



2023
ANNUAL
REPORT

Our Vision.

Every person in Canada with celiac disease diagnosed and empowered.

Our Mission.

While bringing awareness and respect, develop evidence-based tools and foster a supportive community to empower people with celiac disease on their lifelong journey.

Our Core Values.

Empathy – Integrity – Adaptability

Strategic Priority Areas.

- 1. Promote Evidence-Based Solutions**
- 2. Strengthening Standards**
- 3. Ensure Financial Sustainability**
- 4. Increase Education & Awareness**

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President's Message

As we reflect on the past year, I am humbled and grateful for the incredible support and dedication shown by each of you towards our cause. Despite challenges, the unwavering commitment of our community always encourages us forward and enables us to continue making a meaningful impact in the lives of those we help.

All of our accomplishments are a testament to the hard work, creativity, and resilience of our entire community. Whether it was the State of Celiac Survey, the Newly Diagnosed Pathway or the approval of the blood test in Ontario each endeavor brought us closer to our shared vision.

None of this would have been possible without the invaluable support of our donors, whose generosity sustains our operations and fuels our impact. Your belief in our mission empowers us to make a real difference in the lives of people with celiac disease.

I also want to extend my deepest gratitude to our volunteers, who selflessly dedicate their time, skills, and passion to advance our cause. Your tireless efforts are the heart and soul of our organization, and we are profoundly grateful for your contributions.

Looking ahead, we are excited about the opportunities and challenges this year brings. With your continued support, I am confident we will build on our successes and create even greater impact in our community.

My heartfelt thanks to every one of you for your unwavering commitment to our organization's mission.

Together, we are truly making a difference.

With gratitude,



Lizbeth Wall
President,
Celiac Canada Board of
Directors

“Our strength is our people.”

**“Together,
we are
truly
making a
difference.”**



Executive Director's Message

50 years of making change

Fifty years ago, two women from Kitchener, Ontario, decided to take action. After a chance meeting, Kay Ernst and Frances Murphy realized that there was no organization for people with celiac disease in Canada—no support groups, no resources, no one advocating for change.

On a dark and stormy February night in 1973, Kay and Frances held the first-ever celiac support group meeting at the KW Hospital with a handful of people. That's where it all began.

To commemorate our beginnings, we gathered back in Kitchener in February to kick off our special 50th anniversary and celebrate our community. It was wonderful to see people in person from past and present come together. We saluted our Celiac Change Makers—individuals who have made and continue to make a difference in thousands of lives.

How far we've come. Now, as Celiac Canada, we reach 100,000+ people using technology that didn't even exist 50 years ago. Zoom webinars, emails, and social media connect us and our local chapters to every corner of the country. We now have more product choices, enhanced gluten-free food labels, certified gluten-free foods, and research advancements to better understand the disease.

We also recognize we still face the same challenges as they did back in 1973—diagnosis still takes too long, there's no treatment other than the gluten-free diet, and access to safe food remains a challenge outside the home. Canadians also face new affordability challenges in a faster-paced, Dr. Google world.

Cont. over/

**“How far
we’ve
come since
1973.”**

**“Thank you for all your hard
work and advocacy for all
people and families with
celiac”.**

Laurie Christie on Facebook

**“We can’t
do it
without
you.”**

Cont. from previous page.

As well as marking this milestone year, we laid the groundwork for the next 50 years.

We invested in on-staff dietitians to curate more evidence-based patient resources such as our Newly Diagnosed Pathway and specialty-themed events.

We boosted awareness programs to reach more individuals and beefed up fact-based content to empower our community. We amped up our advocacy to move the needle on access to safe food, timely diagnosis, and affordability.

Our national board leaders started on a new strategic plan to lead us into the future.

Thanks to individuals like you and dedicated staff and volunteers, Kay and Frances’s dream lives on, and it must continue for those next to be diagnosed and for future generations.

Please check out our 50th Anniversary website to learn more about our history, see the progress made over the decades, and see what we can accomplish when we all work together.

It has been a privilege to serve and celebrate this community during this very special milestone year. Thank you for your continued support and trust.

Sincerely,

Melissa Secord, CAE

National Executive Director



Melissa Secord

National Executive Director,
Celiac Canada





**2023
AT A
GLANCE**

**Niagara Falls, ON, illuminated green for
#ShineALight on Celiac**

Education



#ShineALight,
High Level Bridge,
Edmonton, AB

EDUCATION BY THE NUMBERS:

22,431 Facebook Support Group
members

2,504 help desk supports by
phone or email

21 webinars **2,847** attendees

1,304 Annual Virtual Conference
attendees

“Thank you so much, you guys have no idea how amazing the information you provide us with is. My daughter and I struggle sometimes and now my sister is celiac also, so it's been a long journey. These emails are so amazing. ”

Katy Ransom

Newly Diagnosed Program

EDUCATION

Evidence-based, relevant information continues to be the core of our education efforts.

In 2023, we gave trustworthy advice and support through our website, social media, helpdesk, and webinars led by our registered dietitians to our 100,000-strong community.

Everyone benefits from our resources and education accessible across Canada to drive diagnosis and boost empowerment. In addition to the public, healthcare practitioners, food manufacturers and public bodies use our resources.

We hosted several webinars in 2023. The most popular “The Latest and Greatest in Diagnosis and Management of Celiac Disease” boasted 417 registrants and 1,600 YouTube views. Other popular webinars were held on taxes, cross-contamination, vaccines, monthly ‘Gluten Free 101’ sessions and a collaboration with the Canadian Digestive Health Foundation (CDHF) on ‘IBS and Celiac Disease’. ‘Webinar Wednesdays’ during Celiac Awareness Month had excellent take up with over 1,182 registrants.

The dietitian education series (2022) rolled out with a webinar to enhance current knowledge on CD, the GFD, testing and supporting those with CD.

Annual Virtual Conference

1,030 attended. When surveyed, 59% said they’d been diagnosed for three years or more, over half were 65+ years, and the majority joined from Ontario, British Columbia and Alberta, respectively.

88% gave an overall rating of 4.4/5 stars and 94% said their expectations were met or exceeded. 95% learned something new and 96% said the conference provided valuable and insightful information.

Help Desk

Our helpdesk answered a total of 2,504 emails and phone calls -- seven enquiries per day. Thanks to Val, Janet & Lynda for volunteer support.

Newly Diagnosed Program (NDP)

The NDP arms the newly diagnosed with evidenced-based information by email and support at the beginning of their lifelong journey.

1,129 signed up. The program was revamped based on feedback from our community, launching newly in early 2024.

Advocacy



#ShineALight,
Carmen de Roi &
Sonia Sidhu, MP
Toronto Sign, ON

ADVOCACY BY THE NUMBERS:

1st ever Parliamentary Caucus created

100 patient submissions to Safe Long
Term Care Act

1,600 completed Federal Transportation
Survey

“It is because of your advocacy, Celiac Canada, that today I announce that blood testing for celiac disease will be permanently covered.”

Hon. Sylvia Jones

Ontario Minister of Health

Advocacy

You tell us what the celiac community needs. We get it done.

In our 50th Anniversary year, we achieved many major milestones that set future generations up for success. There's still a lot of work to do, but here are the highlights of how we are making positive change.

First Ever Celiac Caucus

Led by Liberal MP Sonia Sidhu (Brampton South) and Conservative MP Tim Louis (Kitchener Conestoga) the new caucus opens doors for sharing issues & solutions with like-minded politicians who share an interest in celiac disease and come together to build awareness, change laws, & standards of care. Going forward the caucus will focus on issues around affordability, tax benefits, diagnosis, management & access to safe food.

Access To Safe Food

Over the past two years, the federal government has been engaged in new standards and legislation for long term care. We submitted responses to stakeholder consultations. For the Safe Long-Term Care Act we engaged 100 community members to share their stories with Health Canada in an online survey.

State of Celiac Survey

Following up on the first-ever celiac survey we conducted 20 years ago, we analyzed 7500 responses assessing the needs & challenges our community faces, so we can recommend calls to action in 2024.

Travel Survey

1,600 community members responded to the Parliamentary Standing Committee on Transport to address a top concern - safe gluten-free food when traveling.

Strengthening Standards...

why it matters

Achieved permanent diagnostic blood test coverage in Ontario.

- Patients no longer pay to get diagnosed.

Hosted first Gluten-Free Breakfast on Parliament Hill to influence policy.

- Building on long standing partnership with Health Canada to lead solutions that find, treat and cure celiac disease.

New Gluten-Free Certification Program Standards #4 created.

- Improving safety of 6,000+ products to keep our community healthy.

Participated in the Safe Long Term Care Act consultation and federal standards.

- **Improve** access to safe gluten-free food for those who cannot self-advocate.

Successfully advocated for high-risk food ingredients to undergo federal scrutiny.

- So you can trust the label and ingredients.

International review of clinical practice guidelines completed.

- To identify best practices globally and bring them to Canada.

Weighed in on the Future of Food consultation.

- To protect and improve access to safe GF food and help shape public policy.

Awareness

**#ShineALight,
BC Place,
Vancouver, BC**



AWARENESS BY THE NUMBERS:

8,020 joined us for a total 50k+ on social media who viewed 1.7 mn posts.

8,179 new email subscribers,
up 25% to 42k

17,000+ clicks to the online
Symptoms Checklist

“A big thank you to Celiac Canada for its ongoing commitment to raising awareness and educating on all aspects of celiac disease through its webinars, newsletters and website.”

Janet Carr

Celiac Canada email/webinar subscriber

AWARENESS OVERVIEW - 50th ANNIVERSARY

2023 was a big year, celebrating all the firsts and milestones Celiac Canada has spearheaded since humble beginnings in 1973.

50th Anniversary Year

Celiac Canada celebrated with a new name and logo to reflect our 100% charity status.

50th anniversary celebrations included a mini-website packed with history, milestones, volunteer recognition and research wins. The Canadian Celiac Association, started by two ladies from Kitchener in 1973 is now a small, yet mighty world-leader respected for championing how to find, treat & cure celiac disease.

Awareness is growing rapidly amongst the celiac community of how valuable our educational resources are. Every year the number of people who download brochures, watch videos and read emails and our Canadian Celiac Magazine goes up.

The Facebook Main and Support Groups are ever-growing gathering places where people connect & share information, bringing a sense of safety and belonging.

May Celiac Awareness Month

A lively Facebook party kicked off events, bringing the community together to highlight news, showcasing the State of Celiac Survey highlights (20-year follow-up), new clinical trials and May events.

On May 26th we attended Toronto's Gluten-Free Garage to publicize resources and support we offer, to 3000 foodies at the event. Our experts and dietitians were on hand to answer questions.

Educational efforts in May included Webinar Wednesdays, social media content, and a kids' colouring contest.

On May 16, a groundbreaking in-school activation encouraged parents and 119 classrooms across the country to raise awareness by sharing materials, wearing green, and enjoying gluten-free brownies, sponsored by O'Doughs.

The May awareness campaign featured a 30-second video featuring Sonia's "Could it be Celiac." A PSA on CBC TV, the campaign ran on radio, newspapers, magazines, medical journals, and digitally on YouTube, Instagram, Facebook, Google Search, & Google Display Network.

Overall, engagement during the year and in particular in May, was impressive.

- Over 2.7 mn impressions & 17,000 clicks to web symptom checklist.
- Web traffic surged to 45,000 viewers, 109% increase year over year.
- 478 new email subscribers joined, double the usual monthly rate.
- Social media channels gained followers, reaching a total audience of 50,000.
- 25,438 people viewed Sonia's video on YouTube.
- Five webinars = 1,200 participants.
- Gluten-Free Garage collected 650 Lbs of food for a local food bank.
- 24 national locations illuminated green #ShineALightOnCeliac
- Media interviews audience 12+ mn



Research

#ShineALight,
Science Centre,
Vancouver, BC

RESEARCH BY THE NUMBERS:

7,491 responded to the State of Celiac Survey questionnaire.

\$30,000 awarded for celiac disease research funding.

“The first peer-reviewed funding I obtained for realizing my dream of building a long-term research program in celiac disease was Celiac Canada’s James A Campbell Research Grant. ”

Dr. Elena Verdu

Award-winning gastroenterologist, heads Verdu Lab at McMaster University

RESEARCH OVERVIEW

We support research that finds, treats and cures CD: Reduce time to diagnosis, create effective treatment and self-care options that support those living with celiac to thrive.

State of Celiac Survey

Launched in 2022 as a follow-up to the first-ever celiac survey we conducted twenty years ago. 7,491 responded, making it our biggest piece of research to date!

James King, Lead Analyst, released highlights at our virtual May Kick-Off Event and at the November Annual Conference. King outlined progress over the past two decades and continuing challenges living with CD.

Officially launching early 2024, the survey informs our education, advocacy and support programs to advance Celiac Canada's vision to have everyone with celiac disease diagnosed and empowered.

JAC Research Grants

Celiac Canada's **James A. Campbell (JAC) Research Fund** is the only national celiac-specific research grant program. Since its inception, \$430,000 has been awarded to Canadian researchers.

The JAC Main Grant Research Award Winner is Dr. Maria Ines Pinto-Sanchez, a gastroenterologist and Director of the celiac clinic at McMaster University.

Her top team of nationwide researchers will evaluate the effect of late versus early introduction of gluten-free oats in newly diagnosed patients with celiac disease.

There are no clinical guidelines anywhere in the world about eating oats for people with celiac disease and problems caused by cross-contamination.

This first of its kind study in the world, is a potential game changer for nutrition therapy for people with CD for whom a gluten-free diet is the only cure.

Mark Wulczynski, PhD student won the JAC Young Investigator Research Award. His work explores the role of fibre in the diet-host-microbe interactions in the small intestine at McMaster University under the supervision of the internationally acclaimed Dr. Elena Verdu in the Dept. of Medical Sciences.

Mark hopes the highly publishable results will help clinicians make recommendations for fibre supplementation on a gluten-free diet.

Indigenous and Immigrant Survey

In February we surveyed healthcare professionals across Canada to assess current care for immigrant and Indigenous populations with celiac disease.

The results show a significant lack of education and awareness of celiac disease within indigenous and immigrant communities and their healthcare providers.

We intend to build on this research so we can address gaps and healthcare inequalities in future.

Thanks to Takeda and the Ottawa Chapter for their generous support for this initiative.

Community



#ShineALight,
BC Place,
Vancouver, BC

COMMUNITY BY THE NUMBERS:

100,000 members are in our digital community..

400,000 Canadians have celiac disease, only 20-30% know.

6,000 gluten-free products carry our Gluten-Free Certification mark.

“Thank you for all you do to help us navigate through this disease.”

Anita Pegorer-Fallone

Facebook follower

A COMMUNITY GATHERING PLACE

Often, the first thing people feel after diagnosis is isolated, alone and scared. Celiac Canada steps in immediately to get people on the road to recovery with educational resources, someone to talk to and events to join in with.



Davis Family Farm members with CCA staff at Gluten-Free Garage '23

“Thank you for all that you do for us. The support and resources have been instrumental so far, and far beyond what I would have expected”

Megan Marie, on Facebook



Guests at 50th anniversary launch event, April '23

“Thanks so much for initiating the State of Celiac Survey. Thanks for all you do for the celiac community and their families.”

Vivi Baladie, on Facebook.

“51 years ago, my mother attended the first meeting of the CCA and has volunteered ever since. It’s my turn to continue the good work started by a very dedicated group decades ago”.

**Nancy Dale, Board Member,
Council of Presidents**



Anne Hammer, with daughter Nancy Dale

Chapters



10 Chapters



Regular Council of Presidents
and Regional Support Group
meetings



Chapter Resource Portal

“Local and regional chapters are the heart and soul of our Celiac Canada community, providing personalized support and knowledge to help people navigate their day to day lives and learn how to thrive.”

**Melissa Secord,
National Exec. Director**

Board of Directors



Lizbeth Wall



Andrew Kotys



Wanda Walkden



Eyobe Amberer



Nancy Dale



Rumi Jasavala



Lisa Acimovic



Doris Foster



Don Leslie



Manisha Gupta



Stu Guttman



Steven Poirier

Celiac Canada is run by a volunteer Board of Directors.

Thank you for all you do. For your passion, drive and expertise.

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Jennifer Stebbing
Past President

Lizbeth Wall
President

June '2023-5

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Vice President

Andrew Kotys
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June '2022-4

Manisha Gupta
Steven Poirier
Rumi Jasavala

June '2023-5

Eyobe Amberer
Nancy Dale
Stu Guttman
Lisa Acimovic
Don Leslie

Celiac Canada Community

Medical Professional Advisory Council

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Gastroenterologist

Shelley Case, RD

Dr. Dominica Gidrewicz, Gastroenterologist

Iris Joye, Cereal Scientist

Inez Martincevic, RD

Dr. Maria Ines Pinto Sanchez,
Gastroenterologist

Dr. Justine Turner, Gastroenterologist

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Dr. Lucia Perez Repetto, Family Physician

Caleigh McAulay, RD, Celiac Canada

Don Leslie, PAC/Board Liaison

Melissa Secord, Nat. Exec. Director, Celiac
Canada

Registered Dietitian Working Group

Shelley Case, RD, Chair

Caleigh McAulay, RD

Inez Martincevic, RD

Jess Pirnak, RD

Jedid-Jah Blom, RD

Meagan Vurzinger, RD

Special Mention

Osler Hoskin Harcourt, LLP

Celiac Canada Staff

Melissa Secord
National Executive Director

Julie Greene
Assistant Executive Director

Caleigh McAulay
*Health Promotions and Research
Manager*

Leah Vlastic
Marketing Co-ordinator

Nastascia Lewis-Williams
*Community Liaison and
Administrator*

Consultants

Gloria Baldwin
Fund Development Manager

Nicole Byrom
Consulting Dietitian

Francis Fernandez
Database Administrator

Affiliated Chapters & Support Groups

British Columbia

Calgary

Edmonton

Kingston

Manitoba

Moncton

Ottawa

Prince Edward Island

Quebec Support Group

St. John's

Toronto

Philanthropy



TCS Waterfront
Marathon

PHILANTHROPY BY THE NUMBERS:

147 joined the circle of monthly donors

\$629,618 raised from 4000 donors

70 walked or ran the TCS Waterfront Marathon

“Do something today your future self will thank you for”.

Sean Patrick Flannery

Actor

PHILANTHROPY

Paying it forward. It's a simple but profound approach to life that spurred nearly 4,000 of you to donate a total of \$629,618. Thank you.

You are remarkable donors who gave in many ways. Some attended a fundraising event. Others wrote a cheque. Many clicked to donate. Those wanting a more physical way to show their support ran or walked (virtually or in person) in the 2023 TCS Marathon where 70 participants, nationwide raised \$32,000. TCS awarded us an extra \$1700 for the high number of participants.

In whichever way our donors chose to support, they showed how much they care about the community's needs and the hope for every person in Canada with CD to be diagnosed and empowered to lead their best possible life. Our donors affirmed our desire to change minds, hearts, laws and lives through research, advocacy, education and support services.

Our 50th anniversary year attested to the loyalty of longstanding donors and hundreds of new donors. They are all nothing short of champions, giving what they can in difficult times. We acknowledge their generosity and are forever grateful for their support.

A special thank you

A special thank you to the Davis Family, ON, for their unwavering support for all that we do.

We raised \$6,200 from the Sunflower Seeds program and more dollars as their charity of choice for proceeds from the Halloween Haunt and Sunflower Festival.

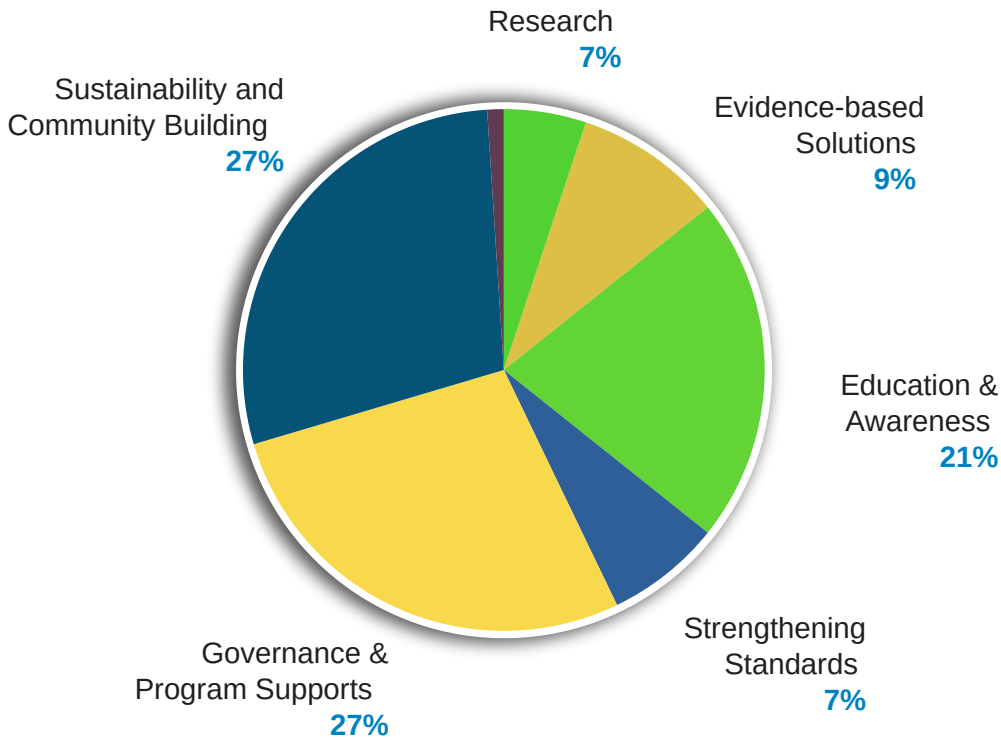




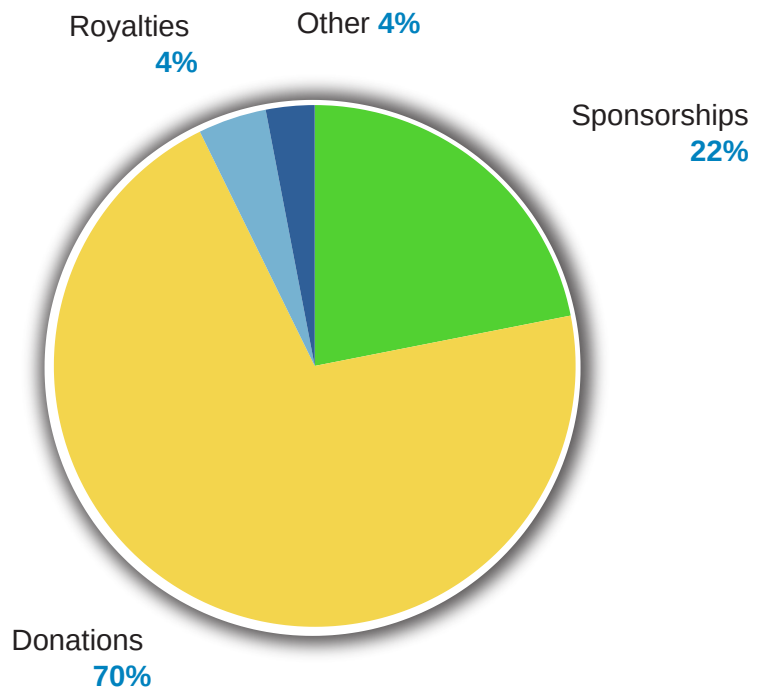
2023

Where funds go

EXPENSES



REVENUE



Donor Honour Roll

Founders Legacy

(\$60,000+)

Anonymous

Founders Circle

(\$10,000-\$49,999+)

Anonymous

Joanne Davis

Canada Gives

CCA Ottawa Chapter

Robert Beddie

CCA British Columbia

CCA Toronto Chapter

Celiac Leaders

(\$3,000-\$9,999)

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Aqueduct Foundation

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David Carey

Julie Cyr

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Denae Elford

Peter Ernst

Cathy Gee

Cathy Gee

Pamela Hine

Patricia Hobbs

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Ian Strachan

Boiler Inspection &
Insurance Co. Canada

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Kenn Tuckey

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Leo & Sandra Verhelst

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Dennis Wiebe

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(\$250-\$999)

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Merideth Fletcher

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Doris Foster

Luc and Allison Gallant

Gabrielle Gamelin

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Carol Gordon

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Karen Green

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Natasha Tams
Bean Sprout project
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United Way
Cape Breton
Cheryl Thiessen
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Denise Tremeer
Sébastien Turcotte
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Anne and Daryl Wing
Gloria Wolff
David Worden
David Worthen
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Cathy Yaskow
Wendy Youzwyshyn
Talia Zenlea
Patricia Ziatas
Cheryl Ziebart
Hedy Ziesmann
Jacqueline Zirpdji

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We can't do it without you. Thank you.

Platinum Partners



Gold Partners



Silver Partners



Partners

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Dr. Oetker
Dr. Schar
Gluten-Free Cart

M & M Meats
Miski Brewing
Only Oats
Robyn's Gluten-Free Baking