### WHO CAN BE NOMINATED?

- People living or who lived in Canada. Nominations can be posthumous.
- Nominations may only be made for one person at a time.
- People can nominate more than one person. People can be nominated multiple times but please note will only be recognized once.

**Nominations Open**  
February 5, 2023.  
**Nominations Close**  
March 31, 2023.

### CATEGORIES:

#### ■ Change Maker (National)

This category can be best described as, "If it were not for this person, we would not be where we are today." The individual has helped drive meaningful change whether it be health, policy or driven success for the CCA and the community with lasting impact.

#### ■ Super Volunteer (National/Regional)

This category is meant for those unsung heroes who are dedicated to helping deliver programs, help and support. They might have been an active volunteer on committees or boards, led local support group meetings or developed programs, helped with food drives or are just always lending a helping hand whenever there was a need.

#### ■ Young Volunteer (National/Regional)

This category is for volunteer efforts of persons 18 years of age and younger.

*Continued on next page*



PHOTO BY MELISSA SECORD

**Left: Anne Wraggett, CCA President 2016 - 2018**  
**Right: June Williams, Ottawa Chapter Past President**



PHOTO BY BEV RUSSO

**Left to right: Volunteers Ruth Penfound, Theresa Cuthbertson, and Joyce Friesen**

“ If it were not for this person, we would not be where we are today.

– Description of *CHANGEMAKER CATEGORY* nomination



PHOTO BY BEV RUFFO

Left to right: Mavis Molloy, RD, PAB; Dr. Ralph Warren, MD, PAB; Jim McCarthy, our Executive Director from 2007 to 2012; Dr. Mohsin Rashid, MD, PAB; Marion Zarkadas, RD, PAB

## ANNOUNCEMENTS

- All nominees will be announced during the April 30, 2023, Celiac Disease Awareness Month online kick-off event and on our website.
- We will do our best to contact nominees prior to announcement.
- Nominees will need to be willing to have their name and/or image publicized.
- Some nominees and their nominators will also be featured in *Canadian Celiac* in May and November editions.
- Nominees (or relevant family/friend) will be notified by April 21, 2023.

To nominate someone, please complete [this online form](#).

If you have questions about this program or form, please email [clientrelations@celiac.ca](mailto:clientrelations@celiac.ca).

*Disclaimer: We have the final discretion on publicizing or removing any nominees.*

**LEARN MORE**  
**WAYS TO GIVE**



**DONATE**

# Gluten-free dining

TRAVEL

## AT THE DISNEYLAND RESORT **Our dietitian, Nicole Byrom, helps make your next gluten-free vacation stress free**

Travel can be stressful when you have celiac disease or other gluten-related disorders. No one wants to be sick while on vacation! If you are planning a vacation to the 'Happiest Place on Earth', we have done the homework for you!

PHOTO BY NICOLE BYROM



Disney is very celiac-friendly

### **SOME IMPORTANT POINTS TO KNOW WHEN PLANNING YOUR NEXT DISNEY VACATION**

- All Disneyland Resort restaurant staff are trained to handle dietary requests, including those needed for celiac disease and other gluten-related disorders.
- When dining at sit-down restaurants, and most quick service locations, you may request to speak to the chef. A chef will come to your table and discuss the menu options available for you. This is a great opportunity to discuss how the kitchen manages cross-contamination. As per the Disney website, *"You can request to speak with a chef or a special-dietary trained Cast Member at most table-service and select quick-service restaurants. In most cases, no advance arrangements are needed."*
- When making online dining reservations, there is a section for you to specify any dietary needs of your party. This includes the mobile ordering app.
- Mobile ordering is VERY popular at the Disney Parks. You can specify allergy requests when mobile ordering for select locations. Not all locations have allergy-friendly options on mobile ordering.
- Some carts or kiosks do not have allergy-friendly menus available.

*Continued on next page*



### TOP 3 GF SNACKS IN THE DISNEYLAND RESORT

1. Dole Whip
2. Popcorn
3. Mickey ice cream bar

**(Notable mention:** those huge turkey legs are GF!)

### TOP 3 QUICK SERVICE LOCATIONS IN THE DISNEYLAND RESORT

1. Smoke Jumpers Grill (Disney California Adventure/DCA)
2. Hungry Bear (Disneyland /DL)
3. Jolly Holiday Bakery Café (DL)

**(Notable mention:** Alien Pizza Planet)

### TOP 3 SIT DOWN LOCATIONS IN THE DISNEYLAND RESORT

1. Goofy's Kitchen (Disneyland Hotel, character dining location)
2. Tortilla Jo's (Downtown Disney)
3. Carthay Circle (DCA)

**(Notable mentions:** Napa Rose & Storytellers Café)

### PLACES TO AVOID

They are delicious... but not safe for those with celiac disease

- Bengal BBQ – quick service location in Adventureland. The Bengal BBQ uses one large grill and cannot guarantee safe gluten-free options. (DL)
- Churro carts – sadly, these items are not GF.
- Corn Dog Castle (DCA)
- The Golden Horseshoe. Dining at the Golden Horseshoe is very difficult for those on a gluten-free diet, so best to avoid if you want to leave feeling full. (DL)

Most of the time, restaurants and quick service locations at the Disneyland Resort do not require advanced notice to accommodate dining requests, including those for celiac disease. However, if you or someone in your party has four or more dietary requirements you should contact [SpecialDiets@Disneyland.com](mailto:SpecialDiets@Disneyland.com) in advance to ask for a Special Dietary Request Form. ♦



PHOTO BY NICOLE BYROM

- [Click here for a complete list](#) of dining locations and menus in Disneyland Resort.
- [Learn more about food allergies](#) and special dietary needs at Disneyland Resort.
- [Check out this magical video](#) created just for those on a gluten-free diet!

# PAC highlight

## TRAVEL

# Dr. Don Duerksen BRINGS KNOWLEDGE AND EXPERTISE HALFWAY ACROSS THE WORLD

Our very own Professional Advisory Council (PAC) Chair Dr. Don Duerksen travelled to Rwanda in 2022 as part of a formal gastroenterology training program.

Rwanda is a small country in central Africa with approximately 12 million people. It is a beautiful country, also known as the 'Land of 1000 Hills'. The capital city is Kigali, and the country is home to the Akagera Game Park as well as to Mountain gorillas. Since 2018, Dr. Duerksen has been involved with a group of gastroenterologists who teach gastroenterology and endoscopy to Rwandan physicians. Over the past five years there has been tremendous development of their endoscopic facilities.

The diet in Rwanda includes lentils, potatoes, rice and other vegetables. There is limited access to wheat particularly for rural living individuals. At present there is very little that is known about the prevalence of celiac disease in Rwanda, however gluten-free products are available in their grocery stores. ♦



PHOTOS BY DR. DON DUERKSEN

# Dear Dietitian

## NUTRITION

# YOU ASKED, WE ANSWERED.

**Our dietitian, Nicole Byrom, helps answer your frequently asked questions**



**Q I am so confused! My daughter has just been diagnosed with celiac disease and I'm not sure if foods containing corn starch are safe for her or not? What about corn flour and corn meal? Are they the same thing?**

**A** We have always recommended for those living with celiac disease and non-celiac gluten sensitivity to purchase flours that carry a gluten-free claim; and this includes both cornmeal and corn flour.

In 2012, the Canadian Food Inspection Agency (CFIA) did a study on corn flour. In the [study](#), 16% of corn flour samples contained over 20 parts per million (ppm) gluten, which is considered unsafe for individuals with celiac disease. Manufacturing processes have remained relatively unchanged since this study was completed, which is why the results of this study are still relevant today.

As always, we want to ensure that our recommendations are current and up to date. During a meeting with Health Canada on November 22, 2022, we requested that corn flour/meal and corn-based products undergo a new review to assess if snack-related items, such as corn chips and corn puffs, have been studied to determine safety. We want to ensure that we are not restricting intake in an already restricted lifestyle.

Corn starch, on the other hand, is a highly processed food product/ingredient and as such is at low-risk of gluten cross-contamination/contact. For this reason, individuals with celiac disease do not have to purchase or consume corn starch with a GF claim. ♦

**We have put together a [new statement on corn](#).**

For all other statements issued by the CCA and PAC please click here: [Position Statements - Canadian Celiac Association](#).

*Have a question you'd like answered in the next magazine, email us at [AskTheCCA@celiac.ca](mailto:AskTheCCA@celiac.ca)*

# Vitamin B12 & celiac disease

NUTRITION

## WHAT IS VITAMIN B12?

**Are you getting enough of this powerful micronutrient?**



BIT245 / ISTOCK

NICOLE BYROM, CCA REGISTERED DIETITIAN

Vitamin B12 is an important water-soluble vitamin that is found naturally in some foods, added to others, and commonly sold as a dietary supplement and prescription medication. Vitamin B12 is essential to carry out many of our daily bodily functions, which include the development and function of the central nervous system, as well as the production of healthy red blood cells that transport oxygen throughout our bodies and the DNA that holds our genetic information. For the cells of our brain and neurological systems to run properly, adequate amounts of  
*Continued on next page*

# “ A vitamin B12 deficiency is more likely ... in those with celiac disease who often have damaged intestinal mucosa ...

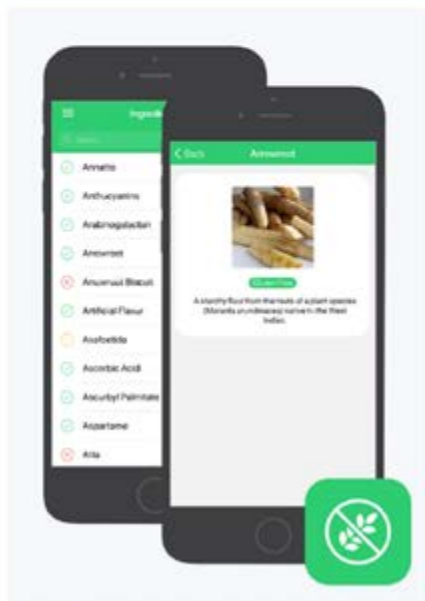
vitamin B12 are necessary. Additionally, vitamin B12 is important for enzymatic processes within our body.

The most obvious reasons why one may have low B12 levels include inadequate consumption and absorption of foods that contain vitamin B12. Megaloblastic anemia, low platelets, or a combination of these can occur when low levels of vitamin B12 persist. Unusually large, abnormal, and immature red blood cells outnumber healthy cells resulting in not enough oxygen being carried throughout the body, causing neurological damage and symptoms such as tingling in the hands or feet, weakness, lightheadedness, exhaustion, and shortness of breath.

A vitamin B12 deficiency is more likely to occur in some groups, as is well known in those with celiac disease who often have damaged intestinal mucosa caused by

an inflammatory reaction to gluten. The body experiences difficulties absorbing vital nutrients and vitamins like vitamin B12 from foods when the lining of the intestine is not functioning properly. Many celiac patients exhibit digestive issues like stomach aches, bloating, gas, diarrhea, constipation, and abdominal cramps. The intestinal mucosa will start to repair itself if a strict gluten-free diet is adhered to. With a decrease in digestive symptoms and healthier intestinal mucosa, the body's capacity to absorb vitamin B12 increases since we know it is absorbed in the latter stages of the small intestine.

Additionally, vegans and vegetarians, particularly those who also have celiac disease, are another population with a higher risk of vitamin B12 deficiency. Only naturally occurring animal food sources like meat and contain  
*Continued on next page*



## It can be difficult to know which foods contain gluten...

Gluten Free 24/7 was created in collaboration with the Canadian Celiac Association. This app helps individuals dealing with celiac disease or gluten sensitivity identify and shop for safe, gluten free foods.

Gluten Free 24/7 app takes the guesswork away and makes it easier to maintain a gluten free diet.

Purchase the app today to help you stay gluten free - 24/7!

Available on the App Store, Google Play and Amazon!





vitamin B12. It is now easier for people to consume enough vitamin B12 thanks to vitamin B12-fortified products such as cereals, nutritional yeast, alternative milk (almond, soy, rice milk), vegan yogurts, and vegan butter. Reading labels on food products will help determine if it has been fortified with vitamin B12 and is gluten free.

Many drugs can reduce the absorption of vitamin B12: metformin (diabetic medication), H2-receptor blockers and proton pump inhibitors (both used to relieve symptoms of acid reflux). Older individuals are more likely to suffer from low levels of vitamin B12 because they produce less intrinsic factor, a protein essential for proper absorption of vitamin B12 into the bloodstream.

### HOW MUCH B12 DO I NEED?

**Age (years) Men & Women (mcg/day) RDA**

1-3	0.9
4-8	1.2
9-13	1.8
14+	2.4
Pregnant & Breastfeeding	2.6-2.8

*\*The Recommended Dietary Allowance (RDA) is the average daily level of intake sufficient to meet the nutrient requirements of nearly all (98%) healthy individuals.*

The daily recommended intakes of vitamin B12, measured in micrograms are the same for both males and females. The chart above showcases the recommended daily allowance by age in years. As you can see, children aged 1-3 need 0.9 mcg/day, 4–8-year old’s need 1.2 mcg/day, 9–13-year old’s need 1.8 mcg/day and everyone over 14 years old needs 2.4 mcg per day. The numbers are slightly increased to 2.6 mcg/day for individuals who are pregnant and 2.8 mcg/day for individuals breastfeeding to support the development of an infant.

### TOP 10 FOOD SOURCES OF VITAMIN B12

1. Canned Clams, per 75 g (74 mcg)
2. Cooked Liver, Beef/Lamb/Veal, per 75 g (60 mcg)
3. Cooked Liver, Chicken/Turkey, per 75 g (18 mcg)
4. Mussels, per 75 g (18 mcg)
5. Nutritional Yeast, per 2 tbsp (~8 mcg)
6. Fortified Cereal, per 1 cup (~6 mcg)
7. Cooked Trout, per 75 g (5.6 mcg)
8. Canned Salmon with bones, per 75 g (3.7 mcg)
9. Fortified Tofu, per 1 cup (3.3 mcg)
10. Cooked Beef, per 75 g (2.5 mcg)



Thankfully, many foods high in vitamin B12 are natively gluten free. The finest nutritional sources of vitamin B12 are animal products, as already explained. For instance, liver and other organ meats like clams, tuna, salmon, and beef are abundant in vitamin B12.

There are a growing number of plant-based goods available for vegetarians and vegans that are fortified with vitamin B12, which means the vitamin has been added to the food during processing. Soy milk and other non-dairy beverages, as well as other meatless substitutes like soy burgers, are examples of fortified goods. To make sure these products are gluten free, carefully read the ingredient labels before making a purchase.

Natural gluten-free nutritional yeast is a plant-based food with a very high B12 concentration. It comes in powder or flake form and is character-

*Continued on next page*



ISTOCK PHOTOS

STEPHANIE FREY / ISTOCK



erized as having a “nutty” or “cheesy” flavour. To increase the consumption of vitamin B12, it is a great addition to salads, omelets, popcorn, or any other savoury food.

### Tips to increase vitamin B12 intake

- Consume milk and dairy products every day; make sure to choose low-fat options
- Consume meat and meat alternatives that are high in vitamin B12
- Always read the food labels to ensure all the foods consumed are gluten free; some gluten-free products are vitamin B12 fortified!
- Look up the vitamin B12 content from the nutrition facts table

### Supplementation

If you are still vitamin B12 deficient, you can consider

an oral supplement. Speak with a registered dietitian or your doctor first. Adults over the age of 50 do not absorb vitamin B12 as they once did. They could consider vitamin B12 fortified meals or speak with their medical team about a supplement. Although there is little risk of toxicity, large quantities could still result in headaches, nausea, vomiting, and diarrhea. There are several doses and dosage forms available over the counter, all at different price points; a pharmacist can also be a good resource.

**Tip** Avoid combining vitamin C and vitamin B12 since the absorption may decrease and vitamin C may destroy vitamin B12.

**Reminder** If you are over 50 years old, vegan, or vegetarian, talk to your doctor or dietitian before using vitamin B12 supplements. ♦



**Support Future Generations and  
Create a Lasting Legacy**

[Celiac.ca/Ways-to-Give](http://Celiac.ca/Ways-to-Give)



# GoGo QUINOA®

## ADD A HEALTHY ZING TO BREAKFAST AND SNACK TIMES

### WITH OUR NEW GLUTEN-FREE BREAKFAST CEREALS!



## TASTE THE WELL-BEING



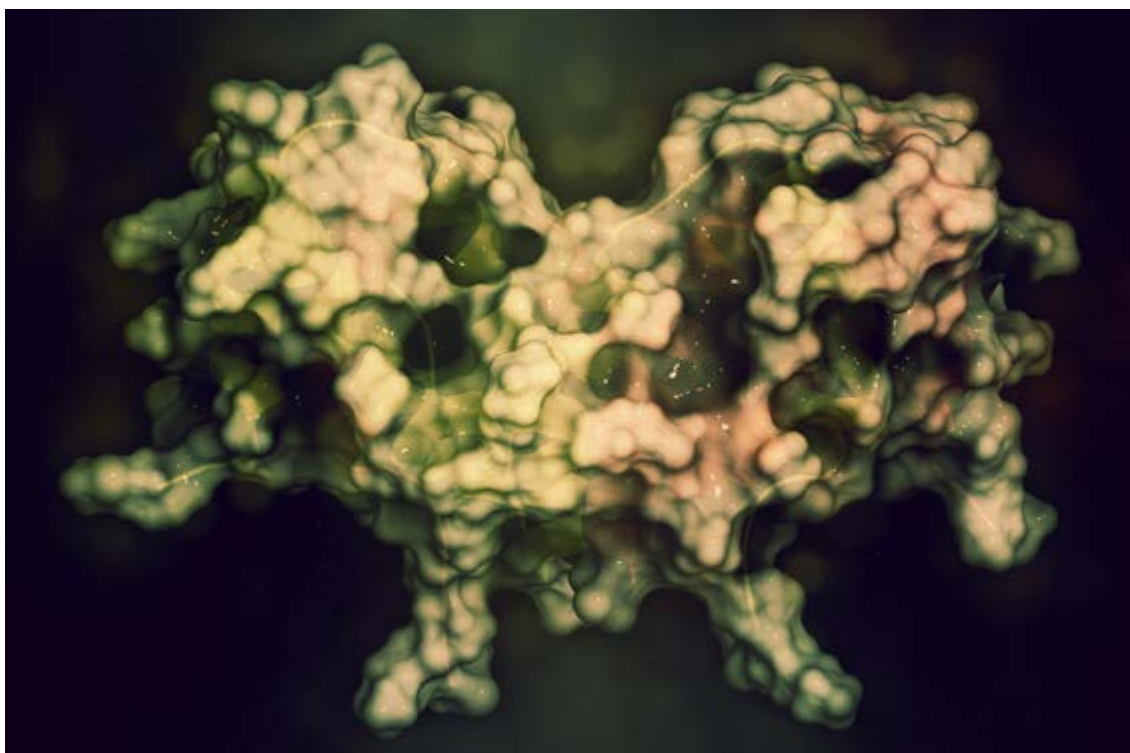
# The future of research

## RESEARCH

# CYTOKINES AND CELIAC DISEASE

**Could cytokines be the answer to disease monitoring in the future?**

WIRESTOCK / ISTOCK



**INTERFERON  
GAMMA (IFN- $\gamma$ )  
CYTOKINE  
MOLECULE**

**Measurement of the cells producing IFN- $\gamma$  in blood could be very useful in clinical trials for monitoring celiac disease, instead of patients having to undergo week-long gluten exposures that are difficult to adhere to**

HEATHER J GALIPEAU, PHD, AND ELENA F. VERDU, MD, PHD

When reading about celiac disease, or other inflammatory diseases, you have likely come across the term “cytokine”. But what exactly is a cytokine and how do they play a role in celiac disease? Cytokines are molecules, produced by cells in our body, that communicate information from cell to cell. Through their signals, cytokines can promote the growth of certain cells, recruit immune cells to areas of injury or inflammation to fight infections or help in wound repair. Overall, when

cytokines help resolve or prevent inflammation, we say they are “anti-inflammatory”. However, when imbalances occur, due to excessive production or impaired clearance of the molecule, they can promote inflammation meaning that the cytokines are “pro-inflammatory”. Research over the years has helped us understand how certain types of cytokines work and what levels and combination of cytokines in the body are pro- or  
*Continued on next page*

“Cytokines are key molecules in the body that help with many functions, including the proper functioning of our immune system.”

anti-inflammatory. There are many different types of cytokines, with similar names, and so it can become very overwhelming. Here we will focus on those that are important in celiac disease and explain why.

One of the most important cytokines in celiac disease is “interferon gamma”, or IFN- $\gamma$ , and is considered “pro-inflammatory”. When someone with celiac disease consumes gluten, inflammation in the small intestine develops. Specifically, immune cells that recognize gluten produce very high amounts of IFN- $\gamma$ . The high levels of IFN- $\gamma$  in the small intestine have several consequences. First, it causes the “epithelial cells” that line the gut wall, to produce other pro-inflammatory cytokines and create (or ‘express’) distress signals. This can further attract immune cells to the small intestine, that continue to produce more IFN- $\gamma$ .

Second, IFN- $\gamma$  activates immune cells present in the small intestine, which usually have a patrolling role to fight infections, to develop a “killer” profile. However, in the case of celiac disease killer type cells do not destroy infective agents, but the epithelial cells signaling distress, causing the “atrophy” or damage typical of celiac disease.<sup>1</sup> Thus, cells that over produce IFN- $\gamma$  are considered a hallmark of celiac disease and can be detected in the blood after a short three-day gluten challenge.<sup>2</sup> **Measurement of the cells producing IFN- $\gamma$  in blood could be very useful in clinical trials for monitoring celiac disease, instead of patients having to undergo week-long gluten exposures that are difficult to adhere to.**

Another important pro-inflammatory cytokine involved in celiac disease is interleukin-15 or IL-15. IL-15 is found at high levels in many, but not all, celiac patients who are consuming gluten. Exactly what causes IL-15 to be produced at high levels in celiac disease is not known. However we do know that



DEPOSIT PHOTO

IL-15 also contributes to the activation of the killer type immune cells that destroys the small intestinal lining.<sup>3</sup> There is one complication of celiac disease, refractory cases, where IL-15 changes the behaviour of immune cells and can promote the development of a rare but dreaded cancer, called lymphoma.<sup>4</sup> Thus, controlling IL-15 with a drug that inhibits its activity (“biological”) is of great interest.<sup>5</sup>

Finally, interleukin-2 or IL-2 is now emerging as a critical cytokine in celiac disease that could be used in diagnosis or to monitor disease status or how patients respond to novel treatments in a clinical study. In celiac patients, IL-2 is produced very quickly after gluten consumption by immune cells, and this can be detected and measured in blood samples. Recent studies found that approximately 4-6 hours after a single gluten challenge. *Continued on next page*

“Another important pro-inflammatory cytokine involved in celiac disease is interleukin-15 or IL-15. IL-15 is found at high levels in many, but not all, celiac patients who are consuming gluten”

# “ Interleukin-2 or IL-2 is now emerging as a critical cytokine in celiac disease that could be used in diagnosis or to monitor disease status ...

lence, IL-2 can be found at high levels in the blood, and this also associated with specific symptoms-nausea and vomiting.<sup>6-8</sup> The really exciting finding in this study was that IL-2 is detected after a single gluten challenge, even when patients are maintaining a gluten-free diet, and it is not detected after gluten consumption in those without celiac disease. This is an importing finding because it could help us diagnose celiac disease in patients that are already on a GFD without the need of long gluten exposure or ‘challenge’, or in clinical studies that are investigating new treatments.<sup>9</sup>

In summary, cytokines are key molecules in the body that help with many functions, including the proper functioning of our immune system. However, under certain conditions, when dysregulated, they drive and maintain inflammation. In celiac disease, IFN- $\gamma$  and IL-15 are pro-inflammatory cytokines that are produced by different cells during active disease and are important for activating the cells that cause tissue damage. In the future we may be able to use this information learned from basic and clinical studies to develop better ways to monitor disease status through the level of these cytokines, or to develop new drugs by resetting the balance. ♦

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## STATE OF CELIAC DISEASE SURVEY

# STATE OF CELIAC DISEASE

## Thank you for helping us with research!

Our online State of Celiac Disease in Canada Health Survey is a major comprehensive health study that will help us learn more about the state of celiac disease in Canada today and how it's changed in the past 20 years. The survey launched September 25th, 2022, and closed December 16th, 2022. Thanks to you, we have had 7491 survey entries and are excited to share our findings in fall of 2023/early 2024.

# Donate Today to Fund Research



## LABORATORY BLOOD TEST REQUEST FORM Provincial Clinical Laboratory



<b>Specimen Collected</b> By: _____ Date: _____ Time: _____	<b>Fasting</b> Yes <input type="checkbox"/> No <input type="checkbox"/>	<b>Payment Responsibility</b> <input type="checkbox"/> WCB <input type="checkbox"/> DVA <input type="checkbox"/> DND <input type="checkbox"/> RCMP <input type="checkbox"/> Self Pay Canadian <input type="checkbox"/> Self Pay Non-Canadian Provincial Medicare # exp. date: _____	Relevant Diagnosis and Therapy		DOB:YYYY-MMM-DD	Sex	Medical Record Number (MF)
Ordering Physician	Contact Info	Copies	Office	Facility and Unit			

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Urea - BUN	Troponin (Green Tube)	Lactate (Gray on Ice)	aPTT	D-Dimer	F
Creatinine - eGFR	C-Reactive Protein	Uric Acid - Urate	Other (specify):		
Calcium - Total	GGT	Prealbumin	<b>Immunology - 1 Red Tube for Each 3 Tests</b>		
Total Protein	LD	Osmolality	Tissue Transglutaminase	IgG, IgA & IgM	

# It's tax season!

## TAXES

# REDUCING the burden of gluten-free living

**A special working group is building the case for changes to tax regulations**

JANET BOLTON, CCA PAST PRESIDENT

As you prepare to sift through receipts and forms to file your 2022 taxes, you may be wondering whether there is tax or income support for people with celiac disease.

The good news is that there is a medical expense tax credit available for the added costs of gluten-free food, as part of the federal tax system. For information on how to navigate this credit, please submit this form on our website to receive a webinar, tools and tips: [Incremental Medical Tax - Canadian Celiac Association](#).

The bad news is that the medical expense tax credit system is very restrictive: it requires extensive work to collect and save grocery receipts and run item-by-item cal-

culations; it is only available to those who qualify based on income; it may not have any value for those who have other medical expense claims and, even for those who qualify, the overall tax savings is very modest.

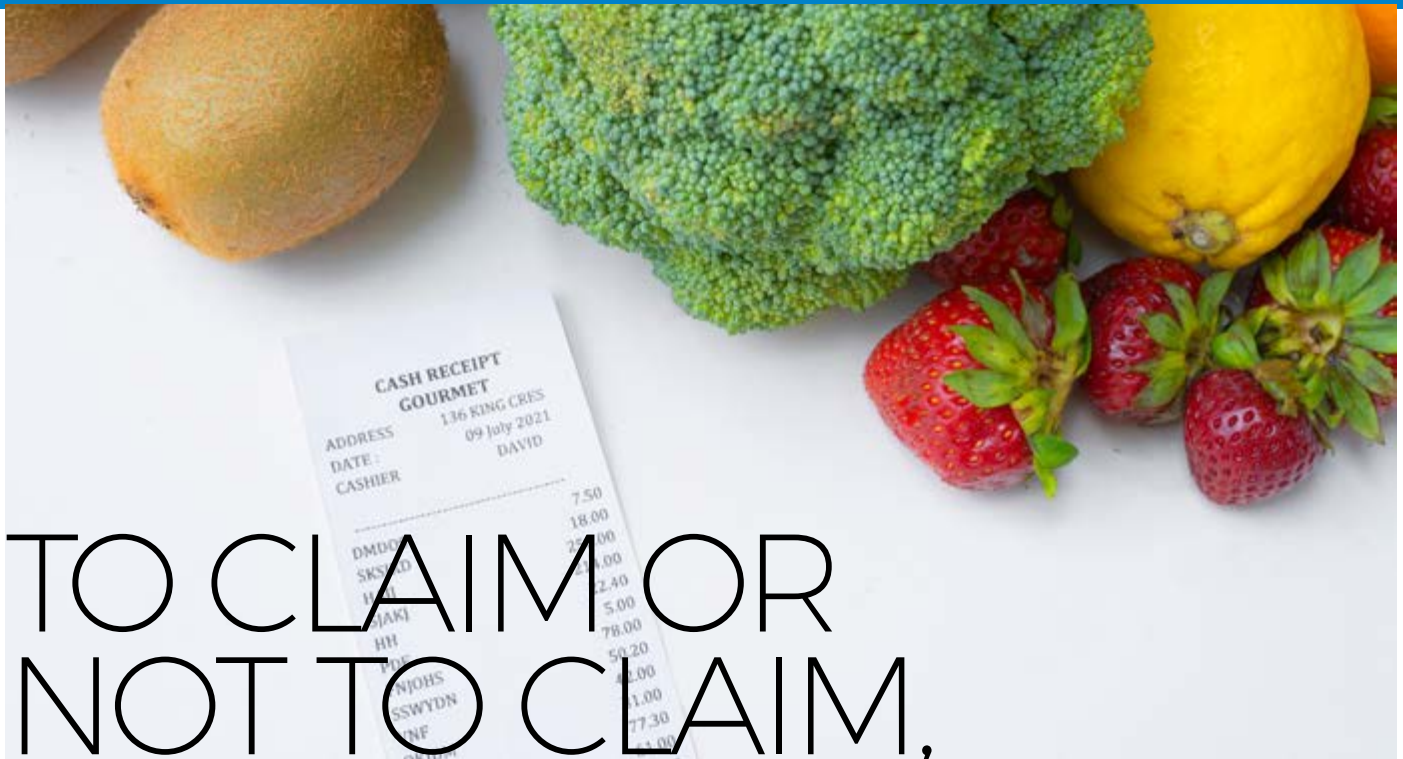
**We are tackling the limitations of the current tax regime head-on. We are advocating for**

- A flat fee method of determining the incremental cost, to make the gluten-free food expense credit more accessible to those who don't have the time or tools to calculate item-by-item cost differentials.
- Recognition that celiac disease impacts families, so the full cost of household gluten-free food purchases should be included in the credit system, with no need to deduct, e.g., the cost of the quarter box of pasta consumed by a non-celiac family member.
- Longer-term, a better, more expansive tax treatment of the gluten free diet, which is the only treatment for celiac disease at this time.

We are reaching out to the Canada Revenue Agency and to other federal government representatives. Please stay tuned to CCA e-mails as we may need your help as this advocacy ramps up!  
*More taxes on next page*



“When I was first diagnosed with celiac disease, my wallet screamed for two years – Robyn Harrison



TAMPATRA / ISTOCK

# TO CLAIM OR NOT TO CLAIM, That is the question

**Just a regular gal trying to save money**

ROBYN HARRISON

When I was first diagnosed with celiac disease, my wallet screamed for two years. Now, you need to understand that I’m frugal when I grocery shop. I limit my packaged products; I buy fresh produce; I keep an eye out for sales. I make the vast majority of my meals at home. Still, after my celiac diagnosis, there was a massive increase in my grocery bill. Imagine my delight when I learned about the tax credit for those with celiac disease: “Thank goodness, I get all of my hard-earned money back!”

Ha! Unfortunately, it’s not **quite** that simple.

To apply for the tax credit or not to apply for the tax credit—that is the question. And it’s a topic of hot debate in the gluten-free community. Let me share with you my experiences with the tax credit so that you can determine whether it’s worth it for you.

Quick note: I am not a tax professional. I’m just a regular gal trying to save money over here. Be sure to talk with your accountant before deciding to claim (or not to claim) the tax credit.

Anything tax-related can seem daunting, but I promise you, I’m a bit of a hot mess when it comes to organization, and I came up with a system that only takes about an hour every year.

## IS IT WORTH MY TIME?

There isn’t a one-size-fits-all answer to this question. It all comes down to whether or not you buy a lot of packaged gluten-free products, have a high net income, and/or have other health expenses.

At the time of my diagnosis, I was a  
*Continued on next page*

# “ At tax time, after calculating my net income, I decide whether or not it’s worth it to go through all of the receipts – Robyn Harrison

self-employed actor and didn’t have a health insurance plan, so all of my health expenses were paid out of pocket. Because of my low net income (thank you, acting career!) and high health expenses, it was worth my time to save my receipts.

If you’re a salaried employee with health benefits and most or all of your health expenses are covered, it might not be worth your time. The exception would be if you have dependents that also have celiac disease.

## HOW I TACKLE MY RECEIPTS IN AN HOUR EACH YEAR

As someone who struggles with organization, I don’t have a running spreadsheet updated on a weekly basis. And—unless you’re certain that you will qualify for the credit—keeping a running total might be a waste of your precious time!

**Here’s what I do** I keep every receipt in a large envelope. I usually just put them in my wallet, and once my wallet starts getting full, I trans-

fer the receipts to the envelope. Then, at tax time, after calculating my net income, I decide whether or not it’s worth it to go through all of the receipts.

### Example

■ Let’s say that I made \$50,000 in net income and I had no other health expenses. My gluten-free costs would have to exceed \$1500 to qualify (3%).

■ For reference, in my first year eating gluten free, I spent an extra \$642.

■ So, in this example, I wouldn’t bother tallying up the receipts. Straight to the recycling bin!

### If you do decide it is worth it to claim the medical expense, here’s what I would do

1. Take out a receipt from the envelope.

2. Highlight the gluten-free item (so it’s easy to see in case I have to recount).

3. Create a tally for each food category: bread, gluten-free oats, pasta, crackers, soy sauce, etc.) Whenever I had one of those items on the receipt, I would place a tally mark in that category.

4. Once I finished going through the receipts, I would add the number in each category. Then, I would put it in a spreadsheet—like the one the CCA offers—to calculate the extra expenses in each category.

5. This process only took about one hour every year, and for the first couple of years after my diagnosis, it was absolutely worth it for me!

### DO I STILL CLAIM IT?

Not right now. Over the years, I stopped buying as many packaged products and mostly eat naturally gluten-free options. I also make all of my gluten-free bread at home, which was my largest expense after going gluten free. Now that I’ve changed the way I shop and bake, I don’t spend enough on gluten-free products to qualify for the tax credit.

If you were recently diagnosed with celiac disease, it might be helpful to add your receipts up for your first year of eating gluten free. That way, you can get a ballpark number on how much you typically spend on gluten-free products. Each tax season, you can determine your net income and use that ballpark number to decide if it’s worth it to go through your receipts. ♦

*If you want to hear more about my experiences with the tax credit, be sure to check out the latest video on my YouTube channel, [Robyn’s Gluten-free Living](#) – and if you want to learn how I make my own scrumptious homemade gluten-free bread, check out [Robyn’s Gluten-free Baking Courses](#).*



# Robyn's Gluten-free Baking Courses



## Banana Bread

MAKES ONE (1) 8.5x4.5" LOAF

### Ingredients

1/2 cup brown rice flour  
1/2 cup gluten-free oat flour  
1/2 cup almond flour  
1/3 cup tapioca starch  
1/2 teaspoon xanthan gum  
1 teaspoon baking powder  
1/2 teaspoon baking soda  
1/2 teaspoon salt  
1 teaspoon cinnamon  
1 cup mashed banana (~2 large)  
1/3 cup canola oil (or melted butter)  
1/3 cup brown sugar  
2 eggs, room temperature  
1 teaspoon vanilla  
2 tablespoons blackstrap molasses  
*Optional:* 1/2 cup chopped pecans

### Method

1. Preheat oven to 325°F (165°C). Grease an 8.5x4.5" pan.
2. In a large bowl, whisk together all of the dry ingredients until well combined.
3. In another bowl, mash the bananas. Add the oil, brown sugar, eggs, vanilla, and molasses. Whisk until smooth.
4. Pour the wet ingredients into the dry, and mix with a spatula. Fold from the bottom of the bowl and scrape down the sides to ensure all the flour is incorporated. (If using chopped nuts, fold them in now.)
5. Scrape into the prepared pan and smooth the top with a spatula.
6. Bake for 45-50 minutes, until the centre looks and feels firm. If the top is browning too much, cover loosely with a piece of aluminum foil (20-25 minutes into the bake).
7. Remove from the pan onto a cooling rack. Let cool completely before serving.

### Get this lesson for free

Create a free account to get instant access to the step-by-step instructional video, printable PDFs, tips, substitutions, & more! 🍌

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# From our community

## RECIPES

Some delicious GF winter recipes submitted by our community to our Facebook group. Get inspired by recipes, new products and peer support on our [Facebook group](#)

# MARLENE'S PUMPKIN ZUCCHINI MUFFINS

## INGREDIENTS

- 2 cups gluten-free oats
- 3 cups gluten free all-purpose flour
- 1 cup or raisins or cranberries
- 4 tbsp baking powder
- 4 tsp pumpkin spice
- 2 tsp baking soda
- 2 cups grated zucchini (liquid removed)
- 1 cup canned pure pumpkin
- 1 cup almond milk
- ½ cup applesauce or honey
- 4 eggs, beaten
- ¼ coconut or canola oil

## DIRECTIONS

- Preheat oven to 375°F.
- Grease muffin tins or line them with paper liners.
- Combine oats, flour, raisins (or cranberries), baking powder, pumpkin pie spice, and baking soda in a bowl.
- In a separate bowl mix zucchini, pumpkin, almond milk, applesauce



- (or honey), eggs, and oil.
- Stir into dry ingredients until just combined.
- Spoon batter into prepared muffin cups.
- Bake for approximately 19 to 20 minutes until a toothpick inserted

into the center of a muffin comes out clean.

24 to 28 servings

*Submitted by Marlene Knit Knerd Bourgeois*



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# AMBER'S POTATO BACON SOUP

## DIRECTIONS

- Chop approximately 4 to 5 decent sized shallots, or 1 large onion, 3 leeks or 7 green onions, whichever is your preference.
- In a large pot, caramelize your chopped onion.
- Peel 4 to 5 large potatoes. Chop & place in a pot with water. Boil until soft.
- If you have a handheld blender, partially drain the potatoes & blend smoothly. If you do not have a handheld blender, place potatoes in a blender along with some

of the water they were boiled in & blend until smooth. You may need to repeat this step.

- In the pot with the onion, add 2 cups of water or chicken stock (vegetable stock works too). I like to add some garlic. Continue to heat. Add your pureed potato mixture to the pot, stir. If the soup is not thick enough, add some cornstarch (or your favourite flour blend). Now, add your crumbled bacon bits to the pot.
- Serve with salt & pepper on the side.

*Submitted by Amber TwoColours*

# ROJ'S GLUTEN-FREE Oatmeal Chocolate Chip Cookies

## INGREDIENTS

### Wet Ingredients:

- ¼ lb. salted butter, pre-softened at room temperature for at least 2 hours
- ¾ cup (loose, not packed) dark brown or (preferably) Demer-ara-style brown sugar
- 1 large egg
- ½ teaspoon vanilla

### Dry Ingredients:

- 1½ cups gluten-free coarse-cut oats
- ½ cup (scant) brown rice flour
- ½ teaspoon salt
- 1 teaspoon xanthan gum
- ¾ cup semi-sweet chocolate chips

## DIRECTIONS

- Pre-heat your oven to 350F.
- In a medium bowl add all the dry ingredients and stir together with a mixing spoon.
- In a large bowl first combine the butter and sugar, stirring them together with a fork. Then add the egg and vanilla and stir into the butter/sugar mix with the fork.
- Add all the dry ingredients into the wet ingredients bowl and stir together with the mixing spoon.



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Make sure you stir/press/flip the ingredients so there are no dry or sloppy spots in the mix. You should end up with a pretty solid, but moist mass of cookie dough.

- Take a heaping teaspoon-full of cookie dough, and form into a flat-topped cookie shape. The individual cookies should be about 2 inches (5 cm) in diameter and about ½ inch (1 cm) thick. This is a solid dough, and the cookies don't change shape much on cooking – they will not flow like traditional chocolate chip cookies when baked. You should end up with about 12 cookies.

- Place cookies on a non-stick

cooking tray and put the tray into the pre-heated oven.

- Bake for 18-20 minutes. Individual ovens differ in temperature accuracy, so monitor the cookies after 15 minutes to make sure they don't burn. The result should be lightly browned on the outside and underside, but still soft in the middle.

- Remove from oven and place immediately on a cooling rack.

- Ready to eat with a glass of cold milk in 15 minutes!

- Store in a sealed container after they've fully cooled, which takes 15-30 minutes.

*Submitted by Roj Miller*



CHAS53 / ISTOCK

# SEANEEN'S CHICKEN VEGETABLE POT PIE

## INGREDIENTS

- 1 pkg frozen mixed veggies
- 2 tbsp margarine
- ½ cup chopped onion
- ½ cup sliced celery
- ½ tsp dried thyme
- 1 can cream of broccoli or mushroom soup *I used yellow label no name brand reduced fat soup*
- 1 can cream of chicken soup *I used yellow label no name brand reduced fat soup*
- 1 cup milk
- 3 cups diced chicken or turkey
- ¼ tsp pepper
- 1 can crescent roll dough *I used Bisquick GF biscuit mix*

## DIRECTIONS

- Preheat oven to 375.
- Cook veggies, drain.
- In a 2 qt saucepan over medium heat melt margarine and cook onion, celery and thyme until onion & celery is tender, stirring occasionally.
- Add soup and milk and stir until smooth.
- In 12" x 8" baking dish combine chicken or turkey, veg and pepper. Add soup mix, stirring gently to mix.
- Unroll crescent rolls without separating.
- Press perforations to seal. Cut

- dough into strips & arrange it over meat mix in lattice. Or make biscuit mix and drop onto meat mixture, being careful not to mound too high.
- Bake 30 min. Cover edges with foil after 20 min if browning too fast.
- Let stand 5 min.

*I can't remember how long I baked it for; I kept taking it out of the oven and checking the "bottom" of the middle biscuits to see if it was baked through.*

*Submitted by Seaneen Waesh*





CANVA PHOTO

# BARB'S COCONUT GRANOLA

## INGREDIENTS

- 2 cups gluten-free oats
- 3/4 cup shredded sweetened coconut
- 1/2 cup slivered almonds
- 1/3 cup pumpkin seeds
- 1/3 cup pine nuts (your choice)
- 2 tbsp brown sugar
- 2 tsp cinnamon
- 1/4 tsp salt
- 4 tbsp coconut oil, melted
- 1/2 cup agave syrup (maple syrup,

or honey)

- 1 tsp vanilla extract
- 1/4 tsp coconut extract (or almond or your choice)

## DIRECTIONS

- In a large wok pan combine all the ingredients, stir over med heat until combined and begin to toast.
- When it starts to brown quickly remove and pour onto a parchment

lined cookie tray to cool.

- Or when warm press into a 9x13 pan and make granola bars. We did this and wrapped them separately for a ready to go treat.

*Adapted by Barb Biega, a member of our Facebook Group*  
*Not a member of our Facebook group? Get inspired by recipes, new products and peer support on our [Facebook group](#).*

# Upcoming events

See what is happening across the country at our local chapters and here at CCA national!

## FEBRUARY

**13 February 2023**  
**CCA national**  
[Gluten free 101: Getting started on the gluten-free diet](#)  
Virtual, 8pm ET

**22 February 2023**  
**CCA national**  
[Nutrition Power Hour](#)  
Virtual, 7:30pm ET

## MARCH

**5 March 2023**  
**BC chapter**  
AGM, New Westminster  
Public Library, 2pm PCT

**6 March 2023**  
**CCA national**  
[Gluten free 101: Getting started on the gluten-free diet](#)  
Virtual, 7pm ET

**12-13 March 2023**  
**Edmonton chapter**  
[Casino night](#)

**16 March 2023**  
**Calgary chapter**  
[Celiac 101 Information session](#)  
Virtual, 7pm-9pm GMT



Please note all times are shown in the time zone of the event location. [Find out more about events and local support group news.](#)

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