Canadian CELIAC

Celiac Champions in Parliament

New caucus fights for our rights

More CCA advocacy

SENIOR'S SAFE LONG-TERM CARE ACT

FUTURE OF FOOD

Safe food on-the-go

UNDER EVACUATION

PORTUGUESE FOOD TOUR

SCHOOL TRIP NIGHTMARE

CCA **board of directors**


ELERIUM / CANVA

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CanadianCELIAC

A MAGAZINE FOR CANADIANS WITH
CELIAC DISEASE AND GLUTEN SENSITIVITY

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COVER PHOTO JEFF_RIVARD / iSTOCK

A magazine for Canadians with celiac disease and gluten sensitivity

FALL 2023

ADVOCACY

SAFE FOOD ON-THE-GO

50TH ANNIVERSARY

TEAMING UP WITH CCA

READY FOR THE NEXT 50

It's hard to imagine we're close to the finish line of Celiac Canada's 50th anniversary year. What a year it's been! If we had to put a theme or a word on the year, it would be advocacy. From the February announcement of coverage for blood testing to our event on Parliament Hill, our big focus has been on moving forward big issues that matter most to our community.

I hope you have had a chance to check out our 50th Anniversary website that looks back at some of the major accomplishments and milestones thanks to the efforts of so many volunteers and leaders along with our event celebrations. It's been educational for me reading **Joanne Murray's** articles looking back at the last decades in celiac disease.

Over the past few months, we've made more history with the launch of the new **Parliamentary Caucus Committee** on Celiac Disease. It is a major milestone thanks to federal Member of Parliament, Sonia Sidhu. The committee opens a door for us to showcase key issues such as better awareness, tax and affordability and ongoing management challenges of the disease. You can read our overview of what a caucus is and what it means to our federal advocacy efforts.

In this issue, we also highlight two summer federal consultations - one on **long term care** and the other the **future of food** in Canada. Both allowed us the opportunity to share the day-to-day challenges our community faces managing their disease and offer solutions to make life healthy and safe. The article on iron deficiencies highlights the need for changes to food regulations.

The need for continued advocacy and awareness is evident in two stories – one on this summer's evacuations of Yellowknife and West Kelowna and the other on internationally organized **school tours**. Both reveal the challenges of navigating life with the disease outside of home and local community.

Finally, I hope you will read about our newest Celiac Canada research award winners. As the single largest funder of celiac disease research, we are grateful to donor support to help move the needle on research that will improve quality of life and advance potential treatments.

This ongoing advocacy work could not happen without support from individuals like you. Compared to many charities we are small, but we are internationally respected for our integrity and evidence-based work. In 2024, you will see the results from our major **State of Celiac Disease in Canada Health Survey** lay the groundwork for our next 50 years. We hope you will join us on this journey!

Melissa Secord, CAE
National Executive Director

CCA ADVOCACY

CELIAC CHAMPIONS IN PARLIAMENT –

New caucus fights for our rights

CHARLES FROST

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

NEW COMMITTEE FOR CELIAC DISEASE

This May, Celiac Canada held the first ever gluten-free breakfast reception on Parliament Hill. Hosted by Members of Parliament (MP) Sonia Sidhu (Brampton South) and Tim Louis (Kitchener-Conestoga), the event ignited an idea to create a Celiac Caucus. A caucus is made up of MPs from all political parties and Senators, who have a common interest in helping solve problems and bring more awareness to an issue or area of interest. *Continued on next page*

> **“…I was inspired to bring people from all political backgrounds together, to work collaboratively on finding solutions.** *–MP Sonia Sidhu*

They meet several times a year during the sitting of the Legislature. We’ll keep you updated of meeting highlights throughout the year.

Ms. Sidhu recently championed political support behind the current National Diabetes Strategy and has a strong desire to help advance issues around celiac disease.

“The stories of resilience and determination from the celiac community have brought Parliamentarians together to create a platform where their voices can be heard.” says MP Sidhu, the Caucus Chair. “With the All-Party Celiac Caucus, my hope is to raise awareness, drive research, and advocate for initiatives that will improve the lives of those living with celiac disease. Together, as a caucus, we can make strides toward a world where celiac disease is better understood, where access to safe and affordable gluten-free options is improved, and where the celiac community can thrive.”

Mr. Louis, the Caucus Vice Chair, currently sits on the Parliamentary Committee for Agriculture and Agri-Food which has held hearings on the cost of food and affordability.

The caucus kicked off in June with its first meeting. Presenters included Melissa Secord, Executive Director of Celiac Canada and Dr. Maria Ines Pinto Sanchez, CCA Professional Advisory Council Member and Clinic Director at the Farncombe Digestive Disease Centre. They were joined by two individuals sharing their journeys - Olympian Christine Nesbitt and Global BC weekend host, Jennifer Palma.

“I’ve always believed in the power of spreading awareness and compassion. Having witnessed the challenges and obstacles faced by individuals with celiac disease and their families, and working closely

Continued on next page

> **“The stories of resilience and determination from the celiac community have brought Parliamentarians together to create a platform where their voices can be heard. With the All-Party Celiac Caucus, my hope is to raise awareness, drive research, and advocate for initiatives that will improve the lives of those living with celiac disease**
>
> *– MP Sidhu, the Caucus Chair*

> **“For celiac disease in Canada, this is a gamechanger. The goal is to continue to increase caucus membership, present key issues that face celiac disease and to find solutions to improve awareness, diagnosis rates, health outcomes, quality of life and research**
>
> *– Melissa Secord, Executive Director*

MP Sidhu toured the adult celiac clinic at McMaster University to find out more about the disease

MELISSA SECORD

Celiac Caucus Chair, Sonia Sidhu, tours McMaster University.

with Celiac Canada, I was inspired to bring people from all political backgrounds together, to work collaboratively on finding solutions." says Sidhu.

"For celiac disease in Canada, this is a game changer. The goal is to continue to increase caucus membership, present key issues that face celiac disease and to find solutions to improve awareness, diagnosis rates, health outcomes, quality of life and research." says Secord.

MP TOURS MCMASTER CELIAC CLINIC

As part of increasing education about celiac disease, MP Sidhu was invited to tour the adult celiac clinic at McMaster University in Hamilton, Ontario. The clinic is the only dedicated adult clinic in the country and is a potential model for standardized care and follow- up. Joined by her daughter Amrit, who has celiac disease, Ms. Sidhu learned how researchers work collaboratively to translate science into clinical practice to improve patient outcomes.

Projects being funded at McMaster University lab by donors to the **James A Campbell Research Fund** – the single largest research funder in Canada of celiac disease research – were highlighted during the tour. The guests had a chance to speak to young investigators and learn how their research aims to inform potential treatment models for celiac disease.

GO IN-DEPTH ON THIS TOPIC!

Listen: to our podcast interview with Melissa Secord and Chair of our Federal Advocacy Working Group, Roberta Kramchynsky to learn more about the federal process and our advocacy efforts. Canadian Celiac podcast.

Watch: Learn more about CCA's collaborative partnerships over 30 years with federal agencies from our 50th Anniversary Breakfast on Parliament Hill. Celiac Canada on Parliament Hill - YouTube

Surf: Check out the Farncombe Digestive Research Centre at McMaster University in Hamilton. Farncombe Family Digestive Health Research Institute [Link Home - Farncombe Family Digestive Health Research ◆

50 CCA CELIAC CANADA virtual CONFERENCE

Registration is now open for Celiac Canada's annual virtual conference. Topics include materials for both new celiac disease patients and those who have been living with the disease longer term. Register to learn the latest about celiac disease in Canada, as well as get perks like opportunities to ask qualified medical individuals questions; win prizes, and learn about the latest from the CCA. This is one you don't want to miss!

Dr. Don Duerksen

Dr. Don Duerksen, MD, is an Associate Professor of Medicine and the Acting Section Head of Gastroenterology at the University of Manitoba. He will be highlighting news from the State of Celiac Survey.

Dr. Alessio Fasano

A pediatric gastroenterologist, Alessio Fasano, MD, is chief of the Division of Pediatric Gastroenterology and Nutrition, director of the Center for Celiac Research and Treatment. He will be highlighting the updates in diagnosis and treatments.

Dr. Nigel Hoggard

Dr. Nigel Hoggard is Professor of Neuroradiology at the University of Sheffield, in the United Kingdom. He will be speaking on the neurological manifestations of celiac disease.

REGISTRATION:

CELIAC.CA

Register by November 11

18 NOVEMBER 2023
12 PM - 5 PM ET

VIRTUAL - ZOOM REGISTRATION

Our stories

KARA CAPALDO, CANVA

SAFE FOOD ON-THE-GO

FLEEING THE WILDFIRES

Evacuee's quest for safe gf food

Running from a wildfire is scary enough. The desperation to finding safe food when you're evacuated adds fuel to the fear. Here's a Q& A with celiacs Andrea Hyde and Sandra Arthur on how they coped with the summer 2023 wildfires in Yellowknife and Kelowna and the lessons they learned for dealing with emergencies. *Continued on next page*

Humans and bison leave Yellowknife as the smoke gets thicker.

COURTESY, ANDREA HYDE

ANDREA HYDE

Tell us about yourself.
I've lived in Yellowknife, NWT for 17 years. I grew up in Barrie, Ontario and was diagnosed with celiac disease at the age of six at Sick Kids Hospital in Toronto, ON. I am 37 years old. I evacuated with my three children. My 13-year-old daughter also has celiac disease.

Tell us about wildfires in your area.
There are wildfires every summer, the last summer that was this bad was 2014, but we weren't evacuated. I never believed Yellowknife would ever be evacuated.

EMERGENCY ALERT / ALERTE D'URGENCE

now

Residents of Dettah and Ingraham Trail are required to evacuate as soon as possible. Yellowknife and N'Dilo residents are required to evacuate by 12pm on Friday, August 18. More info: https://www.gov.nt.ca/en/public-safety /// Les résidents de Dettah et de la route Ingraham Trail doivent évacuer ces secteurs dès que possible. Les résidents de Yellowknife et N'dilo doivent évacuer ces secteurs avant midi le vendredi 18 août 2023. Pour en savoir plus, visitez le https://www.gov.nt.ca/fr/securite-publique

What happened in 2023?
The fires were ongoing all summer, as they always are. There are often smoky days. It was August 13th where the sky turned orange and within hours nearby communities of Hay River and Fort Smith were told to evacuate with a few hours' notice. That created a bit of panic in Yellowknife, and everyone was at the gas stations getting fuel.

I remember thinking to myself that I wasn't sure why I was getting gas because if we did need to evacuate the only road out would be closed (as it had ongoing closures). I filled up anyway because of the panic, I didn't want to be without. I'd never seen the gas pumps that busy. Long lines at every gas station. Everyone just knew something was coming.

Describe your evacuation route and journey. Did you rely on the packed GF snacks and food enroute?
We found out about the evacuation order at the online press conference at 7 PM August 16th (my son's 10th birthday). We were told if you could drive, drive.

For those who couldn't, there would be flights.

Continued on next page

> **“Three meals a day were also provided at the Expo Centre, buffet style ... questionable for celiacs, so we didn’t eat – *Andrea Hyde***

I packed the car that evening and got ready to leave by 5 AM on August 17th. My common-law partner who works for the RCMP had to stay behind in Yellowknife, and my children’s father also had to stay behind in Yellowknife as an essential worker.

Although I have lived in Yellowknife for 17 years, I had never made the drive to Alberta myself as I am not a fan of long car rides. I was nervous to drive for so long. The line up for gas at the first gas stop in Fort Providence was an hour and half wait.

I packed gluten-free snacks I happened to have in the house for the road, things like Made Good Granola bars, cheese strings, and apples.

It took us 15 hours, but we made it to our first stop in Grimshaw, AB where we ate at Subway. At the Coastal Inn in Grimshaw the breakfast had Cheerios labelled gluten free (I obviously know better).

The next morning, we made our way to Edmonton where my parents had booked us a hotel room for four days. We had no idea what resources there would be when we got there.

CANVA

At the Hampton Hilton in Fort Saskatchewan just outside Edmonton, we managed with a typical hot breakfast included such as egg patties and bacon.

We tried to get set up with accommodations by the Red Cross at the Edmonton Expo Centre, but the line was so long it took days before people were able to get accommodations. Three meals a day were also provided at the Expo Centre, buffet style, all of which is questionable for celiacs, so we didn’t eat. On top of that, it was a thirty-minute drive from the hotel.

iSTOCK

After four days in a hotel, we decided to go to Grand Prairie which is another evacuation city run by Grand Prairie Regional Emergency Partnership (GPREP). At first, we got an AirB’nB and eventually a hotel under GPREP. The food in Grand Prairie was similar to Edmonton, you had to drive to a hotel three times a day for meals, which I think would be great if you were not celiac or had other food allergies. Although the buffet-style food looked good, I wasn’t sure what ingredients were in the meals. The one day we checked it out for lunch they had hot dogs and chilli, and the next time at lunch they had chicken fried rice and an assortment of salads.

Were you able to access GF food?

CCA volunteers sent us a package of GF food. Thank you so much!

How long were you evacuated and when did you return home?

I was evacuated for just under three weeks. The biggest

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Andrea and family returning to the NWT.

COURTESY, ANDREA HYDE

obstacle was finances and all the extra money you do need to spend which is unplanned. Securing resources from the Red Cross in large centres does not come easy. Also, the anxiety and overwhelming feeling of when, or if you get to go back.

What lessons did you learn?
There's a fear in me this may happen again next summer, or the smoke may be so bad, so I will create a savings/evacuation fund to be more prepared next time.

What education or support would you like to see for people with celiac disease when evacuated?
If Red Cross or organizations such as GPREP had food vouchers for grocery stores instead of going to the designated food place. Some evacuation sites such as Red Deer or Calgary gave food vouchers instead of the location for set-up meals

It would be great if the Red Cross or organizations such as GPREP had a spot where you could easily get gluten-free food. Or if meals are supplied, provide an ingredients list or have a gluten free or specific allergy friendly option.

Any other tips?
You don't need to really take many clothes. Try to make the best of the situation, which can be mentally hard. But if you have the means, set it up like a "vacation", which only works if you have personal emergency funding resources set aside.

Have patience, you won't have all the information you want when you want it. Do not rely on government resources, they likely are not there. Pack some snacks, if you have the funds try out some local gluten free foods. Don't feel bad for asking for help.

Be adventurous. We found a fantastic place in Grand Prairie for sweets. Off the Wheaton Path, their baked goods were amazing!

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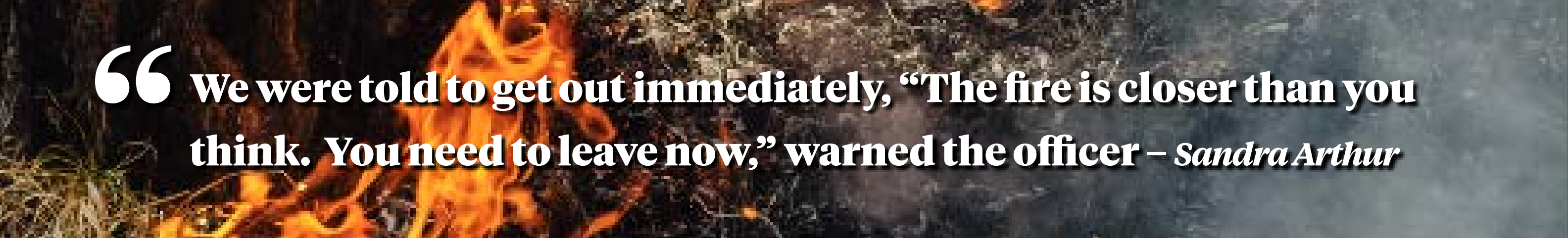
Driving back to the NWT, there were still hot spots and fire along the highway.



> **We were told to get out immediately, "The fire is closer than you think. You need to leave now," warned the officer** – *Sandra Arthur*

SANDRA ARTHUR

Where are you from?
West Kelowna, a small town in B.C, just minutes from Kelowna, a much bigger city. We've lived here just a year.

Tell us about wildfires in your area.
It's very dry all year-round in the Okanagen, a valley from north to south about 200 kms long. It's a winter dessert, you can use a leaf blower to move snow off your driveway.

What happened in summer 2023?
The place was a tinderbox. It was so dry due to extreme drought. The winds were also devastating and fanned the flames all the way to Lake Country, a 45-minute drive away.

The fire started on Tuesday evening August 15th only 7 km from where we live. We were put on alert the next day, and the day after that, on Thursday, we got home after a trip out to find police knocking at our door. We were told to get out immediately, "The fire is closer than you think. You need to leave now," warned the officer.

We had about twenty minutes to pack our things. The wind was bad that evening. Our patio furniture was blowing all over the back yard.

We packed essential documents, clothing and nothing else. I had made a list of what we'd need in the event of an evacuation but forgot to add food.

I don't eat a lot of packaged food so didn't have much on hand. Food was the last thing on my mind. We packed food for our cat but not ourselves.

We'd never experienced an evacuation before as we'd only been living in the area for one year. There wasn't much time to plan and when we first got the alert it didn't seem that urgent. We went from being on alert to 'get out now' in what felt like hours.

> **We'd never experienced an evacuation before as we'd only been living in the area for one year. There wasn't much time to plan and when we first got the alert it didn't seem that urgent. We went from being on alert to 'get out now' in what felt like hours** – *Sandra Arthur*

What happened after you were evacuated?
Most people had no idea what to do or where to go. We went to a nearby theatre parking lot, as did many. The lot was full. We could all see the fire move swiftly north onto the other side of the highway, closer to us.

We needed somewhere to stay but most hotels were already booked, too expensive for us anyway and we had no idea how long we'd need a room. None of our family or friends lived close by except my mom, who lives in assisted living about 35 minutes' drive away. They had a room to rent for out-of-town guests visiting tenants. Luckily the room was available, and we ended up staying there the full eight days we couldn't go home. The problem was there was nowhere to cook.

Others who couldn't afford hotels tried getting help at the evacuation centre. We went there the first morning after evacuation to see if we could get a place with a kitchen, so I could cook my own food but because we'd already sorted a place to stay, we weren't eligible.

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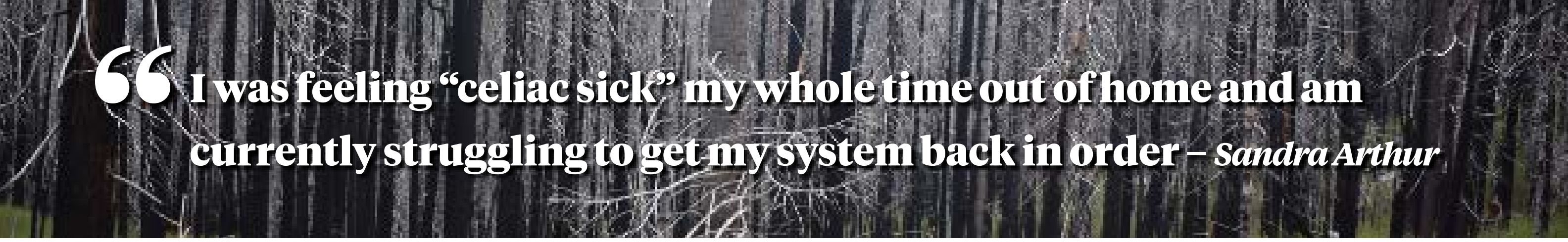

> “I was feeling “celiac sick” my whole time out of home and am currently struggling to get my system back in order – *Sandra Arthur*

SHAUN ROHATINSKY

Photo taken by Sandra’s husband in their backyard by some trees burnt in the fire.

How did you find GF food in the time you were evacuated?
The Salvation Army was great for meals, but not if you were gluten free. They provided three meals a day, which was great for my husband but for me there was only the odd dinner item I could eat safely. I tried a couple of meals but got cross-contaminated. I was feeling “celiac sick” my whole time out of home and am currently struggling to get my system back in order.

After the cross-contamination episodes, I survived on fruit and granola bars. I am also lactose intolerant so that makes it even more challenging. The toughest obstacle for me as the days went by was trying to figure out where to eat.

It was far too expensive to go to restaurants, so I bought GF food from the grocery store but nothing that needed cooking as we had no kitchen. It’s exceedingly difficult to find a restaurant that understands GF and cross-contamination all the way from the kitchen staff down to the servers. We went to a restaurant about 50 minutes away that we knew understood GF cooking and ate there a couple of times.

I had a lot of chili from Wendy’s and Tim Hortons as that always seems to be safe. Who knew how big of a deal it was going to be to eat the same food over and over again? Otherwise, I was extremely glad to get home and have proper meals again. I never want to see another granola bar ever again!

Did you get any help to cope with being celiac?
The Salvation Army urged me to contact their office to let them know I am celiac. They asked me to call/email CCA.

CCA volunteers did respond to an email and mailed me out a box of GF food which was really nice. Unfortunately, I could only get it after the evacuation order was over. I couldn’t access my mail as it was in the evacuation zone.

We did get some financial help from emergency services for food, but it took so long to get an appointment to arrange it, the help came way too late in the game. We were evacuated on a Thursday night and the help came a full week later.

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> “I have woken up many times in the middle of the night to the smell of smoke since we have been home – *Sandra Arthur*

In total, we weren’t able to go home for eight days. Our biggest fear in that time was losing our home. On the Friday night we thought we’d lost our home and wondered how we would ever afford a mortgage for a house that was gone and rent on top of that until our home could ever be rebuilt.

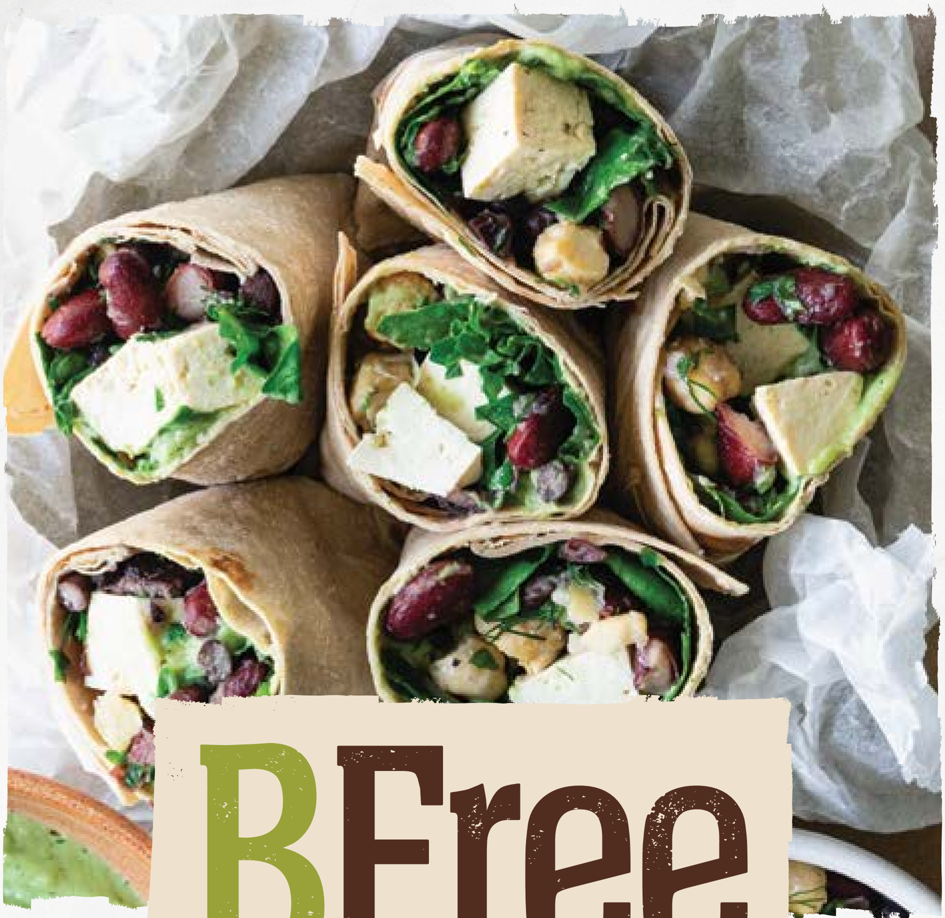
Since then, we have often been on edge as we see the smoke get worse from fires still out of control in our area. I have woken up many times in the middle of the night to the smell of smoke since we have been home.

What would you do next time?
If it ever happened again, it would be so nice if there were restaurants that could be called on for help to provide truly GF meals. In general, I wish all food providers better understood what GF really means. It should be a requirement that all restaurants be educated/certified to understand GF, whether they offer GF food or not.

If we ever get evacuated again, I will go straight to the evacuation centre to be placed in a hotel with a kitchenette.

OUR THANKS AND GRATITUDE

Celiac Canada would like to thank volunteers Lynda Marie Neilson and Val Vaartnou on our Help Desk and the Edmonton, Calgary and BC Chapters for their help in coordinating our efforts with evacuees. Many thanks to Promise Gluten Free, Valley Flax Flour and Schar for supplying donated products.
If you would like to offer your help to someone in times of crisis in your local area, visit our website and complete our volunteer form. ◆



SUPER SOFT très molles
5 TORTILLAS
12g PROTEIN
BFree High Protein Tortillas Hyperprotéiné
AMAZING FLAVOUR! SAVEUR INCROYABLE!
210 g
GLUTEN FREE SANS GLUTEN

2 NAAN BREADS
BFree NAAN BREADS PAINS NAAN
Stone Baked Original · Original Cuit Au Four

Raise the level of care

MONKEY BUSINESS, CANVA

CCA ADVOCACY

NEW SAFE LONG-TERM CARE ACT

Advocating for the most vulnerable

MELISSA SECORD

The government of Canada is working towards a new Safe Long-Term Care Act. It is a principles-based piece of legislation that is intending to raise the level of care so that the most vulnerable in our society, mostly seniors, get the care they deserve.

According to Health Canada website, "...long-term care facilities provide living accommodation for people who require on-site delivery of 24-hour, 7 days a week supervised care, including professional health services, personal care and services such as meals, laundry and housekeeping." Long-term care facilities are regulated provincially. The federal government's role is to provide research and policy analysis on best practices, population data analysis, access and affordability issues, and more.

To start the process for the new Act, the Minister of Health was mandated to complete a review of the national standards for long-term care first. It was completed and revised earlier this year. Celiac Canada participated as a stakeholder to advocate for better care of our community.

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> **…we suggested that the principles of the UN Declaration of Human Rights be reflected to protect access to the right to food, health and life**

The government issued a public document and individuals and organizations had a chance to either complete a survey or send an email. **Nearly 100 individuals took time to voice their opinions** on behalf of the community. CCA also submitted its own recommendations. The full response can be found Latest News from Celiac Canada (Long Term Care Submission).

OUR SUBMISSION HIGHLIGHTED OUR PRIORITIES

- **Ensure adequate funding for food service staffing and food budgets**
- **Make education regarding gluten-free meal service mandatory for food service and other staff in long-term care**
- **Enforce mandatory accreditation for all provinces and territories**
- **Implement indicators of long-term dietary compliance**
- **Ensure Inclusivity in gatherings**

Because of our strong community response along with Celiac Canada's submission, we were asked to participate in a call to further discuss our recommendations with the Home and Long -Term Care Directorate. We raised a number of issues including for people with celiac disease. Areas such as diet and nutrition are not often measured as part of a facilities accreditation assessment and for people with celiac disease, this is critical to their day-to-day safety.

> **We raised a number of issues including for people with celiac disease. Areas such as diet and nutrition are not often measured as part of a facilities accreditation assessment and for people with celiac disease, this is critical to their day-to-day safety**

We also discussed the critical importance of funding the time not only for food purchases but also for the management of the diet by dietitians and nutrition service workers. We shared examples of how intake assessments of patients need to include these team members who are essential to patient-centered care and not just quality of life, but meaningful quality of life. Given it is a principles-based approach, we suggested that the principles of the UN Declaration of Human Rights be reflected to protect access to the right to food, health and life.

We offered our expertise in the management of celiac disease and the gluten-free diet to support positive solutions. In our submission, we provided a copy of our new Guide for Food Service Staff as a potential training and educational tool. We will continue to raise our voice and advocate for our human right to safe food.

Our parting message to the government was: Don't let food be an afterthought.

While there is no timeline for the introduction of legislation, a memo will be prepared for the Ministers involved and then sent to Cabinet. We will keep you posted on our progress to help keep our most vulnerable healthy and safe.

HEALTH STANDARDS ORGANIZATION CENTRED THE NEW STANDARDS AROUND THE FOLLOWING CORE PRINCIPLES

- **Governing LTC Home's strategies, activities, and outcomes**
- **Upholding resident-centred care**
- **Enabling a meaningful quality of life for residents**
- **Ensuring high-quality and safe care**
- **Enabling a healthy and competent workforce**
- **Promoting quality Improvement**

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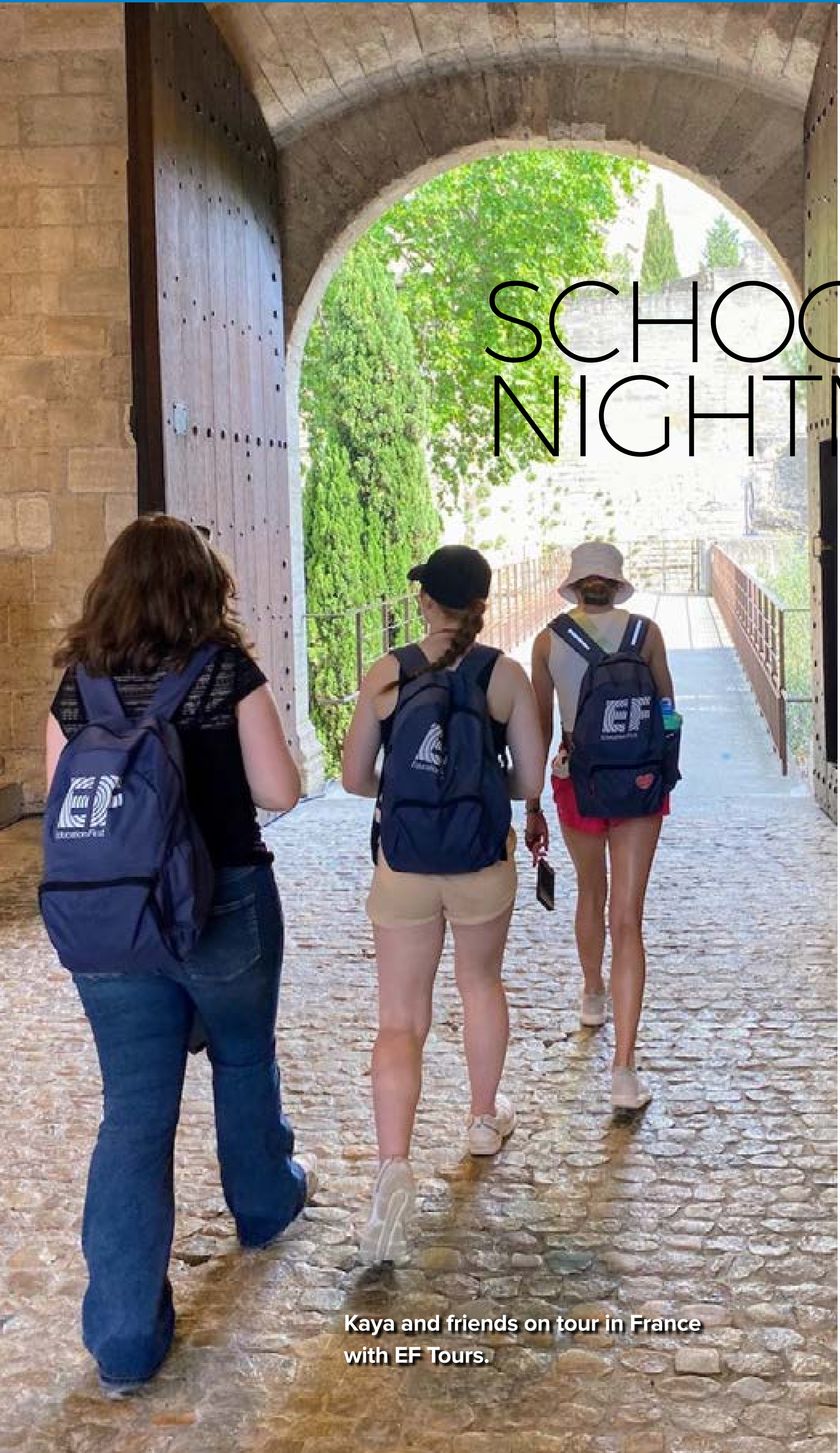

Kaya and friends on tour in France with EF Tours.

SAFE FOOD ON-THE-GO

SCHOOL TRIP NIGHTMARE

Kaya was excited. Her first international trip to France and Spain with her high school. She'd grown up with celiac disease from a young age and was equipped with tools and knowledge to self-advocate, and was assured by the tour company - EF Tours - that they were able to accommodate a gluten free diet on their tours.

The lead teacher also assured the family that he was familiar with celiac and didn't see any reason why Kaya couldn't go on the trip. While she and her family knew there could be challenges, they felt the opportunity was as safe as could be expected and worked to prepare themselves as best as possible.

Kaya would turn seventeen in

Continued on next page

KAYA BURGER

> **She was told to stop complaining, to eat the food and just see if she got sick. She was questioned loudly and publicly** – ***Kaya's mother, Erica***

France, and it seemed the perfect opportunity to try traveling on her own within the safety net of a school trip. Her mom, Erika, told Celiac Canada that they did their homework in the lead up. They wrote to the principal of Kaya's school, the lead teacher of the trip and the tour operator in advance about Kaya's celiac disease and her dietary requirements before booking the trip.

The family was assured that EF Tours was aware of her condition and would organize meals for her. The lead teacher responded to their emails with the following response: "Kaya [is} listed as strictly no gluten as a food requirement and the tour directors are very good at making sure everyone gets what is needed... As soon as we enter a restaurant, we identify the kids with dietary restrictions and usually they are served first so there is no confusion."

"So, we booked it and Kaya was so excited," exclaimed Erika. As a typical family of a child with celiac, they were ultra-prepared. They asked the school to be selective in which small group Kaya was assigned to, so the chaperone was aware of the extra work that might be involved in finding safe food for their daughter.

> **"Kaya [is} listed as strictly no gluten as a food requirement and the tour directors are very good at making sure everyone gets what is needed... As soon as we enter a restaurant, we identify the dietary restriction kids and usually they are served first so there is no confusion.**
>
> ***– Lead teacher***

They made sure she had data on her phone to use restaurant-finder apps in Europe, packed as many snacks as they could fit in her suitcase and included a cutting board and knife. They called the airline in advance to order gluten-free meals. "We tried to prepare for everything we could."

Like many tours, the tour company handled breakfast and dinner. Lunches were on their own, small groups with their chaperone. Given the countries and breadth of the tour, the students were non-stop crisscrossing major sites, putting in tens of thousands of steps, with little down-time but always assigned to a chaperone for safety.

These tours are known for lower cost hotels or restaurants outside of main city centres, which means there's a lot of time spent on tour buses, moving from hotels in the outskirts into the cities for sightseeing. Breakfasts are included in the hotel stay and serve a typical continental breakfast. Suppers are in restaurants, often outside the city, able to accommodate large groups arriving at once on a set menu.

When the group arrives, everyone is served the same thing, often without knowing exactly what they are eating. They eat & leave.

As soon as the trip began, things started to fall apart for the young traveller. Fruit was often her only choice for breakfast, the cafes and bistros where the group stopped had no safe GF options and the group-plated dinners were chaotic and hard to be sure the meals

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Putting in 20,000-30,000 steps a day, she was feeling exhausted and weak without any proper nutrition ... Her medical needs were trivialized

presented were GF. Often green lettuce salad was the only option she could be sure was free of gluten.

Both the teacher leader and the tour director from EF Tours seemed perplexed by her efforts to find out if the food being served to her was safe. "She experienced all of the stereotypical responses a person with CD dreads," says her mother. "She was told to stop complaining, to eat the food and just see if she got sick." She was questioned loudly and publicly whether or not they had told her "at the hospital" that she had to be so careful.

Kaya speaks French fluently and was simply trying to ask the server if the fries she had just been served were from a dedicated fryer. Another time, the EF Tour director mocked her as she ate a bag of plain potato chips instead of a meal, proclaiming that she "was cheating on her little diet".

Kaya quickly burned through her snacks that were becoming her main source of meals. Putting in 20,000- 30,000 steps a day, she was feeling exhausted and weak without any proper nutrition. Her mobile app could pinpoint local options for GF food nearby, but her assigned chaperone would not go there, questioning what the rest of the group would eat. Kaya was not allowed to leave the group and was forced to go wherever the chaperone went.

The only thing Kaya could eat at one restaurant.

KAYA BURGER

> **"Green lettuce is not a meal. It's easy to forget how hungry someone else might be when your own belly is full of croissants and pizza. Where were the adults who were supposed to be supervising this?**
>
> *– Erica*

"Green lettuce is not a meal. It's easy to forget how hungry someone else might be when your own belly is full of croissants and pizza. Where were the adults who were supposed to be supervising this? Why weren't they acting as adults?", demands Erika.

The trip was full of highs and lows for Kaya. She saw many amazing places and enjoyed the new experiences. But she was constantly hungry and stressed about food. Her medical needs were trivialized and she was made to feel as if she was over-reacting and attention-seeking. Erika explained there were some bright spots helping Kaya during the trip, "When they changed her chaperone to someone who helped her find food at lunch time."

Other help showed up when Erika posted on social media, trying to find a way to get safe food to Kaya. Someone saw the post and alerted a teacher, whose spouse was on the trip, albeit on a different tour bus. Nonetheless, he was able to help Kaya navigate the

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Vacation tours and groups need education and sensitivity training to be able to provide wonderful, positive experiences.

restaurant suppers by insisting that the kitchen prepare something suitable for her to eat.

Lastly, a post on a Halifax GF group was shared by a member to a friend-of-a-friend in Paris, and it struck a chord as she herself had been a starving GF kid on a highschool tour long ago. She spent her day traversing Paris in order to bring Kaya safe food.

Despite all the hardships of this trip, kind people appeared to help. "There are good people out there." Erika and Kaya shared their experience on CCA's Peer Support Group on Facebook to caution other parents about school tours, and in particular, EF Tours. Her post received an enormous response with an outpouring of concern and shared experiences.

Many other people shared stories of school trips abroad where they had little food to eat. Yet some did have better experiences. Stephanie said on her child's tour, there was "time every day to go to a store to pick up snacks and it was worked out with the tour guide in advance. Dietary needs were never an issue."

Another post lauded an EF Tour Spain trip and how her son stayed healthy throughout the trip. Erika has since written to EF Tours, her school board and principal. She did not hear back from EF tours. "There was a complete failure on many fronts: the tour company must ensure that their vendors are able to provide proper, sustaining food; the teacher leader should have been advocating and supporting my daughter to find safe food; and the chaperone should have been working to find safe lunch spots rather than prioritizing her own tourist experience. I was so disappointed by the actions of the adults on this trip."

Celiac Canada has also written to the national office of EF Tours and was waiting for a response at the time of publication. As celiac disease becomes more prevalent, more students will be taking tours and vacation tours. Groups need education and sensitivity training to be able to provide wonderful, positive experiences.

Advocating for improved national standards and regulations surrounding food service in national airports and restaurants, similar to many countries in Europe, can improve travel even domestically. ◆

Thanks to Kaya and the Burger family for sharing their story.

> **"There was a complete failure on many fronts: the tour company must ensure that their vendors are able to provide proper, sustaining food; the teacher leader should have been advocating and supporting my daughter to find safe food; and the chaperone should have been working to find safe lunch spots rather than prioritizing her own tourist experience. I was so disappointed by the actions of the adults on this trip**
>
> *– Erica*

The future of your food

CCA ADVOCACY

HEALTH CANADA SET TO MODERNIZE REGULATIONS

As part of its mandate, Health Canada has undertaken a three-pillar approach to review food regulations to keep pace with current trends and to bring food innovations to Canadians in the safest way possible. Anything involving how food is grown, manufactured, labelled and sold in Canada is a safety and health concern

The first step is to review the agility of current regulations. Health Canada recently asked stakeholders to weigh-in on Future Food Regulatory Modernization Priorities. Celiac Canada's response was led by

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DLEWIS33, CANVA

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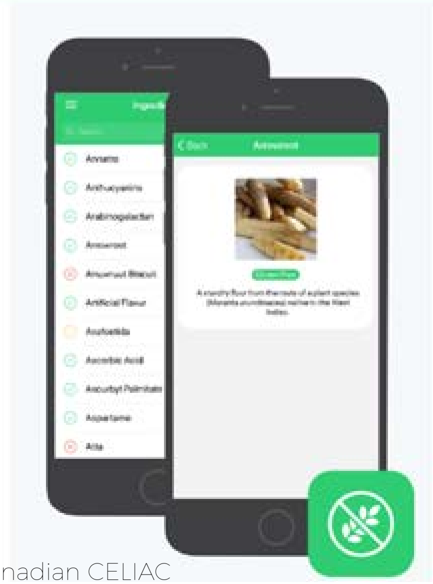
The first step is to review the agility of current regulations. Health Canada recently asked stakeholders to weigh-in on **Future Food Regulatory Modernization Priorities. Celiac Canada's response** was led by Professional Advisory Council Member, Shelley Case, She a Registered Dietitian with a long history of food regulation advocacy for Celiac Canada.

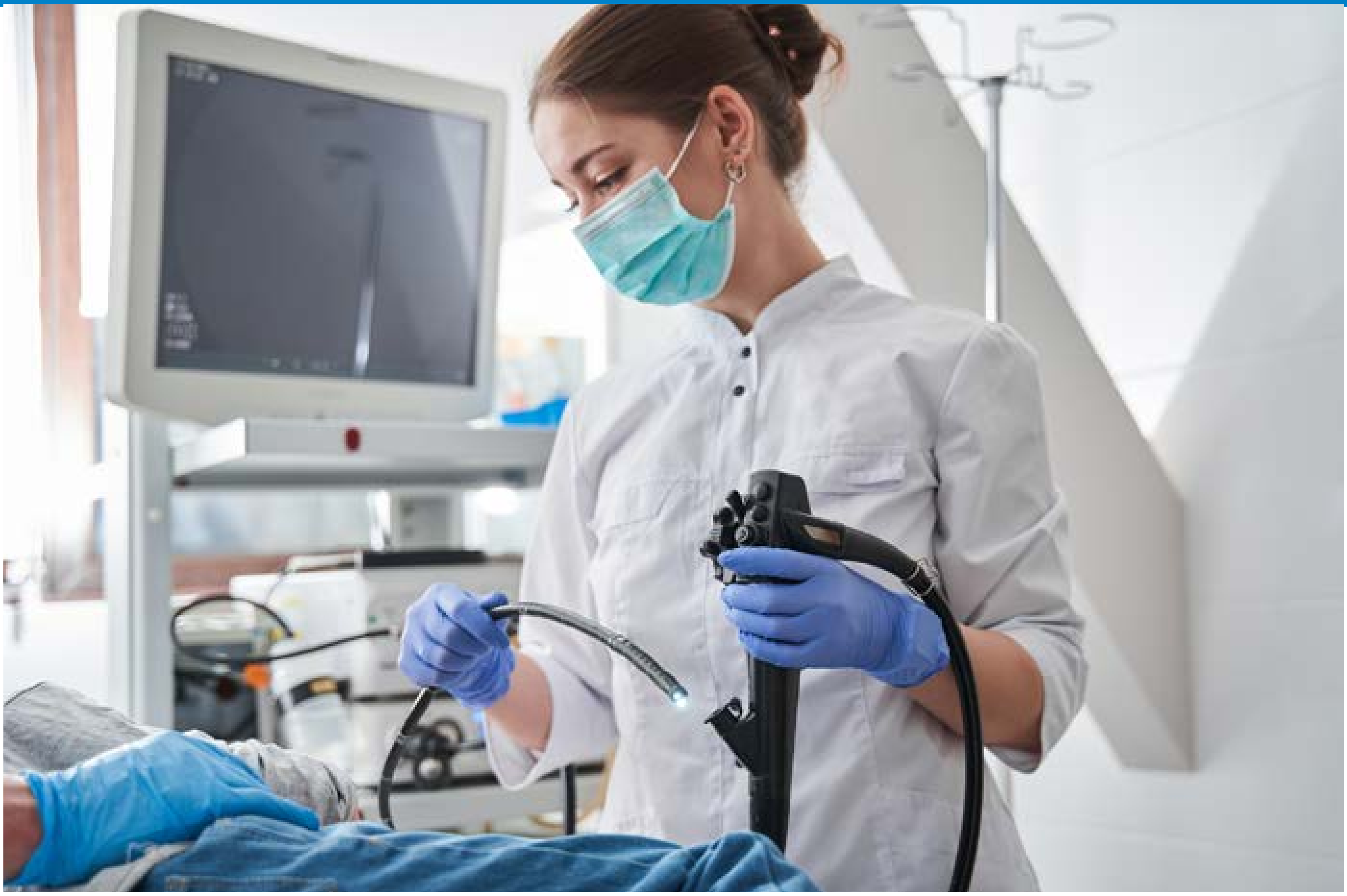
Our submission focused on two Professional Advisory Council Member, Shelley Case, a Registered Dietitian with a long history of food regulation advocacy for Celiac Canada.

Our submission focused on two key areas outlined in the government's consultation paper
- Foods for special dietary purpose
- Fortification of gluten-free food

CELIAC CANADA'S TOP 5 REQUESTS

- Mandatory fortification of gluten-free foods and removing advertising restrictions in D. 03.003
- Foods for special dietary use - B. 24.018 revisions
- Enhanced guidance documents for the use of precautionary allergen and gluten labelling
- Mandatory declaration of allergens and gluten sources in medications
- Proposed new regulations for menu labelling ◆





YAKOBCHUK OLENA, iSTOCK,

INTESTINAL BIOPSY – FINAL STEP TO CELIAC DIAGNOSIS

JOANNE MURRAY

The intestinal biopsy is still considered the gold standard for a definitive celiac diagnosis in most children and all adults. And in our current medical environment, many ask ‘Is it worth the wait?’ for that definitive diagnosis? How much longer do I put my life on hold?

The wait time in Calgary, Alberta for example is rarely a matter of weeks and is usually months. Often many, many months. For too many people, the road to diagnosis has already included the ‘on average’ wait time of eleven years with several physicians and many complicated tests involved before arriving at the blood screening tests that show a positive IgA tTG test result that indicates the likelihood of celiac disease.

Now, the final step to diagnosis is the coveted biopsy. Your physician tells you that it will take another number of months to have a consultation with a gastroenterologist and then another few months before the biopsy will be

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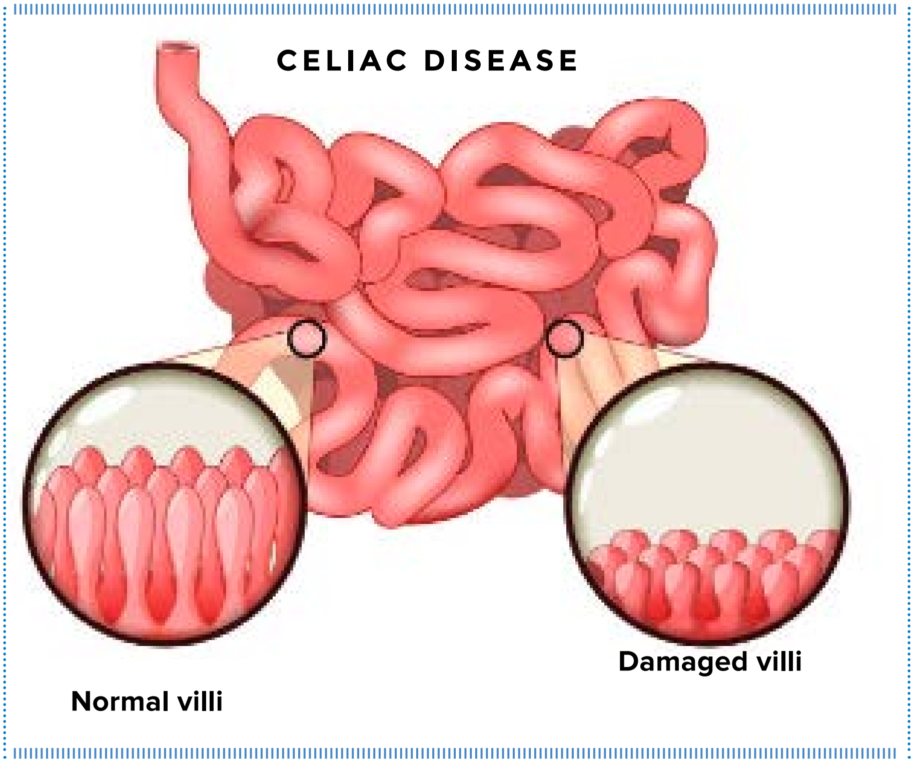
> “The treatment is straight forward, it can even be self-prescribed … you’re told you must not start … until the biopsy is done –*JoAnne Murray*

available to you. By now, your frustration is palpable. You’re usually having miserable symptoms. The treatment is very straightforward, it can even be self-prescribed. And you’re told you must not start treatment until the biopsy is done.

The temptation is overwhelming to ignore the required delay to finally have your life back on track. What do you do? The people who like all things in order grudgingly wait the time for the system to ultimately accommodate them. The risk takers often proceed with self-prescribed treatment with the intent to get themselves well and deal with the fallout later.



TTSZ, iSTOCK,

There are no easy answers. And weighing all the information for decision-making is complicated. Your physician may suggest that self-prescribing the gluten-free diet treatment and doing a gluten challenge later is a wise intermediate solution.

What are some of the questions you need to ask yourself as you weigh the choices?

Let’s talk about Children and Diagnosis in Children

Are they the first members of your family about to be diagnosed with CD or do they have any first-degree relatives who have been officially diagnosed with CD? Are they showing classic symptoms? Are they showing non-classic symptoms that are now recognized as being included in the common presentation of the disease in children?

Are their blood screening results at least 10x a normal result? And has it been reproducible with a second test? Have they had the additional screening tests that aid in confirming a celiac diagnosis?

Have they had the genetic test to determine if they carry one or more of the genes necessary to develop the disease?

Are they at a critical stage of their development where delay in diagnosis would impact their future health and growth? Is their ability to learn being impacted? Are they experiencing mental health concerns that interfere with their experience of quality daily life?

Are their symptoms so severe and intense that they pose a danger to their immediate health?

If they do go gluten free while waiting for the biopsy and have a biopsy once healing has begun, will there still be enough diagnostic evidence for a definitive

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diagnosis without doing the gluten challenge?

Are you prepared to guide them through a gluten challenge at a later time when access to the health system becomes more available? Are you prepared to have a gluten challenge fail?

Some children can be diagnosed by blood tests alone if they meet the specific criteria.

Now Let's Talk about Adult Diagnosis.
Everything that is mentioned above for evaluating potential diagnosis of children can also be asked about adults. Consider going through the checklist and making certain that you can check off all the boxes as being completed and evaluated.

Now, ask yourself, is your quality of life impacted to the extent that you are no longer fulfilling your adult responsibilities? Are you able to set symptoms aside and carry on effectively most days? Are you putting other people at risk because of your health issues? Are you at risk of losing your employment? Is your career path on hold because of workplace health concerns? Is your lack of quality of health and life interfering with family relationships and commitments

> “Perhaps the most significant obstacle that is often overlooked is having your self-diagnosed or only partially diagnosed celiac disease taken seriously. Celiac disease can be viewed as an Anchor Disease. By that, I mean it needs to be factored into any discussion about any other health conditions that you currently have or that may join your life over the next few years
>
> *— JoAnne Murray*

Now that you've had a look at some of the realities of your life as it is today, it's time to look at some of the obstacles that can complicate the future if you don't get that coveted definitive biopsy diagnosis now.

There's a lot of research going on at both the diagnostic level and for future treatment. Historically, opportunity to participate in research has been restricted to those with a biopsy diagnosis.

Once new science comes on track for diagnosis and treatment, there is likely to be some continuing restriction for access to these new programs when they join the list of available procedures. If you look at the current delays of access for procedures like knee and hip replacements and the anticipated delay in having the numbers of physicians, nurses, technologists, therapists and all other support staff, created to provide and manage the needed services, there could be huge delays before you can re-enter the system to complete the next steps of a definitive diagnosis.

Perhaps the most significant obstacle that is often overlooked is having your self-diagnosed or only partially diagnosed celiac disease taken seriously. Celiac

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Close-up of microvilli in a intestinal tract.

disease can be viewed as an **Anchor Disease**. By that, I mean it needs to be factored into any discussion about any other health conditions that you currently have or that may join your life over the next few years. It's one thing to have an incomplete diagnosis recognized by your current health team, but as you gradually find your care being provided by second, third and fourth generation health care providers, the carry forward of the assumed diagnosis gradually falls off the table because there is no proof.

I am now personally facing fourth generation medicine since my diagnosis. Some of my health care providers willingly accept my biopsy diagnosis from almost six decades ago and incorporate it into the investigations and treatments that have now entered my life. Osteoporosis has been a primary consideration for years.

Today, gluten ataxia has also been added to my long-term health focus. Because I can describe my very long undiagnosed history (more than two decades) and pinpoint the moment I had a biopsy diagnosis, both the specialists for these disorders are focusing on my celiac disease as being the **anchor disease** for both these conditions.

> “ Without that biopsy, I would have been just another person with osteoporosis and balance issues. Because I had the biopsy, I am now seen as a person with a serious autoimmune disease (celiac disease) needing treatment for a serious metabolic disorder (osteoporosis) and a serious related brain disorder (gluten ataxia)
>
> – *JoAnne Murray*

Without that biopsy, I would have been just another person with osteoporosis and balance issues. Because I had the biopsy, I am now seen as a person with a serious autoimmune disease (celiac disease) needing treatment for a serious metabolic disorder (osteoporosis) and a serious related brain disorder (gluten ataxia).

Instead of polite placating gestures, my health issues are being recognized as predictable outcomes of long term undiagnosed celiac disease, long term well managed celiac disease and the forces of aging combined. These health concerns can be better managed in my senior years by knowing that they have a relationship to gluten all those years ago, and with diligent food management, I can still enjoy my best life possible moving forward. These are important distinctions and will continue to impact all my future health choices.

Ask yourself. Could this be your story? Will the biopsy benefit you? I knew long before today that the biopsy was important. It was reinforced in my mind today as these specific dots were connected.

There are more and more health conditions that are also recognized as being impacted by a

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> **“All I can really say at this moment is that my biopsy all those years ago saved my world today** –*JoAnne Murray*

celiac diagnosis, but without the biopsy diagnosis, few physicians will tie those pieces of information together. I have heard that some have offered a gluten challenge to remove the doubt, a wise offer on their part. However, when a person is having another serious health concern diagnosed, particularly one that has already weakened their health, it’s a tough sell to persuade that patient to willingly start a gluten challenge.

Then there are the more social types of restrictions. Children can find that their needs for a safe environment are not addressed in the school system if there is no evidence of need. Seniors entering retirement facilities that provide meals as part of the package are often told that special food needs can’t be met or that they can only be met with very costly additional fees.

I encourage anyone struggling with the current restrictions to medical access that prevents them from getting a timely diagnosis, to consider all the thoughts I have put forward. There are no easy answers. I can offer no solutions to the dilemma you are facing. I can only say that without the biopsy diagnosis, some doors are closed to people who have a real need for timely investigation and treatment of their health issues and the connections these issues may have to a celiac disease diagnosis.

Sit down with your family, your physician, your employer (in some circumstances), your member of the legislature, your member of parliament, and any other person who could and should have your best interests at heart as you make your decision. Create a plan for how you will manage your health and this health decision. Ask the questions that will make it easier to understand the restrictions that are limiting your current access to diagnosis. And then ask yourself, is it realistic, is it manageable, is it doable. And if not, why not? And if yes, when?

I wish you all a safe health journey. There are no easy answers. All I can really say at this moment is that my biopsy all those years ago saved my world today. ◆

50TH ANNIVERSARY | PART 3

CCA HISTORY- HIGHLIGHTS 1973-2023

2023 celebrates the CCA's 50th anniversary. Here's the last in our historical review series

MD BABUL HOSEN, CANVA

1993 - 2013: EMERGENCE; AUTHORITY, EDUCATION

In our third decade, we established credibility as the authoritative voice on celiac disease and the gluten-free diet. Our Professional Advisory Board developed the first-ever Canadian Celiac Health Survey and developed the "Pocket Dictionary", published in English and French. We created a research fund named after Dr. J.A. Campbell, and awarded our first research grant.

Highlights

Food

- GF Oats now available
- Foods expanded beyond rice to include many other grains

Organization

- 15 CCA volunteers honoured with Queen's Jubilee Medals
- Volunteers from every chapter trained in Peer Counselling

Medical/Scientific

- First blood tests to screen for CD available
- J.A. Campbell Research fund - first competition for research funding
- Canadian Celiac Health Survey results published
- Resource kit for dietitian developed

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CANVA

> **The goal was to grow the association and move to 100% charity status to help every person with celiac disease get diagnosed and empowered**

2003-2013 (EXPANSION, PROGRESS, PARTNERSHIPS, RECOGNITION)

A decade of many firsts. The CCA takes a leadership role on many fronts with significant scientific publications, advocacy with the federal government and major developments in the availability of safe gluten-free food including working directly with Canada's first grower of GF oats.

CANVA

Highlights

Food

- Gluten-free oats deemed safe and became available in Canada
- Gluten-free beer available
- Gluten-free pizza could be delivered to your home!
- The Gluten-Free Certification Program (GFCP) was born to certify gf foods

Organization

- CCA recognized as the legitimate authority to take our concerns to the CRA (medical tax credit), to Health Canada (no hidden gluten sources in new regulations for food labels) and to participate in the NIH Consensus Conference on Celiac Disease in the US
- All people in Canada who need to eat gluten free, whether celiac or not, included in mandate to support
- Beginnings of a social media presence

Medical/Scientific

- Nation-wide survey on life with celiac disease in Canada resulted in publication of several papers in prominent journals
- Oral Manifestations of Celiac Disease published

2013 -2023 (TOUGHER, BIGGER, BETTER, DIFFERENT)

Serious financial difficulties forced the CCA, never a big spender, to be extra frugal. Cutbacks included less staff, a reduction in face-to-face board meetings, learning to make do. Anne Wraggett, Mark Johnson and Sue Newell held us together.

As membership dropped and chapters dwindled, the Facebook support group exploded and developed into a new format with formal moderating from the CCA to provide timely, accurate information and peer support.

The national board decided to hire an executive director after four years without. The goal was to grow the association and move to 100% charity status to help every person with celiac disease get diagnosed and empowered.

Highlights

Food

- Work with Health Canada finally allowed safe oats to be labelled GF
- Cheerios claimed to be GF but was met with serious pushback in Canada over the lack of disclosure of testing methods used to back the claim. GF label removed in Canada.
- Our Pocket Dictionary came out as an app – Gluten Free 24/7

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In 2021, Ontario initiates a pilot project to cover the diagnostic blood screening tests for celiac disease, after decades of lobbying by the CCA

- GFCP certification grows exponentially (more than 6000 products) and goes international
- Beer no longer exempt from labelling regulations
- Many years of work with Agriculture Canada comes to fruition with new standards for safe production of GF grains and pulses
- Around 2020, CCA launches a program for food banks, 'Save Me for Gluten Free'
- In 2021, Ontario initiates a pilot project to cover the diagnostic blood screening tests for celiac disease, after decades of lobbying by the CCA
- In 2022, federal regulations on labelling of natural health products about to change, with lobbying effort by CCA
- Financially able, just barely, to hire an executive director and welcome Melissa Secord in 2017
- Membership model changed to a donation model and finances improve with active proper fundraising
- Advocacy efforts escalate and Ontario finally covers the cost of celiac blood testing
- Work is ongoing to address confusing, inconsistent use of precautionary labels and gluten in medication
- Registered dietitians on staff
- Name changes to Celiac Canada
- New Parliamentary Celiac Caucus created

Medical/Scientific

- PAC publishes authoritative statements on early introduction of gluten for infants, safety of alcohol, oats, gluten in medications and in lotions and cosmetics and how to read food labels ◆

50TH ANNIVERSARY

CELEBRATING the incredible spirit of community leaders, past & present

Celiac Canada proudly announces the launch of our Volunteer Awards program, honoring outstanding contributions by those who make a difference in the lives of people with celiac disease and gluten sensitivity. The three categories are: -

The **Changemaker** award celebrates a volunteer who has driven meaningful change and created lasting impact in the areas of health, policy, or success for CCA and celiac community, displaying leadership, vision, and innovation.

The **Super** Volunteer award goes to those dedicated to delivering programs, help, and support to the community. The Volunteer could be an active member of a committee, sit on a board, a local support group leader, someone who develops programs or food drives. Maybe they're always there to lend a helping hand.

The **Young Volunteer** award recognizes those 18 or younger, who have shown enthusiasm, creativity, and commitment to volunteering for CCA and the community. This person has been involved in raising awareness, fundraising, or advocating for people with celiac disease and gluten sensitivity.

CCA is beyond grateful to all our volunteers who give their time, energy, and skills to make a positive difference in the lives of people with celiac disease and gluten sensitivity. Thank you for your amazing work! We cannot do it without you.

THE CHANGE MAKERS

COURTESY, MARK JOHNSON

Mark Johnson
Mark was President of the Ottawa Chapter and served on the National Board. Along with Anne Wragget and Sue Newell, they kept the small charity the was CCA going through desperate financial challenges. Despite the incredible change making policies and introduction of North America's first gluten-free certification program, CCA struggled with declining membership. Mark continues to offer is support as MC at our conferences and always ready to lend a hand to all the chapters and support groups.

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CCA is beyond grateful to all our volunteers who give their time, energy, and skills to make a positive difference

THE CHANGE MAKERS

Marion Zarkadas

Marion was diagnosed with celiac disease while working for the government in various positions – Corporate and Consumer Affairs, CFIA and Health Canada. Marion's contributions are too numerous to mention but was instrumental in getting the GF regulation in 1995, Schedule 1220, CCA national health surveys and many others. She also was a dedicated volunteer to the Ottawa chapter and on the CCA Professional Advisory Board for many years.

James A. Campell – Posthumous

Dr. J.A. Campbell was the director of the Nutrition Bureau at Health Canada, an advisor to the Ottawa CCA chapter and chair of the CCA National Nutrition Committee (now the Professional Advisory Council). While at Health Canada, he collaborated with dietitian Marion Zarkadas, who was at the Consumer Corporate Affairs on the many food allergen and gluten labelling issues. Together, they co-authored the first CCA Pocket Dictionary with Vancouver Dietitian, Mavis Molloy, as a reviewer.

Dr. Campbell also wrote sections in the CCA's Celiac Disease Needs: a Diet for Life handbook. He also designed the first Canadian Celiac Health Survey conducted in 1989 that was published in 1992. Dr. Campbell wrote many other publications on celiac disease and the gluten-free diet.

Another huge accomplishment was championing the gluten-free regulation that came into force in 1995. This set the standard for what may be labelled as gluten-free today, in Canada.

For his years of service and significant contributions, Dr. Campbell was given the CCA Honorary Life Membership. The CCA established the Dr. J.A. Campbell Research Fund to carry on his legacy. ◆

COURTESY, MARION ZARKADIS AND DR. JAMES A. CAMBELL

See a full list of awards recipients here [Volunteer Recognition Awards - Celiac Canada]

UNITED WAY SEASON

United Way's workplace appeal is happening now

- If there's a program through your payroll at work, ask about designating Celiac Canada as the recipient of your generosity.
- United Way sends us your donation and we send you a tax-deductible charitable receipt.
- Small increments each pay period make a great impact. Without straining your budget.

BITE-SIZED SNACKS-MAKER, INNO FOODS

CCA sat down with BC-based President In Heon Cha for a Q & A

Please tell us the origin story of Inno Foods

Inno Foods is a leading global supplier of bite-sized, organic snacks designed for diverse diets and discerning taste buds. The name "Inno" reflects a commitment to innovation.

Located in Coquitlam, BC, the Park family opened the Bread 'n' Buns bakery in 1982 that served high-quality bread – bread without preservatives, to be exact.

After serving the local community, the Park family saw something that was missing in the food industry: ingredients that you can trust. The family-owned business decided to expand and personally source all their ingredients, down to the individual farms they partner with.

Inno Foods stills act like a small, family-run business, but now they proudly do so on a global scale, with the mission to continue to produce innovative snacks, cereals and granolas for customers around the globe by sourcing only the finest ingredients.

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

About one percent of the population worldwide has with celiac disease. There is currently no cure for persons suffering from celiac disease or non-celiac gluten sensitivity or intolerance.

The gluten-free diet is the only existing treatment for celiac disease today. To ensure customers with celiac disease or non-celiac gluten sensitivity can also enjoy our anytime snacks, we decided to join and become certified with BRCGS' Gluten-Free Certification Program, which uses a scientifically proven, risk-based

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Almond fruit crunch cereal by Inno Foods

COURTESY, INNO FOODS

management systems approach for effectively controlling gluten and gluten cross-contamination from incoming ingredients to the final product.

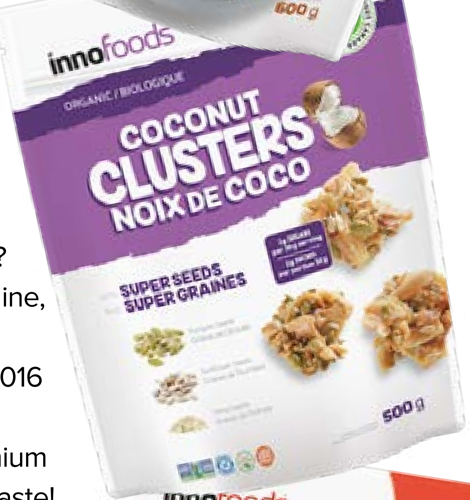
Furthermore, in Canada, BRCGS GFCP is recognised by the leading celiac organization – Celiac Canada. The trusted GFCP logo endorsed by Celiac Canada provides the extra assurance of safety that our consumers value.

In terms of process, what are some of the steps you undertake to keep food ingredients gluten-free? Where do you source your ingredients?
All our facilities follow GFCP guidelines and are certified gluten-free facilities. We only handle gluten-free ingredients. Gluten testing for both ingredients and final products are conducted to validate our GFCP.

We only source gluten-free ingredients from suppliers with recognised food safety management systems in place and who guarantee ingredients as gluten free.

Where can customers find your products? Or how can they buy them?
Our products can be found via our online website: innofoods.shop. We also have our products in retailers, such as Costco, Loblaws, Walmart, and TJX.

What is your most popular product with customers and why?
That would be our coconut cluster line, as we started out with our Coconut clusters with super seeds back in 2016 with Costco. People associate our coconut cluster products with premium high-quality ingredients and great taste!



What is unique about your product? (Aka nutrition, ease of use, easy to adapt in recipes). What are you most proud of?
We focus on innovative products, using a clean ingredients deck, and high-quality ingredients chosen from reputable suppliers. We continuously research and develop on-trend products that also taste good. We are able to adapt to the retailer's requests. For example, today, we are working on new pouch designs that the retail shelf display can accommodate for more accessibility.

Our products can be paired with different foods and/or drink items, such as milk, ice cream, yogurt or even wine (chocolate nuggets). Our crackers are great by themselves but also with dips and other foods! ◆

COURTESY, INNO FOODS

Gluten free in Portugal

JULIE GREENE 2022

SAFE FOOD ON-THE-GO

TRAVEL delights and challenges

One of the most cherished desires of many with celiac disease is to see the world and be able to find safe, delicious food away from home. Not an easy task, yet more and more tour operators are realizing there's enormous demand

Julie Greene tells about the delights and challenges of a Portuguese tour co-ordinated by Lora Hamre, a celiac and Director for Merit Travel in association with Trafalgar Tours and Celiac Canada (CCA).

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merit travel

TRAFALGAR

> **“I thoroughly enjoyed getting to know everyone in the group and hope to remain friends as time goes on** –*Julie Greene*

JULIE GREENE

October 2022. We couldn’t wait. A group of twenty-one brave travelers, myself and Lora were heading to Portugal for ten days! Our itinerary, accommodations, flights and food were all arranged. All we had to do was sightsee and eat. Our first ever gluten-free travel experience with the CCA.

Some of our group members hadn’t travelled outside Canada since 1992 because of the challenges in finding safe food abroad where you don’t speak the language and you don’ t know their rules. Everyone was feeling a mix of emotions: excited, anxious, apprehensive, and nervous. For many, it was their first time on a group travel trip.

Our first hurdle, as in any long-distance trip, was navigating airline food. Onboard, even though we had ordered gluten-free meals for everyone, they were served with a wheat bun and carrot cake containing wheat! Luckily, our group was savvy and knew not to eat it. But it shows you always need to be alert

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Top, a server preparing gluten-free food table side. Left, Julie & Lora eating Pasteis de Nata. Right, Jeanette and Angela on a guided tour.

JULIE GREENE

> **“We shared our journeys to diagnosis and the gluten-free lifestyle and laughed over our funniest symptoms** –*Julie Greene*

and ask questions when things appear unclear. When in doubt, do not eat it! There is still so much work left to do in advocacy for food service.

Our second hurdle was navigating hotel breakfast buffets. So much room for cross- contamination! We asked to be the first group allowed in each morning. That meant early mornings, which was worth it for getting safer food. Some of the group popped to the grocery store and had breakfast foods in their rooms, which was also a great idea. **For more in-depth info. see our top travel tips guide.**

Now for the sights. We started in Lisbon, and made our way North, visiting many places like Cascais, Tomar, Fatima, Coimbra, Nazare (and more!), ending in Porto. We travelled comfortably on a large tour bus, with plenty of space for our bags, purchases, food (it’s always about the food!) and room to stretch out and nap. The bus even had WIFI!

During the trip our guide, Mikael, was with us every step of the tour and made sure all our needs were taken care of at each location. A local specialist also joined us at each spot, to share the history and special features.

Sometimes, it’s hard to hear everything the guide has to say, especially if you’re at the back of a group. So, we used Vox Boxes, also known as “Whispers”, allowing everyone to easily hear all the information without the guide having to yell. The boxes even had hearing aid attachments for the hearing-impaired members of our group. What a difference to the experience.

JULIE GREENE

The food on the trip was amazing, I don’t think I’ve ever eaten so well! Food labelling laws in Portugal are extensive, and there were many gluten-free options along the way. We enjoyed incredible meals at every restaurant we visited, and delicious desserts including gluten-free croissant, donuts, eclairs, cream puffs, gelato, McDonalds, crêpes, and more. It’s a good thing we did a lot of walking!

Merit Travel and Trafalgar Tours worked with the restaurants in advance to make sure they had gluten-free food ready to serve. And then Lora and I double-checked dishes on arrival to make sure things were in order.

Not all meals were included, so our travelers had to use their CCA dining-out cards and find safe options on their own at times. This proved challenging for some of us at first, but as the trip went on, everyone grew more comfortable and felt more confident. There is safety in numbers and being together as a group really helped! Overall, the group felt very safe and supported.

Our group included people from across Canada, couples and friends, and some individuals. We shared our journey to diagnosis or the gluten-free lifestyle and laughs over some of our funniest symptoms. There’s something special about sharing meals with others. It was such a lovely break to eat effortlessly for ten days and be in the company of others who understood what that means to you.

Making special food requests in Portugal was very normal, and didn’t appear to “ruffle feathers” the way it does at times in Canada. It was refreshing not to feel like an annoyance!

I thoroughly enjoyed getting to know everyone in the group and hope to remain friends as time goes on.

Learn more about traveling safely with celiac disease.

Continued on next page

> **“Our trip helped our travellers feel more comfortable eating out and travelling gluten free** – *Julie Greene*

7 PREPARATION TIPS FOR PEACE OF MIND WHEN TRAVELLING

1. Print “dining out cards” – these are cards in the language of the country you are visiting that explain what celiac disease is and why you cannot eat gluten.
2. Look up the words for wheat, rye, barley, malt, oats, semolina, soy sauce, gluten, gluten free in the language of the country you are visiting, to help you read labels.
3. Explore if there is a gluten-free food labelling symbol for the country you are visiting.
4. Walk away from an unsafe meal, no matter what you spend on it or who you’re eating with. No meal is worth being sick while travelling.
5. Pause before you eat: have you asked all possible questions? What is your comfort level with the meal?
6. Pack any medications or aids that help you feel better when and if you get sick. This will give you peace of mind that if you do get sick, you are prepared.

7. If you are travelling with someone, it may be good to walk them through how a reaction looks for you and how long it lasts, as well as how they can best support you.

CANVA

THREE TIPS FOR NAVIGATING HOTEL BUFFETS

- Try to get there first! We coordinated to be the first ones at the buffet each day.
- If you cannot be there first, hard boiled eggs and yogurt are your safest bet.
- Notify your hotel and servers ahead of time, as they may be able to offer a gluten-free toaster and products like a muffin or bun.

DID YOU KNOW? Our trip helped our travellers feel more comfortable eating out and travelling gluten free.

COMFORT LEVEL TRAVELLING GLUTEN FREE

Before the trip, here were the comfort levels travelling as a celiac

58% Not comfortable
25% Somewhat comfortable
16% Comfortable
0% Very comfortable

After the trip, participant comfort levels had greatly improved as follows

0% Not comfortable
50% Somewhat comfortable
25% Comfortable
25% Very comfortable

COMFORT LEVEL DINING OUT GLUTEN FREE

Before the trip, here were the comfort levels dining out as a celiac

38% Not comfortable
46% Somewhat comfortable
8% Comfortable
8% Very comfortable

After the trip, participant comfort levels had greatly improved as follows

0% Not comfortable
38% Somewhat comfortable
38% Comfortable
23% Very comfortable

Continued on next page

> **“There’s something special about sharing meals with others who appreciate safe food as much as you do** – ***Julie Greene***

4 PORTUGUESE FOODS TO TRY

Pasteis de Nata: Portuguese egg custard tart pastry

Francesinha: Portuguese sandwich made with bread, wet-cured ham, linguica, fresh sausage and covered with melted cheese and a hot and thick spiced tomato sauce.

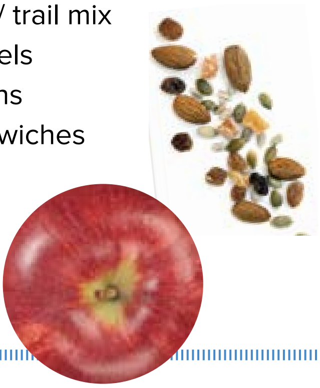
Vinho Verde: Portuguese wine that originates in the historic Minho province in the far north of the country.

McDonalds: Nine gluten-free burger options!

DEPOSIT, CANVA, iSTOCK

WHAT’S IN OUR BAG? OUR GROUP SHARED THEIR TOP 10 FAVOURITE TRAVEL SNACKS AND EATS!

1. Crackers
2. Individually packaged cheese
3. Fruit
4. Mini granola bars and granola bites
5. Protein bars, granola bars
6. Chocolate and candies
7. Nuts / trail mix
8. Pretzels
9. Muffins
10. Sandwiches



2 HELPFUL APPS

“Find my Gluten Free.” It will help you find gluten-free bakeries and restaurants all over the world!

Google Translate: You can hold your phone over a label or take a picture of a label and this app will translate it to English for you.

BEST GLUTEN-FREE RESTAURANTS AND BAKERIES IN PORTUGAL

Lisbon: Zarzuela GF bakery, Rice Me Deli

Cascais: Hacienda don Manuel

Tomar: Bohemia Cerveja

Fatima: Lhanha’s restaurant

Coimbra: Bonna gluten-free bakery

Porto: Mauritania Grill, McDonald’s, Com Cuore bakery, Amorino Gelato, Chez lapin, Terra Nova Restaurante

Nazare: Taberna ◆

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Passau, Germany

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Date	Destination	Activities
Apr 9	**Budapest**	**EMBARKATION**
Apr 10	Bratislava	"Coronation City" Walking Tour OR Tastes of Slovakia OR Bratislava Castle Hike
Apr 11	Vienna	"Imperial Vienna" Tour OR Vienna City Tour by Bike
Apr 12	Dürnstein	Dürnstein Walking Tour & Wine Tasting OR Apricots & Sweets Tasting OR Dürnstein Fortress Hike Danube Bike Tour
	Melk	Benedictine Abbey Tour
Apr 13	Engelhartszell	OR "City of Three Rivers" Walking Tour OR Passau Castle Hike OR Passau Bike Tour
Apr 14	Regensburg	UNESCO City Walking Tour OR Tastes of Bavaria OR Walhalla Bike Tour
Apr 15	Nuremberg	Medieval Nuremberg OR World War II Tour OR Franconian Specialties Tasting
Apr 16	**Nuremberg**	**DISEMBARKATION**

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» Live local entertainment
» Unlimited complimentary Wi-Fi access
» Price includes Prepaid Gratuities, Beverage Package, Taxes, Port Fees and Insurance on your Deposit

Our partnership with AmaWaterways ensures that your voyage is nothing short of exceptional.
The Exclusive Gluten-free Cruise supports Celiac Canada educational & advocacy programs.

Safe & delicious
Every effort is made to ensure a safe voyage so you can relish your food made by experienced chefs in dedicated gluten-free kitchens. Enjoy every moment, worry-free.

All gluten supplies and "stores" will be removed prior to boarding. No gluten- containing items will be present onboard for the duration of the cruise. Regular draft beer will be shut off for the duration of the Gluten-Free cruise.

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TICO Ontario Registration No: 50010723

Plan your family's future

FIZKES / ISTOCK.COM

CREATING A WILL SHOULDN'T HAVE TO BE COMPLICATED

Planning your family's future today will give you peace of mind tomorrow. No matter your age or life stage, creating a will allows you to leave a legacy to protected loved ones and support causes you cherish. You can leave a legacy of hope, helping support future generations to come.

The CCA now offers a free Will Kit which you can complete on-line.

Visit this LINK for information on how you can create a legal Will in 20-minutes or less at no cost to you.

Support Celiac Canada in your Will | Willfora

50th birthday recipe

Chocolate chip cake

Mary from @acoupleofceliacs gifts us with a delicious recipe. Mini chocolate chips scattered throughout with a creamy vanilla frosting between layers and on top. Sure to become a family favourite for any celebration!

MARY THOMPSON

MARY THOMPSON

INGREDIENTS

Cake

- 175 g butter
- 280 g sugar
- 55 g olive oil
- 80 g light buckwheat flour
- 120 g sorghum flour
- 85 g tapioca starch or corn starch
- 1.5 tsp baking powder.
- 1/16 tsp salt
- 3 g whole psyllium husk
- 3 large eggs, room temperature
- 150 g milk, room temperature
- 1.5 tsp vanilla extract
- 150 g mini chocolate chips

Buttercream

- 240 g butter, soft
- 360 g icing sugar
- 1 tsp vanilla extract
- 2 tbsp milk or more for spreadable consistency

INSTRUCTIONS

For the Cake

1. Line the bottom of two 7 inch round (18cm) springform cake pans with parchment paper.

2. Preheat oven to 350°F.

3. In a small bowl combine flours, baking powder and salt

4. In a medium bowl, beat butter for 1 minute, then add sugar and beat for a further 2 to 3 minutes.

5. Whisk together the milk and psyllium husk in a small bowl.

6. Add 1/3 of the four blend to butter mix and beat until just combined. Add milk and psyllium, then more flour. Fold in remaining flour, oil, vanilla and half the chocolate chips.

7. Evenly transfer batter to the two cake pans and smooth out tops. Sprinkle remaining chocolate chips on top of both pans and swirl into the top of the batter with a knife.

8. Bake for 30-45 mins until an inserted toothpick comes out nearly clean. You do not want to overcook.

9. Cool cakes in the pans, for 5 minutes. Turn them out onto a cake rack to completely cool.

For the Buttercream

1. Beat butter, icing sugar, and cream until smooth and easily spreadable. Add a little more cream, if needed or a little more icing sugar for the right consistency.

2. Spread buttercream icing between the two cakes, on top and around the sides. ◆

Buttermilk Pancakes

MAKES ABOUT TWELVE PANCAKES

Ingredients

¾ cup white rice flour
½ cup gluten-free oat flour
½ cup almond flour
¾ cup potato starch
½ teaspoon xanthan gum
½ teaspoon salt
2 teaspoons baking powder
½ teaspoon baking soda
2 tablespoons sugar
1 ¾ cups buttermilk
¼ cup unsalted butter, melted (or oil)
2 eggs, room temperature
2 teaspoons vanilla

Method

1. In a large mixing bowl, combine the white rice flour, gluten-free oat flour, almond flour, potato starch, xanthan gum, salt, baking powder, baking soda, and sugar. Whisk them together until well combined.
2. In a separate bowl, whisk together the buttermilk, melted butter (or oil), eggs, and vanilla.
3. Pour the wet ingredients into the dry ingredients and mix until combined. Let the batter sit for 5-10 minutes to allow the flours to absorb the liquid.
4. Heat a non-stick pan over medium heat. Lightly grease the surface with a small amount of butter.
5. Pour ¼ to ⅓ cup of batter onto the hot skillet for each pancake. Cook until bubbles form on the surface, then flip the pancake and cook for an additional 1-2 minutes, or until golden brown.
6. Repeat the process with the remaining batter, adding more butter to the skillet as needed.
7. Serve the gluten-free pancakes warm with your favourite toppings.

O'Doughs®

Strut your Strata!

Bagel Strata with Smoked Salmon

Serve 6-8
Prep: 20 minutes | Cook: 45 minutes

2 bags	O'Doughs Pumpernickel Bagels, cut into 1" pieces*
1 cup	Greek yogurt, plain
2 ½ cups	Milk
6 large	Eggs
½ cup	Monterey Jack cheese, shredded
4	Scallions, sliced
¼ cup	Capers, drained and rinsed
2 tsp	Salt
1 tsp	Freshly ground black pepper
Garnish	Smoked salmon, additional capers, thinly sliced red onion

1. Preheat oven to 375°F.

2. In a large bowl whisk together yogurt, milk, eggs, cheese, scallions, and capers; season with salt and pepper.

3. Add the bagel pieces and stir so that all pieces are covered in egg mixture; pour into a 9x13 baking dish that has been sprayed with non-stick cooking spray.

4. Bake for 45 minutes, the top should be golden and slightly puffy.

5. Remove from oven and allow to sit for 10 minutes, garnish with smoked salmon, additional capers, and onion.

*Can be substituted for any of your fav O'Doughs Bagel varieties.

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odoughs.com

IRON FORTIFICATION IN GLUTEN-FREE FOODS:

a key nutritional strategy for celiac patients

NICOLE BYROM,
CCA CONSULTING
REGISTERED DIETITIAN

WHAT IS IRON?

Iron is a vital nutrient that plays a crucial role in various physiological processes, including oxygen transport, energy metabolism, and immune function. When your body is deficient in iron you may feel fatigued, weak, irritable, experience shortness of breath, pale skin and dizziness. Maintaining adequate iron levels can be problematic for individuals diagnosed with celiac disease (CD) due to malabsorption issues that persist both before and shortly after diagnosis, potentially leading to the development of iron deficiency anemia.

MISS_J, CANVA

Iron deficiency in the celiac community
People with CD are seventeen times more likely to experience Iron deficiency compared to the general population. For those newly diagnosed, villous atrophy decreases the ability of the gut to absorb nutrients, increasing risk of iron deficiency. Reaching complete villous healing may take several years, during which time iron plays a pivotal role in the healing and repair processes, potentially further depleting already diminished iron stores.

Continued on next page

Current fortification regulations for regular flour

In Canada we have robust enrichment regulations for regular flour created to prevent nutritional deficiencies in all Canadians. Specifically, ***mandatory* iron fortification of regular flour has emerged as a valuable strategy in combating iron deficiency in the general population**. Iron fortification of regular flour has been an enormous public health success and has aided in reducing iron deficiency in the Canadian population.

Clinical studies have shown that the consumption of iron-fortified foods is one of the most effective methods for the prevention of iron deficiency [1]. In fact, to combat micronutrient deficiencies, the World Health Organization/Food Agriculture Organization (2006) guidelines recommend four key strategies including supplementation, fortification, nutrition education and dietary diversity. Of the four strategies, food fortification is considered the most successful and economical approach [2].

Current fortification regulations for gluten-free flour

Regrettably, **Canada's existing mandatory fortification regulations do not extend to GF flour**, resulting in diminished nutritional quality of many GF food products. Individuals adhering to this medically required diet must consequently search for expensive natural iron sources or use supplements, which are not always well tolerated.

At this time, Canadians must rely on a manufacturer's decision to fortify GF product currently about 5% of products. When shopping for GF products, it's advisable to look for fortified items when available.

Raising Awareness and Advocacy

Raising awareness about the importance of including GF flours as part of Canada's current mandatory fortification strategy is vital for all Canadians including healthcare professionals, manufacturers, and consumers alike.

Healthcare providers play a pivotal role in educating patients about the significance of an iron-rich diet and ensuring that clients are aware that most GF products are not currently fortified.

Additionally, consumer advocacy groups can influence industry practices, encouraging more widespread adoption of iron fortification in GF flours.

While Celiac Canada would like to advocate for the mandatory fortification of regular flour to be extended to include GF flours, there is a concern for reduced product availability In the short term, we are asking Health Canada to amend the current marketing authorization to be changed to allow companies to promote their products that have been fortified.

The estimated 400,000 Canadians living with CD deserve an equitable fortification strategy equivalent to that of regular flour products. Mandatory fortification regulations were created to prevent nutrient deficiencies in all Canadians, not just those who can safely consume gluten. By ignoring the need for mandatory fortification of GF flours we are muffling the voices of those who initially created this all-inclusive fortification strategy. The existing voluntary fortification standards are playing a potentially significant role in the increase of iron deficiency in our community and need to be revised.

Click **HERE** to read more about Health Canada's mandatory and voluntary fortification standards.

Continued on next page

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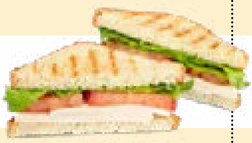
[1] *Iron supplementation and iron-fortified foods: a review* **Crit Rev Food Sci Nutr. 2022;62(16):4504-4525**

[2] *Food fortification strategies to deliver nutrients for the management of iron deficiency anaemia* **Curr Res Food Sci2022 Oct 23;5:2094-2107**

COMPARISONS OF INTAKES ON A REGULAR DIET AND A GLUTEN-FREE DIET

A DAY IN THE LIFE

Side-by-side comparison of daily intakes of iron on a regular diet and a gluten-free diet (100%DV = 18 mg)

MEALS + SNACKS	REGULAR DIET	IRON	GLUTEN-FREE DIET	IRON
BREAKFAST 	Kellogs Corn Flakes (1.25 cups)	9 mg	OneDegree Organic Sprouted Corn Flakes (1.25 cups)	1.2mg
LUNCH 	Sandwich on Wonder Bread White Bread (2 slices)	2.7 mg	Sandwich on Glutino GF White Bread (2 slices)	0.3mg
SNACK 	Breton Original Crackers (6)	1.5 mg	Breton GF Herb and Garlic Crackers (6)	0.4mg
DINNER 	Catelli Spaghetti (85 g)	3.6 mg	Catelli GF Spaghetti (85 g)	0.7mg
SNACK 	Oreo Chocolate Cookies (3)	1.4 mg	Kinnickinnik K-Toos Cookies (3)	0.8mg
TOTAL IRON		**18.2mg**		**3.4mg**
IRON REQUIREMENT		**18 mg**		**18 mg**

MISCELLANEOUS

REGULAR DIET		**GLUTEN-FREE**	
Crackers: Fortified **8% DV**		Crackers: Not fortified **2% DV**	
Bread: Fortified **15% DV**		Bread: Not fortified **3% DV**	
Pretzels: Fortified **20% DV**		Pretzels: Not fortified **0% DV**	
Cake Mix: Fortified **6% DV**		Cake Mix: Not fortified **0% DV**	

% Daily Value (DV) Iron per serving

◆

M&M™ FOOD MARKET

35+

GLUTEN-FREE OPTIONS AVAILABLE

CELIAC CANADA GLUTEN-FREE SANS GLUTEN COELIAQUE CANADA* TM/MC

*Trademark of Celiac Canada.
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With Celiac Canada as our partner, our range of gluten-free choices is now wider and tastier than ever.

O'DOUGHS SCHOOL AWARENESS

Kids teach kids about celiac disease

MK TRENDY DESIGNS, CANVA

To raise awareness of celiac disease in schools, Celiac Canada and O'Doughs, a gluten-free bakery, partnered for a special event May 16th, International Celiac Disease Awareness Day. Students across Canada were encouraged to wear green to show their support for those with celiac disease. We created an email template for school staff and parents to explain challenges kids with celiac face.

School children were treated to educational materials about celiac disease, including a "What is Celiac?" brochure. Kids with celiac were encouraged to explain what it's like living with the disease to their peers. Being able to teach their classmates about their condition opened many conversations.

O'Doughs also sent delicious treats to the first 50 classrooms to sign up for the event – gluten-free brownies.

We rate the program a huge success in raising awareness amongst the general population. 119 classrooms signed up for the awareness campaign. Celiac Canada and O'Doughs hope to build on this success in the years to come. ◆

COURTESY, O'DOUGHS

CELIAC CANADA SWAG SHOP

Get your holiday shopping done early with Celiac Canada's Swag Shop!

- Everything from hoodies, to t-shirts, aprons and more!
- Gift your loved ones or yourself with a gift that makes an impact!

Celiacanada swagshop

Dear Dietitian

This edition shares questions posed during a CCA webinar on

CROSS-CONTAMINATION

Dear Dietitian,

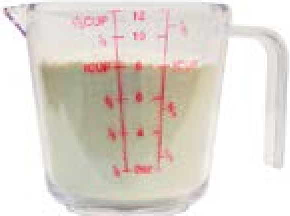
I live in a small apartment, and we do not have a dishwasher. Can I safely wash all dishes together? Or do I need to do separate loads?

Thankfully, you can safely wash all your dishes together in one load. Rinse all your dishes well to ensure no food particles are remaining.

Dear Dietitian,

If someone is baking with regular flour containing gluten, how do I make the kitchen safe for my family members with celiac disease?

We do not recommend people with celiac disease bake with or handle loose flour containing gluten, as flour may become airborne. If a family member is using such flour it is recommended to keep the area well ventilated, use paper towels to line the countertops and ensure the area is well cleaned after.



Dear Dietitian,

Can a single household share an air fryer with both gluten-free and non-gluten-free items?

Air fryers circulate air during the cooking process and may blow particles of previously cooked, gluten-containing food onto the gluten-free items. It is recommended to have a dedicated air fryer for gluten-free members of the household. ◆

CANVA

Want to learn more? Watch this video on [Safeguarding yourself against gluten cross-contamination - YouTube]

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

OPINION

HOW TO PREPARE for the unpreparable when you're gluten free

ROBYN HARRISON

For those of us with celiac disease, there's a familiar dance we all do—meticulously calling ahead, scouring restaurant reviews, and packing emergency snacks—to ensure we can eat safely no matter where we are. But what do you do when, despite all that preparation, you're still blindsided by an unsafe food situation? Most days, I've made peace with managing my celiac disease, but even eight years post-diagnosis, I still have days where it's really tough. I recently faced one of these challenging scenarios. As I was finishing my Master's degree, I attended two week-long sessions where I stayed in a hotel with all meals catered. Even though I was assured I would receive safe meals, this was not always the case.

How did I cope? Check out my 5 Tips for preparing for the unpreparable when you're gluten-free. (P.S. I discuss my experiences in my YouTube video in full detail — **check it out!**)

COURTESY, ROBYN HARRISON

1. Find Someone to Ask

When faced with an unlabelled catered buffet, it was tempting to just grab salad and take a risk on the dressing, but I'm glad I found someone to ask.

While it sucked to stand off to the side for 20 minutes or frantically search for someone to ask at breakfast when I was already in a rush, it's better to know it's safe to eat than risk getting sick.

Tossing my cookies in front of a room of people would definitely be more embarrassing than standing to the side and waiting.

2. Phone a Friend

Maybe you're not an emotional wreck like me, but I tend to break down when faced with challenging food situations. (Which is the last thing you want in *Continued on next page*

> **“... speaking up ... is so important. Not only will it benefit you, but it will also benefit the celiac community as a whole** – ***Robyn Harrison***

a new social situation!). I recommend having someone on speed dial that you can call when things suck. When faced with a tough situation on this trip where I had to leave a restaurant that I couldn’t eat at, I called my husband. I talked to him as I walked over to a celiac-safe restaurant, ordered my food, and we Facetime’d while we had lunch. Without him, I would have felt so alone, and it would have been hard to return to class afterward, like nothing had happened.

3. Treat Yourself

Let’s be honest—catered desserts aren’t great for us gluten-free folks. If there’s anything, it’s usually a sad, pre-packaged brownie while everyone else is eating fresh pastries.

What can you do? Treat yourself!

On this trip, I ran to the closest store and picked up a box of mini Toblerones. I kept a couple in my bag to always have something I knew I enjoyed for dessert. That way, I wouldn’t feel left out and it kept those “why aren’t you having dessert?” questions at bay.

Another way to treat yourself? Take yourself out to dinner. When I had a free afternoon, I took myself to a restaurant I knew had safe gluten-free options so that I could indulge after a week of less-than-appetizing gluten-free meals.

4. Pack (or Find) Snacks

Most gluten-free people already do this, but after my experiences on these trips, it was a great reminder to always have snacks.

I was so sure I would have safe food on this trip that I didn’t bring anything. ROOKIE MISTAKE! Always have at least a protein bar or granola bar on you. Even if you were told you’ll be given a gluten-free meal. You never know when there might be a miscommunication, or when otherwise safe food has come into contact with gluten.

If you forgot to pack your snacks, see if you can find a local corner store or grocery store. Even if they don’t have the best gluten-free selection, at least you’ll have something.

CANVA

5. Speak Up

When you get stuck in these situations, speaking up and making it right is so important. Not only will it benefit you, but it will also benefit the celiac community as a whole.

It can be tempting not to say anything, but you’d be surprised how many people genuinely want to help when they know there’s a gap.

For example, when I brought up that there were no safe gluten-free breakfast options, the next day, I was pleasantly surprised to see that they had set up a separate gluten-free table and bought a dedicated toaster so it would be safe.

It’s my hope that even though I had a rough time on these trips, speaking up will have made a difference for the next person with celiac to attend.

At the very least, my speaking up has brought another dedicated gluten-free toaster into the world—so I'll take the win, even if it's a small one! ◆

RESEARCH

Immigrant and Indigenous CELIAC DISEASE

In February 2023, Celiac Canada (CCA) conducted an online health survey to healthcare professionals across Canada to assess the current care provided for immigrant and Indigenous populations with celiac disease.

The two main objectives were to identify the prevalence of celiac disease in immigrant and Indigenous populations and to better understand the pathway to diagnosis and management.

Even though we contacted over 500 health care professionals in clinics across Canada, only 37 responded.

Key takeaways

- Nearly a quarter of respondents reported having only 1-2 patients a year coming for celiac disease management at their clinic.
- When asked how often a blood test to screen for celiac disease occurs in their clinic, the most common responses were "never" (27%), "1-2 times per year" (24%) and "I don't order blood work" (30%)
- Most clinics reported having a predominantly Caucasian population.
- Of the two respondents who reported having nearly 100% Indigenous population at their clinic, no patient was currently being followed for celiac disease.
- Health care professionals reported the most common issue that prevents patients from adhering to a gluten-free diet is lack of knowledge about gluten-free foods or how to read labels, and the affordability of gluten-free foods.


CANVA

The study has shown that there is a significant lack of education and awareness of celiac disease within indigenous and immigrant communities and their healthcare providers in Canada. Canada's governments, individuals and organizations were compelled to review and respond to the 94 Truth and Reconciliation Commission calls to action. Numbers 18, 19 and 20 all address inequities in health care and outcomes and seek to close the gap between Aboriginal peoples and non-Aboriginal peoples.

We wish to thank Takeda and the Ottawa Chapter for their generous support for this initiative.

This health survey was small but we're hoping it can be used to lead to future studies and research in this area so we can address the gaps and inequality of healthcare in Canada related to celiac disease.

State of Celiac Disease – Survey results coming soon!

- State of Celiac Disease Health Survey - THANK YOU - Kick off to Celiac Awareness Month 2023 - YouTube Conference Promo.
- Sign up for our annual fall conference to hear Dr. Don Duerksen and Caleigh McAulay discuss highlights from the State of Celiac Disease Survey (link to sign up: CCA Conference Schedule - Celiac Canada) ◆

Clincal practice

RESEARCH

REVIEW HIGHLIGHTS GAPS IN REAL-WORLD CELIAC DISEASE CARE

International clinical practice guideline review

FATCAMERA, CANVA

CALEIGH MCAULAY

Clinical practice guidelines summarize evidence supporting the diagnosis and management of common clinical conditions. Medical practitioners use clinical guidelines to ensure current recommendations are followed.

Recently, physician members of the CCA's Professional Advisory Committee (PAC) participated in an exhaustive review of guidelines on the diagnosis and management of celiac disease. Guidelines from countries around the world were reviewed because currently, **there are no Canadian clinical practice guidelines for celiac disease**.

This review, recently published in the Journal of the Canadian Association of Gastroenterology concluded that current clinical practice guidelines in celiac disease have not been rigorously developed and there is a need for Canadian clinical practice guidelines with high methodological quality to help guide medical practitioners

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> **“...easily understandable guidelines empower patients to make more informed healthcare choices ... – *The review’s authors***

in the diagnosis and management of celiac disease.

The review’s authors suggest that, “Inconsistent recommendations can confuse providers and funders, leading to a delay in diagnosis and unnecessary diagnostic procedures. We hope future guideline developers will use the strengths and weaknesses identified in this review to help physicians, government institutions and patients.”

The paper discussed the lack of patients or family doctors being consulted in the development of the guidelines. nor running a pilot program to see if to see if the guidelines were applicable or appropriate in clinical situations.

The authors stressed, “...easily understandable guidelines empower patients to make more informed healthcare choices and to consider their personal needs and preferences in selecting the best options.”

Moreover, several guidelines failed to recommend ongoing follow-up care and management which is critical to long-term health for those with celiac disease.

The most concerning finding was “the growing gap between guideline developers and users has been described as a ‘crisis of evidence-based medicine’ which can lower the quality of care in CD and hinder successful patient outcomes.“

Clinical guidelines need to meet real-world expectations to truly help improve patient outcomes. It is hoped that this review will overcome the deficiencies of the other guidelines and create some of the strongest here in Canada. ◆

Read the review here
Review and Critical Appraisal of Clinical Practice Guidelines of Modalities Used in the Diagnosis of Celiac Disease - PMC (nih.gov)

STATE OF CELIAC DISEASE SURVEY

A closer look into THE STATE OF CELIAC

Learn more about what the future of Celiac Disease could look like

Thanks to donor support of Celiac Canada’s Research Fund for enabling this survey, which will transform lives, policy and future research.

As 2023 closes in, Celiac Canada is getting ready to to share the results of the 2022 State of Celiac Survey.

With over 7000 participants, the data collected will be used to improve the quality of life for people with Celiac Disease in Canada.

State of Celiac Disease Health Survey - THANK YOU - Kick off to Celiac Awareness Month 2023 - YouTube

RESEARCH

2023 J.A. CAMPBELL RESEARCH GRANTS

Congratulations Dr. Maria Ines Pinto-Sanchez & Mark Wulczynski

Each year, we put out a call for two research grant applications - the J.A. Campbell Research Award and a Young Investigator Award. Since 2000, thanks from individuals like you, Celiac Canada has been the largest single-funder of celiac disease research in Canada dedicating over $430,000 towards finding a cure, treatment and better-management of the disease

J.A CAMPBELL AWARD

Dr. Maria Ines Pinto-Sanchez

The winner of our J.A Campbell Award is Dr. Maria Ines Pinto-Sanchez, a gastroenterologist and Director of the celiac clinic at McMaster University. Dr Sanchez will evaluate the effect of late vs early introduction of gluten-free oats in patients with newly diagnosed celiac disease.

YOUNG INVESTIGATOR AWARD

Mark Wulczynski

The winner of our Young Investigator Award is Mark Wulczynski, a PhD student working to understand diet-host-microbe interactions at McMaster University under the supervision of the internationally acclaimed Dr. Elena Verdu in the department of Medical Sciences.

COURTESY, DR.MARIA INES PINTO-SANCHEZ AND MARK WULCZNSKI

Congratulations Mark & Ines!

Link: Research Awards - Canadian Celiac Association - Medical Funding

Help support and inspire young researchers to investigate celiac disease in Canada by supporting our dedicated Research Fund today. Donation Form (donorperfect.net) ◆

RESEARCH

GLUTEN-FREE PRODUCT RECALLS and their impact on consumer trust

Why accurate labeling and corporate responsibility matters

SIYU LIU, DALIA EL KHOURY AND IRIS J JOYE
UNIVERSITY OF GUELPH, ONTARIO

Recalls of food products related to gluten contamination have highlighted the importance of accurate labeling. Consumer concern regarding gluten-free product recalls is significant, but is not heightened after experiencing a recall. Companies pursuing transparency in the process, identification of the source of contamination, and mitigation strategies going forward are likely to retain consumer trust. Continued consumer education regarding interpreting nutrient labels, identifying sources of information on product recalls, and understanding procedures to follow upon suspected gluten contamination are needed.

Thanks to over 1,000 of CCA community members who participated in this study. Iris Joye is a member of CCA's Professional Advisory Committee.

Link to full article

HOW TO REPORT A RECALL
If you suspect that you or a loved one have experienced food contamination, follow these steps:

Step 1: Seek medical attention if needed.
Step 2: Contact the retailer and the distributor named on the label of the package. Keep the package for important information to better answer questions from any of the investigating stakeholders.
Step 3: Contact the Canadian Food Inspection Agency (CFIA) which has the powers to investigate, and issue recalls and require companies to comply.

CFIA contact information can be found at this website: Food and Recall Emergencies.

For a product carrying a GFCP trademark, also contact BRCGS

Accurate and timely information is the key. Everyone playing their part helps make the Canadian food safety system to best in the world, protecting consumers and businesses alike.

For more information, visit our Food Safety and Recall on our website. ◆

SUPER EXCITING EVENTS

for you to learn about managing and thriving in life with CD

HERE'S A RUNDOWN OF NATIONAL ACTIVITIES

NOVEMBER

November 13

- Gluten Free 101 Webinar

November 18th

- Annual Virtual Conference

November 26th

- CCA Connects newsletter

November 28th

- Giving Tuesday

DECEMBER

December 4th

- Holiday Survival Webinar

December 10th

- Gluten Free 101 – Holiday Edition Webinar

SNEAK PEAK INTO NEXT YEAR…

JANUARY

January

- Mental Health Webinar
- Gluten Free 101 Webinar

FEBRUARY

February

- Thyroid Canada and CCA Webinar
- Gluten Free 101 Webinar

CHAPTER EVENTS

Calgary chapter

- Annual General Meeting 2023

Date: November 15, 2023
Time: 7:00 pm - 9:00 pm
Location: Virtual over Zoom
Community | Members
You are invited! Join us.
Please register to get Zoom link.
You need to have held a membership for 60 days prior to the AGM to be eligible to vote.
Agenda: Establish quorum
Opening Remarks & Introductions
Approval of Minutes from 2022
Year in Review
Election of Board Members

Quebec chapter

CANVA

- Chat hour

Date: Tuesday November 15
Time: 8pm on Zoom
Theme: Holiday Cooking & Baking
Find out more

- GF Holiday Get-Together

Date: Friday December 1
Location: Scores Restaurant
444, Dorval Avenue,
Dorval H9S 3H7
(514) 636 6060
Note – this Scores franchise has an owner who is GF- not all Scores are GF safe. Find out more

Continued on next page

▮ Chat hour
Date: Tuesday January 17, 2024
Time: 8 pm on Zoom
Theme: Caregiving with someone with celiac disease [Find out more]()

▮ Chat hour
Date: Tuesday March 19, 2024
Time: 8pm on Zoom
Theme: Travelling with celiac disease and eating out
[Find out more]()

PEI chapter
▮ Gluten-Free Holiday Market
Date: Nov 18, 1:00 p.m. – 4:00 p.m. AST
Location: 420 University Av, Charlottetown, PEI C1A 2Y9
A fun-filled gluten-free event for a good cause! Enjoy exciting activities while supporting the PEI Celiac Canada Chapter. The best part? Children under 12 are FREE!
Adults $5. [Find out more & RVSP]()

MNSTUDIO, CANVA

EVENT CATCH UP

What a great line up of events held over the summer! Catch up on the highlights

July – August
▮ Davis Family Sunflower Festival
A fantastic annual fundraiser set in fields of flowers, packed with thousands of visitors. Thanks to the Davis family for helping us get the word out about CD.

August
▮ Empowering Students and Caregivers: Navigating a Gluten-Free Back to School sponsored by O'Doughs. [Watch the replay.]()

September
▮ Safeguarding Yourself Against Gluten Cross-Contamination sponsored by O'Doughs [Watch the replay.]() ◆

MELISSA SECORD

Davis family presents a cheque to Celiac Canada after the successful Sunflower Festival

MAKING AN IMPACT

Gagnon who ran to support his recently diagnosed fiancée.

COURTESY, THOMAS GAGNON

They crossed the finish line and stepped up for celiac disease

62 Celiac Canada heroes stepped up in October and ran or walked, either in person or virtually, in the TCS Waterfront Marathon. We honor their energy, perseverance, and commitment in helping celiacs across Canada lead a healthier and more empowered life. Their fundraising efforts and passion for the cause was instrumental in exceeding our goal! We raised over $31,000.

On behalf of all of us at Celiac Canada, Thank you!"

Fundraising continues till November 15th. Donate now to support a team member reach their individual goal. ◆


Grains entiers naturels
100% canadien
Riche en fibres
PURITY FROM FARM TO TABLE
PURETÉ DE LA FERME À LA TABLE
ONLY OATS
Gluten-Free Oat Flour
Gluten-Free Rolled Oats
Flocons d'avoine sans gluten
100 ml
5 ml 1tsp
15 ml 1tbsp