

IT'S CELIAC AWARENESS MONTH

Canadian **CELIAC**

**Global BC News Anchor,
Jennifer Palma, shares
her journey with
celiac disease**

Plus

**CHECK OUT
OUR FIRST
CHANGE MAKERS**

**GRAPPLING WITH
FATIGUE? HERE'S WHY.**

**TOURING EUROPE
GLUTEN FREE**

MATTHEW'S TIPS FOR KIDS

SPRING RECIPES

**CCA TAKES ON
PARLIAMENT HILL**



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Canadian CELIAC

A MAGAZINE FOR CANADIANS WITH
CELIAC DISEASE AND GLUTEN SENSITIVITY

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WJAREK / ISTOCK

A magazine for Canadians with celiac disease and gluten sensitivity

SPRING 2023



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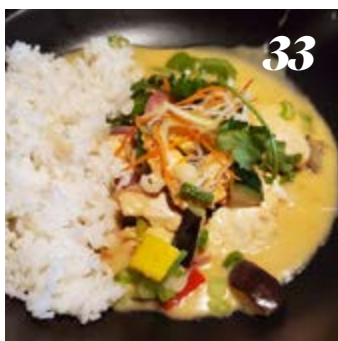
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From the Executive Director

50TH ANNIVERSARY

A GOLDEN OPPORTUNITY



CHARLES FROST



Executive Director, Melissa Secord with volunteer and Change Maker Marion Zarkadas

As we continue our 50th anniversary celebrations, we have been showcasing the collective hard work and dedication of individuals and volunteers over the past five decades. It is because of their steps that we stand here today with hope for a better future and each step builds on the next. Whether it is clear labelling on gluten-free food sold at retail, the development of world-class food safety standards or research that helps us improve access to better treatments, this foresight and passion to make life better allows us to carry the torch forward.

We stand here today finally, with Ontario joining the rest of the country with provincially insured diagnostic blood tests for celiac disease, thanks to over a decade of work and support by our community. Read our **Advocacy update** on this new milestone that will help thousands of individuals get the diagnosis they deserve.

The recent advocacy wins, and the timing of the Federal Budget

aligned with our first-ever gluten-free reception on Parliament Hill. Our 50th anniversary was a golden opportunity to kick off **Celiac Disease Awareness Month** in our nation's capital and to educate members of Parliament and senators about celiac disease, the need to close the diagnosis gap, and to improve affordability, tax fairness and bring healthier food to our tables.

Our feature patient story of news anchor **Jennifer Palma** is just one example of individuals who need our collective help but also show how self-advocacy will always be an important part of the patient journey. While our expert volunteers create new tools to reach food service hospital or assisted living workers across the country, we want to arm you with the tools you need to stay empowered.

Without people like you, this work couldn't have been accomplished. We are incredibly grateful for individuals like you who enable the change needed to improve lives today and in the future. Wishing you an empowered Celiac Disease Awareness Month!

Melissa Secord, CAE
National Executive Director



CONGRATULATIONS ON YOUR 50TH ANNIVERSARY



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BETTER BREAD, THAT'S A





CCA shines a light on CELIAC DISEASE

CELIAC DISEASE AWARENESS MONTH

HERE'S A RUNDOWN OF NATIONAL ACTIVITIES

May 1

Our team will be on Parliament Hill advocating for tax fairness and affordability, equality in fortification of gluten-free food and improving awareness to help close the diagnosis gap.

Kids colouring contest is open! Win a \$100 prize. It's easy! [Download](#) one of our colouring sheets, colour it in and send us a photo!

May 13

The annual Give-A-Thon begins today! Please give.

Check out the community celebrations happening across the country today in honour of our 50th birthday! See page 50.

May 16

It's international Celiac Disease Awareness Day! [Check out events happening across the country.](#) The international community is coming together to #ShineALightOnCeliac. Iconic buildings all over the world, including Toronto's CN Tower and Toronto sign, Montreal's Olympic Stadium and Vancouver's Science World, will be illuminated green at dusk to raise awareness. Be sure to share with us on Instagram, Facebook, and Twitter how you are shining a light on celiac.

May 28

If you are in the Greater Toronto Area, come visit us at the [Gluten Free Garage event](#) and bring a non-perishable to support our **Save Me for Gluten Free** food bank initiative and get some advice from our 'Ask the Expert' booth.

JOIN US FOR WEBINAR WEDNESDAYS

MAY 10, 7PM ET

Is gluten causing your health problems? Join Nicole Byrom, RD, and Meagan Vurzinger, RD, to learn more about celiac disease.

MAY 17, 7PM ET

Getting Started on the Gluten-Free Diet, with Nicole Byrom, RD.

MAY 24, 7PM ET

IBS and Celiac Disease – What's the Connection? Join Nicole Byrom, RD, and Nishaat Patel, RD, to learn about IBS and celiac disease.

MAY 31, 7PM ET

The latest and greatest in Diagnosis and Management with Dr. Benjamin Lebwohl.

FOR MORE INFORMATION AND TO REGISTER

Thank you to our Platinum Sponsor, Promise Gluten Free.



Grab a selfie at a light-up event near you and share with us on social media by tagging us @CCACeliac!

INTERNATIONAL CELIAC AWARENESS DAY LIGHT-UP EVENTS

On Tuesday, May 16, the International celiac community is coming together to #ShineALightOnCeliac. Iconic buildings all over the world will be lit up green to raise awareness for Celiac Disease. Grab a selfie at a light-up event near you and share with us on social media by tagging us @CCACeliac! “You could win a prize from Promise Gluten Free”!

- Government House, St. John’s, NL, May 18
- Charlottetown City Hall, Charlottetown, PEI, May 16
- Dieppe City Hall, Dieppe, NB, May 16
- Complexe Jules-Dallaire, Quebec City, QC, May 16
- Olympic Stadium, Montreal, QC, May 16
- Ottawa Sign, ByWard Market, ON, May 15
- Burlington Pier, Burlington, ON, May 3
- Toronto Sign, CN Tower, Toronto, ON, May 16
- Winnipeg Sign at the Forks, Winnipeg, MB, May 16
- Manitoba Legislative Building, Winnipeg, MB, May 16
- Medicine Hat TeePee, Medicine Hat, AB, May 16
- Lethbridge City Hall, Lethbridge, AB, May 16
- High Level Bridge, Edmonton, AB, May 16
- Epcor Tower, Edmonton, AB, May 16
- Fairmont Hotel, Edmonton, AB, May 16
- Legislature Building, Edmonton, AB, May 16
- Community Centre, Sherwood Park, AB, May 16
- Calgary Tower, Calgary AB, May 16
- Reconciliation Bridge, Calgary AB, May 16
- Telus Spark, Calgary AB, May 16
- Airdrie City Hall, Airdrie, AB, May 16
- Port Moody City Hall, Port Moody, BC, May 16
- Civic Plaza, Surry, BC, May 15
- Pier, White Rock, BC, May 16



CN Tower, Toronto, ON

MELISSA SECORD



Science World, BC

BC CELIAC CHAPTER

Find out more about events and local support group news: <https://www.celiac.ca/living-gluten-free/peer-support/>

Please note all times are shown in the time zone of the event location.

ADVOCACY | POLITICAL ACTION DAY

Celiac Canada HOLDS FIRST PARLIAMENT HILL ACTION DAY and honours innovators



For the first time in its history, we held a political action day on Parliament Hill. The day coincided with the launch of Celiac Disease Awareness Month and was the second 50th anniversary celebration event.

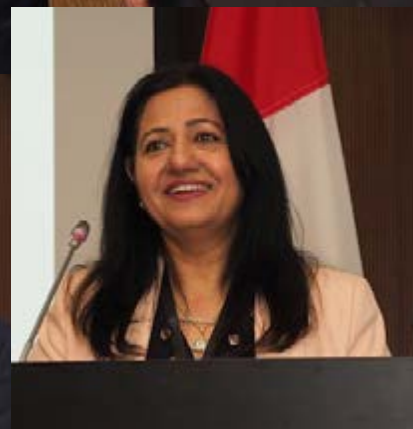
Members of Parliament and Senators were invited to join us for a gluten-free breakfast sponsored by **MPs Sonia Sidhu** (Brampton South) and **Tim Louis** (Kitchener-Conestoga) to learn more about celiac disease and the issues facing individuals in their daily lives. We'd like to give a big shout out to the nearly 300 community supporters who sent an email to their MPs to invite them to the event.

The event included interactive booths such as Guess the Price! and Is this Gluten Free? to demonstrate the every day challenges that face our community. A third display provided an overview of the lack of fortification of gluten-free food - one of our three advocacy issues. The event was extra special for Ms. Sidhu who invited her daughter Amrit to share her own recent diagnosis of celiac disease.
Continued on next page

Caleigh McAulay and Shelley Case take a quick photo in between running to meetings.



Our gluten-free reception hosts, MP Sonia Sidhu (left) with her daughter Amrit, MP Tim Louis joined Executive Director Melissa Secord



PHOTOS BY CHARLES FROST

She eloquently spoke about the day to day struggles for people from affordability to access to safe gluten-free food.

The event included an overview of the collaborative efforts between Celiac Canada and the government of Canada over the past 30 years from improved labelling of gluten sources to food surveillance and major research. This work could not have been done without dedicated volunteers and committed staff members from Health Canada.

Certificates of appreciation were awarded to **Health Canada** employees past and present who have collaborated with CCA in helping to advance key policy and regulation changes and recognizing issues that impact the quality of life for people living with celiac

Continued on next page

“I have so many more questions, so much to learn after hosting this event.”
- Tim Louis, MP.
MP Sonia Sidhu (right) and MP Tim Louis (left)

CCA president, Jennifer Stebbing with Adam van Koeverden, Parliamentary Assistant to Minister of Health



MELISSA SECORD



Members of Parliament join CCA delegates for a group photo



Recipients of certificates of appreciation Matt Bown, Michael Abbott, Jean-Marc Gelinas with Melissa Secord



Super Volunteer Bev Ruffo and recipients of Change Maker awards Marion Zarkadas and Shelley Case



Melissa Secord with Super Volunteers Margaret Duthie and June Williams and MP Sonia Sidhu

disease. Recipients were: Olga Pulido, Lance Hill, Dr. Samuel Godefroy, Michael Abbott, Jean-Marc Gelinas and Matt Bown.

Our Volunteer Recognition continued with **Change Maker** awards being given to Shelley Case and Marion Zarkadas and posthumously to Dr. Vern Burrows and Dr. JA Campbell for their outstanding leadership on changing policies and developing educational materials that have demonstrably changed lives across Canada. Super Volunteers Margaret Duthie, June Williams and Bev Ruffo were also recognized.

Continued on next page

PHOTOS BY CHARLES FROST

“ A special members statement by Tim Louis was also shared during Question Period with the delegation in attendance

“ Darting in and out of the rain and wind, the team spoke about the issues of tax reform for the incremental medical tax claim, fortification and increasing awareness.

After the breakfast reception, a small delegation including CCA President Jennifer Stebbing, Vice President Lizbeth Wall, Shelley Case, Caleigh McAulay, Roberta Kramchynsky and Executive Director Melissa Secord, met with a number of Members of Parliament and policy staff. Darting in and out of the rain and wind, the team spoke about the issues of tax reform for the incremental medical tax claim, fortification and increasing awareness. A special members statement by Tim Louis was also shared during Question Period with the delegation in attendance. The afternoon wrapped up with a light-hearted moment with Shelley Case tickling the ivories with MP Louis after our meeting – [watch here!](#)

This event would not have been possible without financial and volunteer support from the Ottawa Chapter. Special thanks to **Roberta Kramchynsky** for government relations assistance, our emcee **Marie Ghanem**, Shelley Case for meeting preparations, **3Apples Bakery** for the gluten-free bakery items and **Charles Frost** for photography and **Nastascia Lewis-Williams** for event support. ♦

Ottawa volunteers Carmen Rupp-Eke and daughter Rosie Rupp-Eke at the booth “Is it gluten free?”

3Apples Bakery owner Matthew Dobry with Jennifer Stebbing and Vice President Lizbeth Wall



CHARLES FROST

MELISSA SECORD

“ Gluten-free packaged food products are on average from 150% to 500% higher than their regular gluten-containing equivalents



ADVOCACY | CELIAC GROCERY REBATE

TAXES & affordability

Federal grocery rebate falls 150% short

JANET BOLTON, YAZAN MATARIEH, BOB REID
AND MELISSA SECORD

The “grocery rebate” announced in the recent federal budget – designed to help make the cost of food more manageable which is laudable - falls dramatically short for those with celiac disease.

Gluten-free packaged food products are on average from 150% to 500% higher than their regular gluten-containing equivalents. For an average home, the cost of a gluten-free diet is on average \$1,000 per adult more than a household that does not need to be gluten free.

The government proposal that recently passed provides \$153 per adult and \$81 per child for those who qualify.

We are asking the Government of Canada to provide people diagnosed with celiac disease with an increased one-time Grocery Benefit of \$230 per adult and single supplement and \$122.50 per child.

STATE OF CELIAC DISEASE IN CANADA HEALTH SURVEY REVEALS ECONOMIC PRESSURES

■ **92.6%** of respondents feel the cost of gluten-free food is now more expensive compared to the pre-pandemic cost of which nearly **2.5%** have now had to access a food bank and **36%** have had to adjust their finances for GF grocery items.

■ **85%** of respondents reported the cost of gluten-free food as the top problem our community faces on a daily basis.

Continued on next page

“ We have an active working group to address the challenges of the current incremental medical tax claim for gluten-free food

ADVOCACY | MEDICAL TAX CLAIM ON GLUTEN-FREE FOOD

TAX FAIRNESS & modernization

We have an active working group to address the challenges of the current incremental medical tax claim for gluten-free food.

Even if Canadians affected by celiac disease manage to abide by all the administrative demands of making a claim, the credit still has a very limited impact on their bottom line. In fact, only a tiny percentage of the additional cost of gluten-free food is covered.

Take the example of a household with four members, two of whom have celiac disease, and none of whom have any other health conditions. The family will likely spend an extra \$4,000 annually on gluten-free food than another family not affected by celiac disease. **If the taxpayer incurring the cost for the family has an income of \$60,000, the value of the credit received will be roughly \$30, representing a mere fraction of a percentage point (0.75%) of the cost incurred by the family.** If this taxpayer earns \$70,000 or \$80,000 a year, the credit will not be available to them at all. ♦

CELIAC CANADA RECOMMENDATION

- Provide administrative relief in the form of a flat fee annual refundable credit amount (minimum \$1,000) that the CRA would recognize as a legitimate claim, together with a waiver of any requirement to track grocery spending or retain receipts.

Read our letter to Parliamentarians:
[Tax Fairness and Affordability - Canadian Celiac Association](#)

**Save yourself hours of
grocery shopping time.**



Journey into celiac

Global BC News Anchor shares her journey with celiac disease



PHOTOS COURTESY OF JENNIFER PALMA

Global BC news anchor Jennifer Palma at home.

Continued on next page

“... was sent immediately for an emergency endoscopy. When the results came back, I was shocked to hear it was CD – Jennifer Palma

“
**I was so sick,
my husband had to
carry me up the stairs**

NICOLE BYROM, RD

Global BC news anchor Jennifer Palma has lived with celiac disease for several years and shares with us her tips and tricks to be successful, what she struggles with and what has connected her to this community.

Q Jennifer, when were you diagnosed with celiac disease and what were your primary symptoms?

A I was an adult in my early 30s when I was officially diagnosed with celiac disease (CD) but had not felt well since I was a child. As a child I naturally avoided certain foods like pasta and pizza, as they never agreed with me. By the time I was diagnosed I was extremely sick. Just prior to my diagnosis I was unable to walk. I looked gaunt and frail, and I was always bloated and feeling unwell. In fact, my producers called to check in on me asking if I was OK because I looked so sick. One day at work I could not stop vomiting and assumed I had a bad case of the flu. That day I came home, and my husband had to carry me up the stairs. I could not keep anything down including water. Thinking this was the flu, I nursed myself with tea and toast, which only



As a journalist, Palma says advocacy is our number one tool.

made it worse. Two days later, I ended up going to the doctor and was sent immediately for an emergency endoscopy. When the results came back, I was shocked to hear it was CD.

Q Do you have any other relatives with celiac disease?

A Yes, although I was the first person in my family to be officially diagnosed. I suspect my mom has had CD for many years as she was extremely sick during the 1990s and experienced an unexplained 50lbs weight loss. During this time, our doctor could not figure out what was causing her to be so sick, so she ended up travelling home and changing her diet to be entirely gluten free (GF). My mom has never

been formally tested for CD, but I suspect this was the problem as she felt much better on the GF diet. After my diagnosis, I recognized some of my own symptoms in my five-year-old daughter. Subsequently, I had both of my children tested, and my daughter tested positive. This was several years ago and my daughter, who is now a teen, is an amazing advocate for the disease!

Q What is your biggest barrier with the gluten-free diet and what do you miss the most?

A I do not miss any specific food products from before I was diagnosed because I was so sick, however per
Continued on next page

“ We are lucky here in Canada and I have full confidence in food companies and bakeries as their products ... are so delicious – Jennifer Palma



As a child, she would watch the news instead of cartoons. Her love for current affairs led to a degree in International Studies.

haps a croissant? We are lucky here in Canada and I have full confidence in food companies and bakeries as their products have come such a long way and are so delicious. I have a local gluten-free bakery that I love to visit. I consider myself incredibly lucky to live close to such a wide variety of amazing options. Overall, there tends to be a gluten-free equivalent to any product that I really loved.

Q You have such a busy career; how do you manage GF food requirements on a daily basis? Do you have any tips or tricks for our community?

A This was a big concern of mine when I was first diagnosed, be-

cause I was doing a lot of reporting and trying to squeeze food in where I could! If safe food wasn't available, then I would be left hungry. So, I learned to take food with me all the time. Always be prepared. I have been lucky because at Global News they are very cognizant of CD and various allergies. Our cafeteria is very inclusive for all diet types, which made my life much easier. Even during in-person meetings there are always safe options for me to choose from.

Q Has celiac disease brought any positive aspects into your life?

A Yes, I have met so many cool peo-

ple! When people find out you have CD it opens a new conversation to learn from each other. This community is incredible. Learning from others has been such a great gift.

Q Celiac disease has a 15% diagnosis rate in Canada. As a journalist, what's your thought on how we can, as a community, come together to increase diagnosis rates and help others feel better sooner?

A Advocacy is our number one tool to help raise awareness. Platforms like social media campaigns are very impactful in getting the word out on the signs and symptoms of celiac disease. Events like a walk or jog to raise awareness can also be successful. Gathering people together for a common cause is impactful. There are so many misunderstandings in CD. People often think of this as an allergy, but as we know it is an autoimmune disease that causes people to become sick. I share my diagnosis with people to help increase understanding of what CD is and how it affects people. If you can get information into people's hands, especially on their phones, that would help to increase understanding of this disease and in raising awareness.

Q Grocery food costs and affordability have been in the news a lot lately. What's your perspective on the issues?

A At the end of the day, the gov-

Continued on next page

“ I always hope that somewhere along the line, I can help someone like I have been helped by other’s experiences – Jennifer Palma

ernment needs to be involved. The government recently brought together grocery executives to ask some tough questions on the rising cost of food. I do not see the cost of groceries coming down soon, and for GF foods, this is a huge issue. It also comes down to people getting diagnosed. As the population increases there is more power behind a campaign. When I grocery shop, I think about food banks and about those living with CD. If you cannot afford the GF diet, you will continuously be sick and have a weakened immune system. In my case it took two years for my intestinal system to heal. Not being able to afford safe foods will only contribute to much greater problems.

Q Our community loves to travel. Do you have any travel tips or places to visit that are good for those on a GF diet?

A I love to travel, but often wonder, what am I going to eat when I am there? I always look to see what a typical diet is where we are travelling to so I can be equipped with knowledge upon arrival. Within North America I feel confident, but outside the borders of North America I like to take a closer look at what the typical diet is of that country and how it can work for my dietary requirements. You can always fall back on salad! I always take snacks with me for flights to ensure I have something to eat for the journey. For countries where English is not spoken, I like to learn key words to communicate my



Jennifer was the first to get diagnosed in her family then her daughter who is a strong teen advocate.

GF requirements. I found Montreal to be a fabulous place for GF bakeries. If you can get to Montreal, we had an excellent experience there!

Q What helps you to live confidently and successfully with celiac disease?

A Diagnosis for sure! Also, knowing that organizations such as Celiac Canada are there to support the community. I lean on my friends and others with CD, and we share our experiences. I really do like talking about it. I always hope that somewhere along the line, I can help someone like I have been helped by other’s experiences. If anyone out there is feeling as awful

as I did, my recommendation is always to get the blood test. Having CD also makes me think about my diet. I am very mindful about my food choices and what I put into my body. Better understanding how food affects your body has been a gift for me. Paying attention to your health is so important. If you learn how your body operates, it can in turn help you to operate in the world. It helps you better understand your own limits and boundaries, and in turn better help others. ♦

You can watch the full interview with Jennifer Palma here: [Jennifer Palma, Global BC News Anchor discusses her celiac diagnosis.](#)

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“ Finally, the approximately 128,000 people in Ontario with celiac disease ... are a giant step closer to diagnosis and treatment. – *Melissa Secord* ”

ADVOCACY | BLOOD TESTING

Pan-Canadian coverage for DIAGNOSIS ACHIEVED

**Sylvia Jones,
Minister
of Health
and Deputy
Premier of
Ontario**



ALEX RUSSEL

BOB REID AND MELISSA SECORD

The Ontario government’s decision to make simple but crucial blood tests for celiac disease available at no cost to patients will improve the quality of life for as many as 128,000 Ontarians and potentially save Ontario’s health care system as much as \$1 billion.

“Finally, the approximately 128,000 or more people in Ontario with celiac disease – who don’t even know they have it – are a giant step closer to diagnosis and treatment. This is a watershed moment, one which will benefit tens of thousands of people who can

now finally get answers about what has been ailing them for too long,” said Celiac Canada’s National Executive Director, Melissa Secord.

“Our government is making critical investments to connect you to the care you need, closer to home,” said Sylvia Jones, Minister of Health, and Deputy Premier of Ontario. “Ensuring patients can receive celiac tests, at no cost to them, means faster and easier access to a diagnosis and treatment for Ontarians across the province.”

Family doctors and other health services providers were notified via a provincial health bulletin about the continued coverage.

Up until November 2021, the cost paid by the patient for the blood test was \$100-\$150 and proved to be a deterrent for many Ontarians on low or fixed incomes. Celiac disease is genetic, so the potential cost to a family of four to get screened was over \$400. ♦

To learn more about the change, visit [Celiac Blood Test Ontario](#)



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50th anniversary

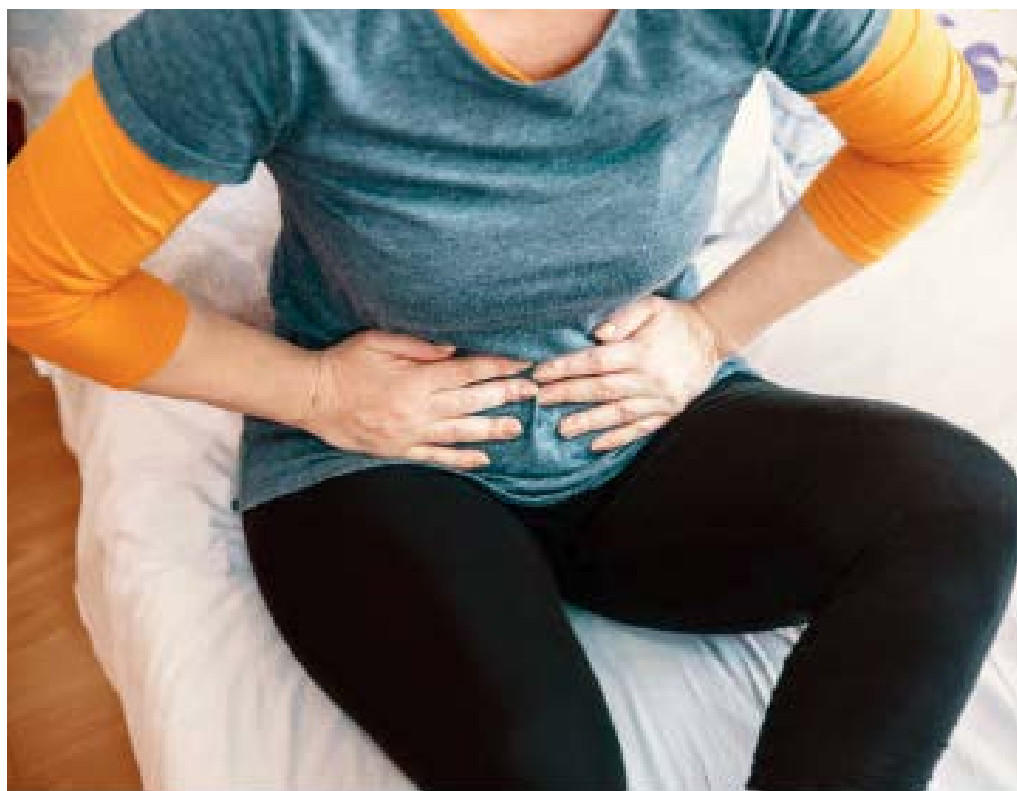
50TH ANNIVERSARY | PART 2 For Part 1, please refer to the February 2023 edition of Canadian Celiac Magazine

Let's share SOME HISTORY

Advancements in diagnosis and treatment of celiac disease 1960-1990s

JOANNE MURRAY

It's time for part two of this three-part series of excerpts of articles that were originally published in the Calgary Chapter newsletter. This installment looks at the advancements in the diagnosis and treatment of CD through the years from 1960 and 1990s. Through these years, there were advances in science and technology that made it somewhat easier to identify celiac disease in the people who presented with classic symptoms of the disease or family histories that supported investigation. And we were still a long way from providing an easy and reliable screening mechanism to identify the many people who were falling through the cracks because their presentation of illness was atypical for the investigation standards of celiac disease.



Medical Advancements

From the medical perspective, there were a few advancements in equipment and testing. The Crosby-Kugler and Watson capsule biopsy equipment was phased out and the early versions of the modern **endoscopy** equipment allowed significant changes to the biopsy procedures. Having a means to visualize the esophagus, stomach and proximal
Continued on next page

“ These improvements in the medical testing for CD resulted in more people being diagnosed through these two decades

small bowel as the equipment was advanced through the mouth, as well as an incorporated snipping device to provide a biopsy sample, meant that fluoroscopic guidance of the endoscope was rarely used. Over the course of the two decades, the endoscope was also improved to allow for the clipping of several biopsy samples, which assured better representation of tissue samples and greater chance of samples of damaged tissue being harvested. The optical components were also improved, with better detail of the gut tissue and better quality of the procedure images. Just as we saw a shift from VCR to DVD equipment in our family rooms, there were parallel shifts in medical recording devices. Technological advancements produced monitors, screens and the means to record that paralleled the changes that we experienced with improved television and recording equipment in our homes.

These two decades were also a time that new lab tests were developed, including tests that could lead to a celiac diagnosis. The **EMA** (endomysial antibody test) was introduced in 1983 and the **AGA** (antigliadin antibody test) was introduced in the same general timeframe. These tests improved the diagnostic pathway, but both had significant limitations. The EMA is an immunofluorescent test and requires very specialized ma-

“
Over the course of the two decades, the endoscope was also improved to allow for the clipping of several biopsy samples, which assured better representation of tissue samples and greater chance of samples of damaged tissue being harvested

terials as well as very specific skills in interpretation. It is also expensive to run. It is, however, highly specific (99%) for celiac disease, though limited in sensitivity (85%), so misses about 15% of people with active celiac disease. The EMA is still in use today because of its high specificity. The AGA test was limited in both specificity and sensitivity, registering positive markers of ~85% in both areas. It was an improvement in diagnosing celiac, but the limitations interfered with reliability in its use. The AGA test is no longer available in most labs as we now have 21st century

tests that are easy, reliable and inexpensive to run.

These improvements in the medical testing for CD resulted in more people being diagnosed through these two decades. Unfortunately, the diagnostic process was still very dependent on a patient presenting with classic symptoms which now included DH (dermatitis herpetiformis) in addition to the classic intestinal symptoms. The beginning of the reliable testing that we expect today only became available with the dawning of the new century, further advancements in science and technology and the critical mass that occurred when the medical community finally recognized that CD was a common disease and presented with a plethora of symptoms. When it was determined that ~1% of the general population worldwide had CD, diagnosed or undiagnosed, there was a collective gasp of recognition that the disease had been massively underdiagnosed for decades.

In 1992, Dr. Michael Marsh introduced the Marsh Histopathological Spectrum, commonly known as the **Marsh Classification of CD**, to standardize the pathological interpretation of gut tissue damage. This classification is now recognized and used worldwide.

Continued on next page

“ Bread and pastries began to enter the specialty food market, though were very limited in taste and texture ...

Expanding Food Access

As the evidence began to pile up that CD was both a childhood AND an adult-onset disease, it was recognized that there were some very distinct needs that required attention, those relating mostly to food that was safe for the gluten-free diet. Like many other areas of Canada, bakers in Alberta began to focus on creating local gluten-free products. Bread and pastries began to enter the specialty food market, though were very limited in taste and texture because the primary ingredients were rice, corn and tapioca flours. Merchants also entered the gluten-free marketplace and health food stores either expanded their product lines to include gluten-free ingredients and products or opened independently based on their focus on domestic and imported gluten free products. Other companies were established in other areas of Canada as well. Those of us who had been struggling with finding specialty foods prior to these decades were suddenly rewarded for our patience with an ever-increasing marketplace where we were offered a variety of new products, many of them tasty and few of them nutritionally balanced.

National manufacturers became familiar in the 1990s with names as Kings Mill Foods (rebranded



“ Those of us who had been struggling with finding specialty foods prior to these decades were suddenly rewarded for our patience with an ever-increasing marketplace where we were offered a variety of new products, many of them tasty ...

as PaneRiso), Kinnikinnick, Glutino and El Peto joined the gluten-free food movement bringing us many guilty pleasures such as chocolate covered wafer cookies and waffle style ice cream cones. It was during these years that international standards of gluten free also evolved. The 1995 revision to the Codex Standard declared that a claim of gluten free could be placed on an item that contained less than 200 ppm, a very shocking allowance by today's standards of 20 ppm. To put that in perspective, it wasn't until 1994 that the Health Protection Branch of Health Canada (the precursor of the CFIA) issued its first food allergen recall based on chemical analysis for peanuts using the newly available ELIZA testing methods. ♦

This decade saw the growth of a national organization, called “Canadian Celiac Association”, with chapters established Canada-wide

50TH ANNIVERSARY | CCA BY THE DECADES

1973 - 1993 EXPANSION & EMERGENCE



JANET DALZIEL AND BEV RUFFO

This decade saw the growth of a national organization, then called “Canadian Celiac Association”, with chapters established Canada-wide. We opened the first National Office, hired our first staff member, and held annual conferences hosted by chapters, providing opportunities to share friendship, information, support and wonderful gluten-free food.



KEY HIGHLIGHTS

Food

- Increasing demand for better quality gluten-free food and clearer labelling regulations
- Science unsure of GF status of many grains, e.g., millet, sorghum
- Emergence of new GF food providers, with improved quality and availability

Organization

- Use of crossed grain symbol as CCA logo
- First National fundraising campaign (\$25,000)
- First National office in Mississauga, Ontario with first Executive Director Rosie Wartecker hired.

Medical/Scientific:

- The first National Celiac Disease Survey developed with 5,000+ individuals completed making it one of the largest of its kind in the world. CCA partnered with Health Canada and Coeliaque Quebec.
- Creation of first ‘Pocket Dictionary’, a handy directory identifying safe and unsafe ingredients.
- J.A. Campbell Research Fund created to invest in Canadian-based research to improve quality of life and inspire young scientists into the field of celiac disease research. ♦

During the kickoff of our 50th year ... we celebrated several volunteers who have made a lasting impact on the lives of people with celiac disease

50TH ANNIVERSARY | CHANGE MAKERS RECOGNIZED

IF IT WERE NOT FOR...

MELISSA SECORD AND LIZBETH WALL

During the kickoff celebration of our 50th year in February, we celebrated several volunteers who have made a lasting impact on the lives of people with celiac disease. Founders Kay Ernst, Nora Reck and one of our first presidents Frances Murphy were all posthumously recognized.

Kay Ernst and Nora Reck



Kay Ernst



Nora Reck

Kay Ernst and Nora Reck had a chance meeting back in 1972. Kay, a mother of a son with celiac disease, and Nora who had what was then known as Adult Celiac Sprue - realized there was no organization or support to help them manage this disease. After speaking with some local gastroenterologists, they decided to form a society. The first of its kind for celiac disease in North America. They planned their first ever education evening at the Kitchener-Waterloo General Hospital thanks to nurse, Isobel Field. They were interviewed on a local Kitchener Waterloo cable station and even featured in a story in Chate-laine magazine. There was a blizzard the night of the first meeting in February 1973 but that did not deter people from attending to learn more about their disease.



Frances Murphy

Frances joined the board of directors in May 1975 and became President from 1979 – 1981. During her time, she was a driving force for the growth of chapters across Canada.

The organization bloomed with committees, medical advisors and fundraising. From the humble beginnings of one KW chapter, the CCA flourished with chapters starting in Hamilton, Calgary, Fredericton, Montreal, Edmonton, and Toronto and others to serve a growing community network.

Continued on next page



Sue Newell

Fondly known as ‘Celiac Sue’, Sue Newell has touched thousands of lives with her knowledge of celiac disease. She was THE source of information and compassionate feedback for our growing Facebook Group in its infancy and developed patient resources and the content for the Celiac News magazine. Sue was instrumental in supporting policy work and volunteered to step in to help our office to help stabilize it during financially difficult times.



CCA President Jennifer Stebbing, Sue Newell, Vice President Lizbeth Wall and Waterloo Member of Parliament Hon. Bardish Chagger

Anne Wraggett

Anne joined the CCA National Board in 2012 and served as our president for four years from 2013. Anne, along with volunteers Mark Johnson and Sue Newell were instrumental in keeping the CCA alive during very lean financial years without an Executive Director to run the operations. Anne has been a strong advocate of the Gluten-Free Certification Program since its inception in 2012.

Continued on next page



CCA President Jennifer Stebbing, Anne Wraggett, Vice President Lizbeth Wall



The Davis family, CCA President Jennifer Stebbing and Vice President Lizbeth Wall

The Davis family

If you think that the sunflower has become the ‘honorary flower of celiac disease’ you can thank the Davis Family of Caledon, Ontario. The family has welcomed thousands of people to their farm to walk and play amongst the flowers and in doing so has raised nearly \$90,000 in support of celiac disease. For the past three years, the family has also donated packets of sunflower seeds with proceeds also going to support programs and resources. Their impact and generosity have been simply ‘sunsational.’ ♦

**LEARN MORE
WAYS TO GIVE**

DONATE



FOOD MARKET



PRIME RIB BEEF BURGERS

GOURMET CHICKEN BURGERS

ANGUS BEEF BURGERS



GLUTEN-FREE GOURMET BUNS



BEEF AND BACON SKEWERS



CLASSIC STUFFED POTATOES



SIRLOIN BEEF MEATBALLS



MARINATED CHICKEN AND BACON KABOB

STEAKHOUSE SEASONED BEEF KABOB

HONEY JALAPEÑO FLAVOURED STUFFED PORK TENDERLOIN



MARINATED LEMON AND HERB CHICKEN KABOB

BLUEBERRY BLISS CHEEZECAKE



New! DOUBLE CHOCOLATE ICE CREAM COOKIE SANDWICHES



CHOCOLATE CHIP COOKIE ICE CREAM SANDWICHES



35+ 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.

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SAME-DAY DELIVERY



Shop online at www.mmfoodmarket.com

GFCP Program Partner



PHOTOS MEG KIBYUK

We sat down with Stacey Hilscher and Meg Kibyuk to share their passion for gluten free

Meet CUT COOKING



A gluten-free company focused on all-purpose flours, conceived over a morning coffee between best friends

Continued on next page

“ Without a doubt, the best part about what we do is supporting families that are new to a gluten-free life.

CCA: How did Cut Cooking begin?

With an idea conceived over a morning coffee between best friends – Stacey Hilscher and Meg Kibyuk, CUT Cooking Inc. was created. Combining their talents and passion, a company dedicated to easing the hardships that can come from adopting a gluten-free lifestyle was established. Stacey had adapted her kitchen to accommodate her and her son’s celiac diagnosis and, hearing from members of the gluten-free community, we knew that together we could help other families do the same.

We have developed an unbelievable all-purpose flour blend, along with an extensive recipe catalog, to help make the difficult transition to a gluten-free diet much more approachable and less intimidating. Without a doubt, the best part about what we do is supporting families that are new to a gluten-free life. We have the privilege to help families discover that cooking, baking and eating gluten free doesn’t have to mean that you need to sacrifice texture and flavour. The entire process of becoming a gluten-free household can be overwhelming and intimidating. We know from experience that it’s easier to do when you have a community that understands and supports you. Our goal is to support individuals with the tools and resources to be successful, starting with a reliable gluten-free flour blend and easy recipes that use it.

CCA: Why did your company decide



“

The Celiac Canada name on our product means that families can use our flour and know that we’ve taken all necessary precautions for a celiac safe product. It means that we value the safety of our product and that we understand the importance of transparency

to join the Gluten-Free Certification Program, and what does that mean to your company and customers?

The Gluten-Free Certification Program (GFCP) is such a pillar of trust and reassurance in the gluten-free community. We want our customers to be able to pick out our flour from the others on the shelf with one glance, knowing that we’ve taking the extra steps required to make them feel confident in their choice. The Celiac Canada name on our product means that families can use our flour and know that we’ve taken all necessary precautions for a celiac safe product. It means that we value the safety of our product and that we understand the importance of transparency.

CCA: In terms of process, what are some of the steps you undertake to keep food ingredients gluten free? Where do you source your ingredients?

Our ingredients come from sources that are certified gluten free, both in the processing facilities and at the farming level. We only use ingredients that have passed threshold testing for the gluten protein, and cross contamination - assuring that our product is less than 20 ppm.

CCA: Where can customers find your products? Or how can they buy them?

Our website is a great place to get started. We have a detailed retailer list that will allow you to find the stocked location closest to you.

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Want to learn more about Cut Cooking? Visit [their website](#)

Looking for more GFCP products? Visit [our product finder](#)

Our flour is stocked in over 60 Safeway, Sobeys and IGA locations in western Canada, along with many supportive boutique stores. We also have a convenient e-commerce store, and we offer directly delivery for our customers in the Calgary, AB area. If you live outside of our area, you can find our flour on Amazon.ca.

CCA: What is your most popular product with customers and why?

Our All-Purpose Gluten-Free Flour Blend is fantastic. It can be a challenge, especially with gluten-free baking, to get the same taste and texture that you'd expect. We have worked hard to develop a gluten-free flour blend that you can substitute 1:1 in your favourite recipes and get amazing results. Using our flour in your recipes means that you'll never compromise on taste or texture. It has incredible versatility from baking to deep frying.

CCA: What is unique about your flour?

We're proud to have developed a gluten-free flour blend that is also free from all of the top allergens. We know that, quite often, other dietary restrictions are paired with gluten intolerance. Our flour is dairy free, nut free, peanut free, corn free, soy free as well as gluten free. It was important to us in the development process that we minimize those risk factors and accommodate as many dietary restrictions as we can. ♦



CUT COOKING LEMON LOAF

Our gluten-free lemon loaf is light and full of texture, moist and fluffy. The perfect balance of tart and sweet. It packs well for lunches or trips to the park!

INGREDIENTS

Batter

- 1/2 cup butter
- 1 cup sugar
- 3 large eggs
- 1/3 cup plain Greek yogurt
- 1 tsp almond extract
- zest of 1 large lemon
- juice of 1 large lemon
- 1 1/2 cup CUT Cooking Gluten-Free Flour Blend
- 1 tsp baking powder
- 1/4 tsp baking soda
- 1/4 tsp salt

Glaze

- 3/4 cup icing sugar
- 3 tsp lemon juice

DIRECTIONS

- Preheat the oven to 350°F.

- Using electric mixer, cream butter and add sugar.
- Beat in eggs, and all additional ingredients.
- Combine well but do not over mix.
- Transfer to loaf pan. Batter will seem sticky or thick. That is ok!
- Bake in mini loaf pans for 25-28 min. Bake in full loaf pan for 45-50 min.
- Make glaze by combining lemon juice and icing sugar. Stir well to ensure no sugar lumps.
- Once loafs are finished baking, cool on rack for approximately 5 min. Then go ahead and drizzle glaze over.
- Allow to cool completely before removing from baking pan.



Deliciously
GLUTEN FREE



Learn more at oetker.ca

PART ONE

GLUTEN FREE IN EUROPE

Join Celiac Canada volunteer, Lynda Marie Neilson as she travels across Europe



PHOTOS: LYNDA MARIE NEILSON

Dining on the cruise: Chicken curry at specialty restaurant Nami Sushi, English tea on the ship and crab cake in the ship's main dining room

Continued on next page

“ A lot of people are apprehensive about cruising due to food; however, I have hardly had any problems – *Lynda Marie Neilson*”

LYNDA MARIE NEILSON

In Spring 2022 we embarked on a three-month, post-retirement trip to Europe which consisted of a cruise from Fort Lauderdale to Rome, a short visit to Italy, a cruise from Venice to Barcelona, Spain and then five weeks in Spain before returning home to Vancouver. This is a review of the trip on the cruise ships and in Italy!

Taking a cruise can be fun as you do not need to pack and unpack every few days. A lot of people are apprehensive about cruising due to food; however, I have hardly had any problems. We travel with Holland America (HAL) as I have found that their gluten-free offerings (and ability to convert regular food items to gluten free) are excellent. We have also been on other cruise lines, and they are similar except for Royal Caribbean which has a limited amount they will do “off menu”.

HAL was offering lots of perks for traveling at this time, such as free reservations in each of the specialty restaurants on the ship. As we normally eat in the Main Dining room, as that is where the allergy kitchen is located, eating in these restaurants was a new experience for me. When I visit the main dining room the first time, I “test out” different waiters.

We were very lucky to get a wait team on our first try on our first cruise



Gluten-free sandwich for lunch on the cruise, prawns and spinach at specialty Italian restaurant Canaletto



and second try on our second cruise, who understood what celiac disease means. At that time, after talking to the head waiter, I requested of the Maitre'd to sit in the waiter's section for dinner each night (which required booking a reservation).

Seating has changed on cruise ships – no longer are the huge 10-12 person tables – they now have lots of two, four and some six person ta-

bles. So, booking a table for the two of us was not an issue and we had a great time at dinner each night. As all cruises do, when you have food issues, you are given the menu to order for the next night's dinner and during the sea days I was also given the lunch menu to order from too! This was also done when we had a reservation in one of the specialty restaurants.

Continued on next page

“As for visiting Italy, it is indeed a celiac delight! Anyone you asked knew where you could get gluten-free food – Lynda Marie Neilson



Trio of gelato on cruise

Everything went very well at the specialty restaurants –Nami Sushi, Canaletto (Italian) and Pinnacle Grill. I especially liked the Pinnacle Grill where I was able to have a HUGE lobster!

We stopped at many ports on the cruises, and I was able to use the translation cards from [celiac travel.cards](http://celiactravel.cards). I believe I took them

in eight different languages for all the ports we would be visiting! I did not eat at all the ports, but they sure are handy to have on hand in case.

As for visiting Italy, it is indeed a celiac delight! Anyone you asked knew where you could get GF food – even at a hole in the wall corner store had gluten-free

crackers! At the buffet that was included with the hotel room, I just had to ask for gluten free and a plate of muffins, bread and cookies would show up. It truly is a wonderful place to travel to and the Italians are just so happy to serve you! ♦

Coming up next issue - Part II – Five weeks gluten free in Spain!

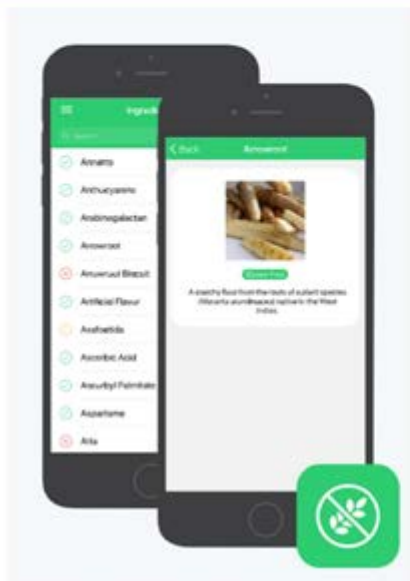


It can be difficult to know which foods contain gluten...

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!



Patient perspective

5 THINGS *I wish people knew about having celiac disease*

ROBYN HARRISON

When I was diagnosed with celiac disease in 2016, I knew that going gluten free was going to be hard, but I completely underestimated just how hard it would be. For me, dealing with people who don't "get it" is even harder than passing up on wood-fired pizza or freshly baked croissants. So, for Celiac Disease Awareness Month, I'm sharing five things I wish people knew about having celiac disease.



PHOTO SUPPLIED BY ROBYN HARRISON

1. **It's real**

I've come across people who think that gluten free is just a silly fad, or that gluten-free people are just being dramatic. (I blame that "Wheat Belly" book that exploded back in 2011...)

But I'm *not* just following a fad.

I'm *not* just avoiding a few hours of discomfort or an upset tummy. And I'm not making up an excuse to skip the breadbasket at dinner or donuts at the office. (Trust me, if I could indulge in bread or donuts without any consequences, I would be first in line!)

Celiac disease is very real. I eat a gluten-free diet and follow the precautions that others may consider "extreme" to avoid devastat-

2. **Social events centered around food are stressful for me**

Honestly, food anxiety hits me pretty much any time I'm eating outside of the comfort of my own home: restaurants, get-togethers with friends, work events, and travelling are not what they used to be. When I go to a restaurant, I'm half there and half thinking about whether they cooked my meal on the same grill as the burger buns. When someone brings me a baked good, I'm half excited and half

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“... awkward ... is telling your friend or family member that you can't eat the meal they just made for you – Robyn Harrison

thinking about whether they confused gluten free with vegan (true story).
It's like playing gluten roulette.
I wish it wasn't this way, but this is why celiac disease awareness is so important.
More awareness means more options, more understanding, and less cross-contact.

3. I hate asking questions about food preparation as much as you hate hearing them

Nothing makes me cringe more than sitting down at a restaurant – especially with a big group of people –and having to pick apart the menu with a server.

But I have to do it.

If I don't, my gluten-free pasta may come out with a giant slab of garlic bread on top. And then I have to send it back. (Also, a true story!) Or, if I just cross my fingers and assume that “gluten friendly” means “gluten free”, then I may end up sick.

In some ways, it's even harder when a friend or family member has prepared food for me. I'm so scared that one of my questions is going to reveal that the food wasn't prepared safely. Or that one of the ingredients contained gluten. The only thing more awkward than asking a ton of questions is telling your friend or family member that you can't eat the meal they just made for you.

I don't enjoy asking a billion questions to make sure something is safe, but I don't have a choice.

4. I don't want to “just stay home”

“Well, if eating is so stressful for you, just stay home. Just never eat anywhere other than your home for the rest of your life!”

Does anyone else feel their blood boil when they hear this one?

It's completely unreasonable to expect people to do this. Especially since about 1 in 100 people have celiac disease!

I'd rather be invited to something than not get invited at all. If I plan ahead and make sure I eat beforehand, I'm fine to just grab a coffee or a drink and come to hang out.

Please don't leave out your celiac friends because you think they wouldn't want to come; that isn't always the case. (But also, don't be offended if they do decline an offer. Not everyone is content to watch their friends eat burgers and fries while they sip on a milkshake.)

5. I'm so grateful when you take it seriously

Last but not least, I am incredibly grateful when others take my celiac disease seriously. When someone goes the extra mile to accommodate my dietary needs, it means the world to me. It's a small act of kindness that makes a big difference in my quality of life.

Whether it's a family member keeping ingredient labels for me to check, a friend finding me a new gluten-free bakery, or a thoughtful fiancé who won't indulge in dessert unless there's a gluten-free option for me, I appreciate it more than words can express.

If you can relate, please feel free to share this article ([or my YouTube video](#)).

Happy Celiac Disease Awareness Month, from a fellow celiac! ♦



Empowering your health

Grappling with fatigue? HERE'S WHY

Why you are tired may not always be straightforward

NICOLE BYROM, RD

Have you been diagnosed with celiac disease and are feeling tired? Here are five reasons that you may be feeling sluggish after your celiac diagnosis.

Iron deficiency anemia (IDA)

IDA causes fatigue due to a lack of oxygen being delivered to your body's tissues. 68% of those newly diagnosed with celiac disease (CD) have low iron levels, contributing to fatigue. The best solution is to follow a strict gluten-free diet to allow your gut to heal and better absorb nutrients, including iron. If your iron levels are extremely low your physician may discuss the option of iron infusions, while your gut is still healing. To learn more, check out this video: [Anemia and Celiac Disease](#)

Hypothyroidism

CD and autoimmune thyroid diseases, like Hashimoto's thyroiditis (HT) and Graves' disease (GD) frequently coexist. Those living with HT may experience increased fatigue, muscle weakness and depression. Check with your physician if you think this may be an issue for you.

Being glutened

For many, accidentally ingesting gluten may be the cause of your fatigue. This symptom may be in combination with other symptoms, or on its own. When newly diagnosed, to better understand your own symptoms, try keeping a symptom journal.

Feeling overwhelmed / depression

With any new diagnosis people may feel overwhelmed, anxious and depressed. Depression can play a role in poor sleep quality and lack of energy. In our recent 'State of Celiac Disease in Canada' Health Survey, 41% of people reported depressive feelings prior to diagnosis and 31% said they were still experiencing depressive symptoms following their diagnosis. Speak to your physician if this is the case for you.

Not related to celiac disease

It is easy to scapegoat CD as your primary cause of fatigue. However, be sure to examine all aspects of your life to address the root cause. Fatigue is a general symptom that may be caused by several health problems including many that are not related to CD. ♦

BFree

GLUTEN FREE
SANS GLUTEN

DAIRY FREE
SANS PRODUITS
LAITIERS

NON GMO
SANS OGM

VEGAN FRIENDLY
VÉGÉTALIEN



NEW



Growing up celiac



THE MOMENT I WENT GLUTEN-FREE, I was Matthew 2.0!



PHOTO CREDIT

MATTHEW DAVID VYAS, AGED 11

You know, sometimes people get celiac disease. Kids do. I did. One percent of the population has it. It may not seem like much, but it is quite a lot. So, you're not alone.

When I got diagnosed with celiac three years ago, I thought it was the end of the world. It even happened to be on my birthday. The night before, I ate a whole bunch of pizza and cake with gluten. It gave me a stomachache.

Before I got tested, I had canker sores and tum-my aches. Every night I would feel sick because I didn't realize I had been eating something I was allergic to. But the moment I went gluten-free, I was Matthew 2.0. No more stomach aches. No more canker sores. I felt whole.

So, if you are ever having canker sores and bad stomach aches, get tested for celiac! You will likely feel much better after you stop eating gluten. Sure, you might miss out on some pizza at a party. Maybe you couldn't eat pasta for dinner at a friend's. Maybe you couldn't go to your favourite

Continued on next page

“ And quite a few bakeries and restaurants have many gluten-free options. You will find something you love! – Matthew David Vyas



restaurant anymore. Yes, it's disappointing, but it is not the end of the world.

There is such a thing as delicious gluten-free pasta. There is such a thing as amazing gluten-free pizza. And maybe you never realized your favourite food at a restaurant was gluten-free this whole time! My favourite restaurant was the Tasty Indian Bistro. When I got celiac disease, I was so disappointed because I thought there was no way it would be gluten-free. But it was. My dad called to ask, and they said it was fine. I was so happy! Quite a few bakeries and restaurants have many gluten-free options. You will find something you love! For example, there is a bakery called Lemonade. It is amazingly delicious. I like their Chocolate Caramel cake and the Summer Berry Mousse and it is 100% gluten free!

Matthew's 4 helpful tips for Celiac Disease

- Make sure you have pots and pans that are only used for gluten-free foods, or just clean the pot well.
- When someone offers you food, make sure you read the ingredients first before you try.
- Make sure to bring your own food to any gathering or party.
- Wheat's not worth the cheat.

GROWING UP CELIAC?

Check out our kids resources at celiac.ca



GROWING UP CELIAC

COLOURING CONTEST



Download a colouring sheet and splash it with colour!

Email it to us at communications@celiac.ca or post it on your Instagram feed or story.



Use #Growingupceliac and tag
@CCACeliac.

Open to CAD residents under 18.
Winner will be announced May 31, 2023.

Good luck!

Dear Dietitian

Cross-Contamination Basics

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

Q I have heard the terms ‘cross-contact’ and ‘cross-contamination’ used interchangeably to refer to the unintentional presence of gluten in foods. Which term is correct?

A According to Health Canada, the term ‘cross-contamination’ is the accepted term to use in Canada when referring to the unintentional presence of gluten in a food item. The term cross-contact is commonly used in other countries and holds the same meaning when regarding gluten contamination. Health Canada’s definition of cross-contamination is “the unintentional physical movement or transfer of a biological, chemical, or physical hazard from a person, object, or place to another.”

Q Can I share condiments with my gluten-consuming family members?

A Whenever condiments are exposed to a utensil that has come into contact with a gluten-containing item, this poses a risk. The safest way to share condiments is by using squirt bottles, or clearly labelling gluten-free jars and containers in your fridge and cupboard. Remember, it is important to ensure that the tip of a squirt bottle does not come into contact with a gluten-containing food item. For more information on living in a shared kitchen check out this short video: [Shared Kitchen & Cross Contamination - YouTube](#)

Q How do I ensure that our BBQ is a safe place to cook gluten-free food items, when it has previously been used to cook gluten-containing food items?

A To make BBQing safe and delicious it is best to provide a physical barrier between your food and the grill. Tinfoil is an excellent solution for safe grilling, or you may wish to use a clean BBQ stone. Remember that utensils are a source of cross-contamination on the grill, so have a set of dedicated gluten-free tongs to use specifically for your food item. ♦

Have a question you’d like answered in the next magazine? email us at AskTheCCA@celiac.ca



Research



NENSURIA / ISTOCK

RESEARCH | CLINICAL TRIALS

WHY WE NEED YOU

**Celiac Canada asked
Dr. Dan Leffler and
Dr. Amelie Therrien
why we should
participate in
clinical trials**

DR. DAN LEFFLER AND DR. AMELIE THERRIEN,
TAKEDA PHARMACEUTICALS

If you are reading this article, we assume it is because celiac disease is important to you, whether it affects you or a family member or a friend or all of the above. Celiac disease is at an inflection point. We have a robust and deep understanding of how, in people with celiac disease, gluten leads to activation of the immune system and intestinal damage. We are beginning to have a better understanding of what causes symptoms in celiac disease (interestingly there is not a strong link between intestinal damage and symptoms), and why some people get celiac disease and others do not. We also have a number of really important new tools for studying celiac disease,
Continued on next page

“ Finally, we have exciting and promising clinical trials for new medications for celiac disease



CA-ASSIS / ISTOCK

“
There is just a single key ingredient needed to allow researchers to make rapid and meaningful progress in celiac disease that will improve the lives of patients for generations. That ingredient is you!

including tests for gluten exposure in stool and urine, tests of inflammatory markers in blood which can reflect recent gluten exposure, and very advanced tests of immune system function. Finally, we have exciting and promising clinical trials for new medications for celiac disease targeting nearly every known important part of celiac biology.

There is just a single key ingredient needed to allow researchers to make rapid and meaningful progress in celiac disease that will improve the lives of patients for generations. That ingredient is you!

Currently the single thing that is limiting our ability to drive the celiac disease field forward is patient participation. While the celiac disease community has been supportive, progress to date has been possible through the efforts of a relatively small group of individuals, probably making up no more than 1 of every 100 celiac patients who have altruistically donated their time and effort to participating in research studies. If even 20% of people with celiac disease participated in research, it would dramatically accelerate progress and enable the possibility of a functional cure in our lifetimes.

There are many types of research, from as simple as filling out a survey to as involved as participating in a study of a new medication. In response to many questions, below we will focus on what is involved in participating in a study of a new medication for celiac disease.

We understand that taking an experimental drug or a small dose of gluten for research can be frightening. First, any drug that may be given to you has undergone years of preliminary studies in the lab, sometimes using blood and intestinal cells donated by celiac patients to show the molecular benefits of the drug, then involving animals and healthy humans to confirm the safety of the dosing given to you (what we call Phase 0 and Phase 1). This data is evaluated by an independent ethical board committees on which patients' representatives are sitting at some institutions, to be sure that the procedures involved and the risks are acceptable. It goes the same with including some gluten intake in a study. Although unfortunately some people have acute and debilitating symptoms if they are exposed to a small amount of gluten, research over the years have led to a better understanding of the dose of gluten that can be given in the short-term to celiac patients without causing severe damage to their intestines and how effects of gluten resolve once the person has resumed a gluten-free diet. Depending on the type of study, use of some amount of gluten can be essential to proving that a medication can protect people from gluten exposure in real life. *Continued on next page*

“As you can imagine, development of new therapies involves at least a decade of work, both from the scientific and the celiac community

To make sure that a medication is truly effective, we need hundreds of participants through various phases. We mentioned Phase 0 and Phase 1 studies, which usually do not involve people with celiac disease. Then, Phase 2a and 2b studies look at the optimal dose to have a good effect, safety and overall effectiveness on your symptoms and intestines. Anything unexpected is reported immediately to the central team and the ethical board committee and there is a decision to continue or stop the trial, to avoid putting the other participants at risk. Also, it is not uncommon to analyze the results from the completed participants

mid-way into the trial to see if there is a trend that the medication is indeed effective. It may happen that a clinical trial be halted after this analysis, as we do not want to have participants invest time and possible gluten exposures if we know that in the end, the drug will likely be unsuccessful.

When Phase 2 studies are conclusive, Phase 3 are initiated, which are the largest studies, involving many centers / countries to make sure that the drug is really effective in a large amount of people. Again, anything unsuspected happening to a participant is reported and the trial may be halted mid-way if preliminary analy-

ses are not promising.

As you can imagine, development of new therapies involves at least a decade of work, both from the scientific and the celiac community. Researchers are doing everything they can to minimize the risks for the celiac population and we encourage you to check frequently with Celiac Canada (or your local patient organization) and GI doctor to see what studies are available and which may be appropriate for you. Together we can ensure a brighter future for celiac disease. ♦

To see a listing of clinical trials in Canada, [click here](#).



“ ... the advent of serological screening helped to improve delays to diagnosis commonly reported on in CD populations

RESEARCH | AN UPDATE

State of Celiac Health Survey: *an update*

Brief and preliminary findings

JAMES KING

Analysis from The State of Celiac Disease (CD) in Canada Health Survey has officially begun.

While this process is still in the early stages, here are some initial findings of interest to share in advance of Celiac Disease Awareness Month.*

The majority of respondents were female (83%), slightly higher than what was observed in prior surveys from the Celiac Canada (approximately three-quarters).¹⁻³ The average age of participants (approximately 54 years old) was similar to prior reports (approximately 56 years old).¹⁻³ Almost one-fifth of individuals had their diagnosis based on serological results only (i.e., no biopsy-confirmation). Although over 80% of individuals still described an intestinal biopsy as part of their diagnosis, this may suggest a potential shift in how healthcare providers and at-risk individuals are navigating the identification of CD.

With this in mind, the advent of serological screening helped

“ ... prior surveys in Canada demonstrated individuals often had to consult with several healthcare professionals (e.g., family doctors, gastroenterologists, dermatologists) in their efforts to understand the cause of symptoms or other complications

to improve delays to diagnosis commonly reported on in CD populations. Indeed, prior surveys in Canada demonstrated individuals often had to consult with several healthcare professionals (e.g., family doctors, gastroenterologists, dermatologists) in their efforts to understand the cause of symptoms or other complications.^{1,2} The average time to diagnosis in the

historical data has been reported to be almost 12 years; however, this estimate is based on survey responses from the 2000s.

Still, the current survey has shown over one-third (38%) of respondents saw a delay to diagnosis of 10 years or longer. It is important to note that some responses in this I

Continued on next page

“ It is also critical to consider how time from symptoms to diagnosis may have an association with overall quality of life before and after diagnosis

“early findings suggest consistency with other research that has not shown elevated risk of severe outcomes from COVID-19 in CD ...

latest survey could include individuals who previously responded to prior surveys of the CCA, therefore reflecting times when serological testing and awareness of CD was not as prevalent. Conversely, just under one-quarter (23%) of respondents reported a diagnosis within two years of symptom onset.

It is also critical to consider how time from symptoms to diagnosis may have an association with overall quality of life before and after diagnosis.

Prior to diagnosis, with the exception of those who reported no symptoms, there is between 45% to 70% of respondents who saw their quality of life as fair or poor. Although there may be a marginal increase in this proportion with the longer delay to diagnosis, there does not appear to be a dramatic difference across the spectrum of diagnostic delays. With the quality-of-life assessment after diagnosis of CD, there is also no clear divergence between the different lengths of time from symptoms to diagnosis. But the proportion of those rating their quality of life as poor or fair has shifted, with less than 20% of respondents reporting these outcomes following diagnosis. It would offer some additional insight in understanding exactly how long it has been

HEALTH SURVEY BY THE NUMBERS

- **83%** female respondents
- **54 years** average age of participants
- **1/5th of individuals** had their diagnosis based on serological results only
- **80%** still described an intestinal biopsy as part of their diagnosis
- Almost **12 years** the average time to diagnosis in the historical data
- Over **38%** of respondents saw a delay to diagnosis of 10 years or longer
- Under **23%** of respondents reported a diagnosis within two years of symptom onset
- **45%-70%** respondents saw their quality of life as fair or poor prior to diagnosis
- Less than **20%** respondents rated their quality of life as poor or fair following diagnosis.
- **95%** of respondents indicated having received a vaccination for COVID-19
- **47%** reported having been infected with COVID-19
- Over **95%** were able to remain home during Covid-19 infection
- Less than **2%** required hospitalization with COVID-19

since diagnosis to further understand how that might play a role in self-reported quality of life. Nevertheless, these initial findings highlight the overall significance of a timely CD diagnosis to improve quality of life.

While measures of reducing transmission of COVID-19 such as limited gatherings and mask mandates have significantly decreased in the last several months, research on how the pandemic and the infection itself has impacted CD will continue for many years.

This line of inquiry was not the sole purpose of the current survey, but initial results warrant consideration to get a sense of its impact in the CD community. Just over 95% of respondents indicated having received a vaccination for COVID-19 in comparison to the 91% (as of March 26, 2023) as having received at least one dose among Canadian adults.⁴ Almost half of participants (47%) reported having been infected with COVID-19, and of these individuals, over 95% were able to remain at home during the illness (less than 2% required hospitalization or admission to intensive care). Generally speaking, those who noted having a COVID-19 infection were younger on average (50 years) compared to

Continued on next page

“Stay tuned for more ... analysis and findings from what our community has noted as key factors throughout their experience with CD!”

those who did not report an infection (57 years). Further exploration of this data may identify other differences across certain factors, but early findings suggest consistency with other research that has not shown elevated risk of severe outcomes from COVID-19 in CD compared to those without CD.⁵

Stay tuned for more in-depth analysis and findings from what our community has noted as key factors throughout their experience with CD! ♦

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It's all about the food!

Here are some of our favourite gluten-free recipes for your spring menu

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Robyn's Gluten-free Baking Courses

Morning Glory Muffins

MAKES 12 MUFFINS

Ingredients

- ¾ cup brown rice flour
- ¾ cup almond flour
- ¾ cup oat flour
- ½ cup tapioca starch
- ¾ teaspoon xanthan gum
- 2 teaspoons cinnamon
- ½ teaspoon ginger
- 1 ½ teaspoons baking soda
- ½ teaspoon salt
- 3 large eggs
- ½ cup vegetable oil
- ½ cup sour cream
- ½ cup brown sugar, packed
- 3 tablespoons maple syrup or honey
- 1 ½ teaspoons vanilla
- 1 ½ cups peeled, grated carrot
- ¾ cup peeled, grated apple
- ¾ cup shredded unsweetened coconut
- ¾ cup chopped walnuts or pecans
- ¾ cup raisins



Method

1. Preheat oven to 375°F (190°C). Grease a muffin tin (enough for at least 12 muffins).
2. In a large bowl, whisk together all of the dry ingredients (brown rice flour, almond flour, oat flour, tapioca starch, xanthan gum, cinnamon, ginger, baking soda, and salt) until well combined. Set aside.
3. In another bowl, combine the liquid ingredients (eggs, oil, sour cream, brown sugar, maple syrup, and vanilla) and whisk until well combined. Set aside.
4. Prepare the add-ins: Peel and grate the carrots and apple, and chop the nuts. Set aside.
5. Pour the wet ingredients into the dry, and mix with a spatula. Make sure to fold from the bottom of the bowl and scrape down the sides to ensure all the flour is incorporated. Fold in the grated carrot, apple, chopped nuts, coconut, and raisins. Mix until well incorporated.
6. Use an ice cream scoop to drop the muffin batter in the prepared tin. Gently smooth out the tops using the spatula.
7. Bake for 20–25 minutes, until lightly golden brown.
8. Let cool in the muffin tin for about 10 minutes, then remove and place on a cooling rack. Enjoy!

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Upcoming events

CELIAC AWARENESS MONTH

See what is happening across the country at our local chapters and groups

MAY

1 May 2023

Ottawa Chapter & CCA National

■ Breakfast on Parliament Hill

6 May 2023

Calgary Celiac Chapter

■ Gluten Free Food Tour, Avenida Fresh & Local Market, 1-3pm. Join us for a tour of four gluten-free kitchens at the market! Buy tickets and [learn more](#).

Newfoundland & Labrador Chapter

■ Join us for dinner at Landings Restaurant. [Learn more](#).

9 May 2023

Newfoundland & Labrador Chapter

■ Talk Tuesday! Are you newly diagnosed? Join us for a session with a Registered Dietitian. [Learn more](#).

12 May 2023

Edmonton Chapter

■ Kinnikinnick will be hosting their Show Kitchen in honour of Celiac Canada's 50th anniversary. Our chapter will provide information during this event.

13 May 2023

Moncton Chapter

■ Join us for a pancake brunch and our AGM. Open to chapter members and guests only. 11am-2pm. Contact Sheila Parker 506-536-1867 or [email](#) for more details.

PEI Chapter

■ Celebrate Celiac event, celebrating the 50th anniversary of CCA and honouring PEI chapter volunteers. Gluten-free cake, ice cream, GF food vendors, door prizes, raffles and more! Sherbrooke Community Center, 26998 HWY 2, Summerside, PEI. 2-4pm.

Quebec Support Group

■ Bowling Event (all ages). 6510, St. Jacques West, Montreal West (Cavendish) 514-482-7200. 2-4pm. GF snacks will be provided. [Find out more](#) or [email](#) to register.

Calgary Chapter

■ M&M Food Markets are offering gluten-free samples. Kids Meet-up \$5. Join us for a skating party. [Learn more](#).

Edmonton Chapter

■ Celiac Kids Rock Support Group. We will host our first in-person meeting of 2023 "Mindfulness in May" at our offices at the JFC. 10:30am – 12pm.

16 May 2023

CCA National

Join us at the Toronto Sign at Nathan's Phillip's Square for Shine-A-Light, product giveaways, photos and community gathering. 7:30 - 8:30pm

Ottawa chapter

■ The Ottawa sign will be lit up in recognition of celiac awareness day and we will be doing a photo at 6pm. Please contact Jenny Brown 613-878-5016 or [email](#).

Calgary Chapter

■ Dinner with a view. [Learn more](#).

BC Chapter

■ Join us for dinner at Jan's on the Beach in White Rock. [Find out more and RSVP here](#).

Edmonton Chapter

■ Celiac Awareness Dinner at Continental Treat Fine Bistro (Jasper Ave Location). Come celebrate and enjoy a gluten-free meal with your community. 7pm.

23 May 2023

Quebec Support Group

■ Chat Hour, virtual meeting on zoom, 8pm. This is an occasion to *Continued on next page*

Find out more about events and local support group news:

<https://www.celiac.ca/living-gluten-free/peer-support/>

share and chat with others living with celiac disease. Celiac Canada peer supporters will be present to help guide the conversation. [Register here](#) for free.

Newfoundland & Labrador Chapter

■ Talk Tuesday! Join us for a session with Chef Steph! [Learn more.](#)

28 May 2023

CCA National

■ Join us at the Gluten-Free Garage at Artscape Wychwood Barns. Bring a GF non-perishable for the Daily Bread Food Bank and 'Ask an Expert.'

Calgary Chapter

■ Servus Calgary Marathon, 9am-4pm, 1410 Olympic Way SE (Stam-

pede Grounds). Join our team and help us raise funds to support the chapter! [Learn more.](#)

Newfoundland & Labrador Chapter

■ Talk Tuesday! Join us for a session with Kera McGrath on mental health and celiac disease! [Learn more.](#)

JUNE

1 June 2023

BC Chapter

■ Celiac News Quarterly from BC comes out! [Learn more.](#)

25 June 2023

■ Vancouver Half Marathon. [Join us and have some fun!](#)

JULY

22 July 2023

Edmonton Chapter

■ Gluten-Free Pancake Breakfast.

AUGUST

6 August 2023

Calgary Chapter

■ Rod McDaniel Celiac Kids Camp takes place from August 6-11, 2023. Located in beautiful Kananaskis Country, close to Bragg Creek. [Learn more.](#)

September

16 September 2023

■ Annual Ride Walk Run for Celiac, Rundle Park, Edmonton. ♦

Please note all times are shown in the time zone of the event location.



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