



CANADIAN CELIAC ASSOCIATION

2022 ANNUAL REPORT



CANADIAN CELIAC ASSOCIATION



L'ASSOCIATION CANADIENNE DE LA MALADIE COELIAQUE



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. Promoting Evidence-Based Standards
2. Strengthening Standards
3. Increasing Education and Awareness
4. Ensuring Financial Sustainability

ON THE COVER:

Pictured on the cover are a few of the many people who have shared their celiac journey to help us increase awareness and diagnosis.

“

As an individual with celiac disease, I know the incredible impact of having my celiac disease diagnosed several years ago – it saved my life. And the work of Canadian Celiac Association has made all the difference. When I was first diagnosed about 40 years ago, I couldn't even buy bread. How things have changed. My sister and great-niece have also been diagnosed with celiac disease – my great-niece as a young baby. We know the impact.

”

**Helen
Hamilton, Ontario**

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Our Lifelong Journey Continues with You

On behalf of the board of directors for the Canadian Celiac Association (CCA), I am pleased to share our 2022 Annual Report with you and to thank you for your support – whether that be as a first-time contributor, someone who is entrusting us with your monthly gift, or you have made a significant investment to help us drive programs and new resources – we appreciate every dollar to help improve lives of people living with celiac disease.

We are on this journey with you and your family.

It is rewarding to see the high calibre of individuals who are coming forward to join our board of directors. They are committed and passionate to transform how we live with our disease and to improve the lives of all of us living with this lifelong condition. We are on this journey with you and your family.

As we continue to advance our strategic priorities, we made investments in human resources and programs to reach more Canadians at risk for the disease and to work towards making your life easier. Our strength is our people. Whether it is the volunteer who answers your call on the client support desk or our Professional Advisory Committee who develop science-based content, or individuals making delegations to government to advance our cause, our priority is to making life better.

Our strength is our people.

As we look ahead, CCA is focused on transformative change over the next decade. Improving diagnosis rates, making life more affordable, and increasing access to safe gluten

free foods and pharmaceutical treatments are key. We want Canada to be the best place to live with celiac disease!

Thank you for your support and we look forward to being your partner in this lifelong journey.

Jennifer Stebbing
President,
Canadian Celiac Association
Board of Directors



Approaching 50, Pressing the Accelerator

2022 was another jammed pack year for the Canadian Celiac Association (CCA) as we continued to press the accelerator. We heightened our awareness campaigns, empowered more people, and made more advancements on more advocacy issues – all thanks to our incredible donors and supporters.

We saw positive wins for the community in natural health product labels and the extension of the diagnostic blood testing pilot in Ontario which will both see a direct impact on the lives of people across Canada.

Our science-based education programs continued to reach thousands of people to help them either learn about the disease or to manage their quality of life through informed decision-making. Our Nutrition Day held during our annual conference with McMaster University was one of our highlights to show collaboration to bring better education to our community.

Our outreach and awareness campaigns have never been stronger. Clean, crisp and focused messages are reaching more people across Canada than ever. It's rare now that someone hasn't heard at least the term 'celiac' these days. Our website continues to evolve with more French and multilingual resources to be more inclusive across Canada.

Finally, we saw our State of Celiac Disease in Canada Health study receive an incredible 7,400 responses to help us learn more about your day-to-day health and steps we need to take to continue improving the health of over 400,000 Canadians.

Every day is inspiring at CCA. Our small but dynamic team diligently and enthusiastically focuses on how we can best support individuals with celiac disease across Canada stewarding your precious gifts. We are humbled by your support and trust.

Melissa Secord
Executive Director
Canadian Celiac Association

Our Nutrition Day held during our annual conference with McMaster University was one of our highlights.

The State of Celiac Disease in Canada Health study received an incredible 7,400 responses which will help us learn more about your day-to-day health.



2022 AT A GLANCE



\$500,000 raised

More than **50,000**
meaningful connections

“

My son is very interested in reading all the research made accessible through the Canadian Celiac Association and is ever positive about the day science finds a solution for people with celiac disease to alleviate the acute pain he and I both suffer when we are ‘glutened’.”

Kathryn, BC

Education



CCA TALKS: NEUROLOGICAL COMPLICATIONS OF CELIAC DISEASE

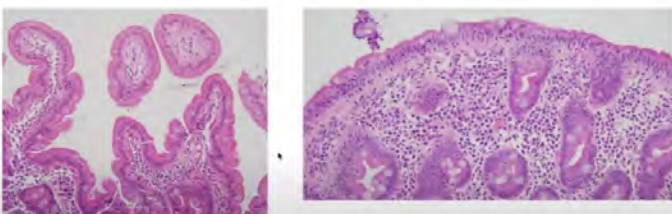


Nutritional deficiencies in CeD

- CD is associated with several nutritional deficiencies, which could be explained by malabsorption when the disease is active.¹
- The inflammation is improved with adherence to a GFD and should lead to improvement in nutrient absorption.
- However, a GFD itself has limitations in nutrient value and can lead to nutrient deficiencies in the follow up
- Dietary counseling and nutrition monitoring to assure patients are meeting the recommended dietary intakes.

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Biopsy



CCA TALKS: IRON DEFICIENCY & CELIAC DISEASE



BY THE NUMBERS:

Fostering a supportive online community of **19,463** people across Canada

Over **10** collaborations with organizations and institutions such as universities, food banks, and other patient disease groups

1,945 people supported through our help desk phone line and email

915 people attended our virtual conference

21 webinars with over **5,000** attendees

“

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

”

Katy Ransom

Evidence-based, relevant information continues to be at the core of our education efforts. In 2022, we provided trustworthy advice and support through many platforms, including our website, social networking, helpdesk, and webinars led by our registered dietitian. Our community includes over 45,000 people, all of whom benefit from our resources. We make education accessible to all people in Canada to help drive diagnosis and increase empowerment. Specific groups who access our resources in addition to the general public include healthcare practitioners, food manufacturers and public bodies.

We hosted several webinars in 2022 with our largest and most popular being “Neurological Complications of Celiac Disease”. This was hosted by Dr. Iain Croall with over 530 registrants. This YouTube video has received over 5,446 views. In addition to this popular webinar, we hosted our first ever ‘Celiac After Dark’, two highly popular tax seminars, a meal planning/budgeting webinar, an education session on non-alcoholic fatty liver disease and our monthly ‘Gluten Free 101’ sessions. Our ‘Webinar Wednesdays’ during Celiac Awareness Month had excellent reception with over 2,021 registrants for the IBS, neurological, mental health and anemia webinars.

Our audience does not always have the capacity to watch webinars, therefore we also provide shorter educational videos. Those released in 2022 include a ‘5-minutes to Label Reading’, ‘Family Screening’, ‘What does 20ppm Mean on a GF Diet’ and ‘Vitamin D and CD’. In addition, we created a short educational series for older adults, focusing on fibre, bone health and medication.

Finally, we created an education series for dietitians specially designed to enhance current knowledge on testing, treating and supporting those with celiac disease. The goal of these sessions is to increase testing, ensure consistent messaging throughout practice and drive empowerment. In 2022, we delivered three of these sessions.

Events

Total number of events provided by our Health Promotions Team:

- 21 webinars
- 2 cooking demos
- 2 education events for dietitians

Conference

Our 2022 Annual Conference hosted 915 people over two days. Our survey results found that 97.5% of respondents stated that we met or exceeded their expectations. In addition, 96.5% of respondents stated that they learned something new, or their knowledge was improved.

Help desk

Our helpdesk answered a total of 1,945 emails and phone calls combined. This is an average of over 5 inquires per day.

Newly Diagnosed program

We launched our NEW Newly Diagnosed Pathway to help people receive evidenced based information and support at just the right time. 92 people registered by the end of December 2022.

Advocacy

SAVE ME
cca acmc
for gluten-free

Helping those with celiac and food insecurity

Purchase non-perishable gluten-free food items

Download and print our 'SAVE ME FOR GLUTEN FREE' decals and adhere to your bag.

Take to your local food bank or put in your grocery retailer collection bin.

celiac.ca



BY THE NUMBERS:

1,503 letters sent by our community in support of getting coverage for the Ontario Screening Blood Test

4,624 signatures collected in the lead-up to take action on the coverage for the Ontario Screening Blood Test

Over **1,000** pounds of food donated at Gluten-free Garage event

“

I was diagnosed with celiac disease in my 50s and it changed my life, as one of my symptoms was migraine headaches which lasted for 3 days at a time. The new quick diagnosis method nowadays is wonderful. Thanks to CCA for pushing to get it recognised in Ontario.”

**Allison,
Kitchener, Ontario**

STRENGTHENING STANDARDS OF CARE

We help remove the physical and social barriers within communities to ensure access to opportunities and support for people affected by celiac disease.

Helping change policy – our advocacy efforts in 2022 were focused on:

Pan-Canadian coverage of the celiac blood test for diagnosis

We saw the extension of the Ontario Ministry of Health pilot that included free diagnostic blood tests for celiac disease into March 2023. Thanks to the community for helping us raise our voice by sending 1,503 letters to members of the Ontario legislature along with 4,624 petition signatures. The pilot extension was the result of early positive results and support from community-based labs, patients, and clinicians.

Improving access to safe consumer products

People with celiac disease need to be able to easily identify safe gluten-free products. We have a long-standing relationship with Health Canada (HC) where we can identify and bring issues of concern forward. Here is just some of our activity this year:

- Participated in stakeholder consultations that helped bring forward new clear and standardized warning labels for natural health products which include vitamins, supplements and other natural health remedies.
- Performed a study on gluten-free oat labelling that demonstrated inconsistent interpretations of oat labelling regulations.
- Took part in HC consultations to review the gaps in regulations with online retail food purchases; and finally,
- Advocated for a number of ingredients, such as nuts and spices, to be studied to ensure they meet the Health Canada standards of acceptable gluten-free foods.

Long term care standards

One of the greatest fears of our community is not being able to self-advocate and rely solely on the knowledge of others to prepare and serve our meals. Seniors are our most vulnerable in long term care and institutional settings. We participated in the national consultations reviewing the long-term care standards. Results will be available in early 2023. In the meantime, we undertook a study of institutional catering staff to better understand their level of knowledge to begin creating educational resources to help improve the level of care for our most vulnerable population.

Incremental Medical Tax Claim

Affordability and the cost of GF food is the number one concern for our community. Unfortunately, the current tax regime of claiming for the incremental difference in the cost of GF food is arduous, lacks fairness for disadvantaged Canadians and results in very little results for those who take the time to collect receipts all year long. A task force was struck to research past tax decisions, perform Freedom of Information Requests and consult legal tax experts. This fact-finding will help inform a strategy to bring forward to the Minister of National Revenue and Finance in 2023.

Fundraising



BY THE NUMBERS:

48 participants in the
TCS Charity Challenge

\$500,000 dollars raised

877 sunflower packets sold



Thank you for organizing this educational opportunity to meet and hear important topics given by professional, well-informed speakers who are dedicated and up to date with the ongoing scientific celiac research. I also enjoyed listening to the helpful suggestions given to assist in improving celiac patients' lives.

Anonymous



According to the Canada Revenue Agency last year over 10 billion dollars was donated to charity. *Alone we can do so little and together we can do so much* (Helen Keller).

That statistic represents the big picture of giving. Closer to home, we invite our very own supporters and friends to take a bow and receive our heartfelt gratitude for the role you played in helping to ensure that every person in Canada with celiac disease is properly diagnosed and empowered to live a life of well-being free from fear and health insecurity.

In 2022 CCA's individual giving heroes, close to 2,500, contributed almost \$500,000. This represented nearly 60% of the entire revenue budget.

Yes, you understood the need and took action.

You ran or walked in the TCS Charity Challenge and raised \$20,000. You bought a total of 877 Sunflower Seed packages in support of CCA. You, even during difficult times, wrote a cheque or went online and answered the call by giving directly to an annual appeal. Many of you understood the importance of sustained giving and became monthly donors (over 150 individuals chose to give this way).

Furthermore, you spread the word and sought support from your employers by seeking a matching corporate gift, or asking that your employer, club, or association would consider CCA as their charity of choice for an event.

Your enthusiasm was boundless, and we are grateful for your loyalty.

Donors are truly the *crème de la crème* of society and the lifeblood of CCA. We cannot do what we NEED to do without you. THANK YOU!

Awareness



BY THE NUMBERS:

Over **2 million** impressions

6,410 people took the celiac disease symptom checklist

Over **7,000** new people joined our community



For people with celiac disease, CCA is our coach every step of the way. Leading research and keeping abreast of the latest knowledge. Advocating with government to protect our food. Teaching us how to navigate our long-term health. Raising awareness to help others get a timely diagnosis. Our patient community is our team, supporting each other to reach our best selves and I am proud to be part of it.



**Christine Nesbitt,
Eight-time world
champion, and
Olympic gold and
silver medalist.**

INCREASING DIAGNOSIS

Raising awareness of celiac disease and the various symptoms is crucial to increasing diagnosis rates and getting more people to better health, faster. And the more people diagnosed will grow our community and help us accelerate towards treatment options and a higher quality of life.

Our awareness campaign “Could it Be Celiac” ran in May for Celiac Awareness Month. Throughout the year we continued to drive awareness through social media, events, public relations and community engagement.

“Could it be celiac?”

This year’s May awareness campaign focused on Sonia’s story, and highlighted the unusual symptoms that celiac disease can present with, and Sonia’s emotional journey to get diagnosed.

The goal? To make people who are curious about the state of their health take our symptom checklist.

Thanks to our campaign and community, we were able to raise awareness of the symptoms and achieved a whopping 2-million social media impressions. We drove over 40,000 people to our website in May alone and 6,410 people completed our online self-assessment tool to see if they should be tested.

**Awareness is a part of the Strategic Area: Education and Awareness.*



Research



BY THE NUMBERS:

7,491 participants in the State of Celiac Disease in Canada Health Survey

30,000 dollars available for celiac research funding

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

***Dr. Elena Verdu,
award winning
gastroenterologist
head of the
Verdu Lab
at McMaster
University***

ADVANCING TREATMENT AND CARE

Having access to a variety of effective treatment and care options for symptom management, wellness and self-care will help people on their unique celiac journeys.

We support research that leads to better understanding and new treatment options, we advocate for access to safe food, and provide programs and services that support living with celiac to live their fullest lives.

Understanding Celiac Disease.

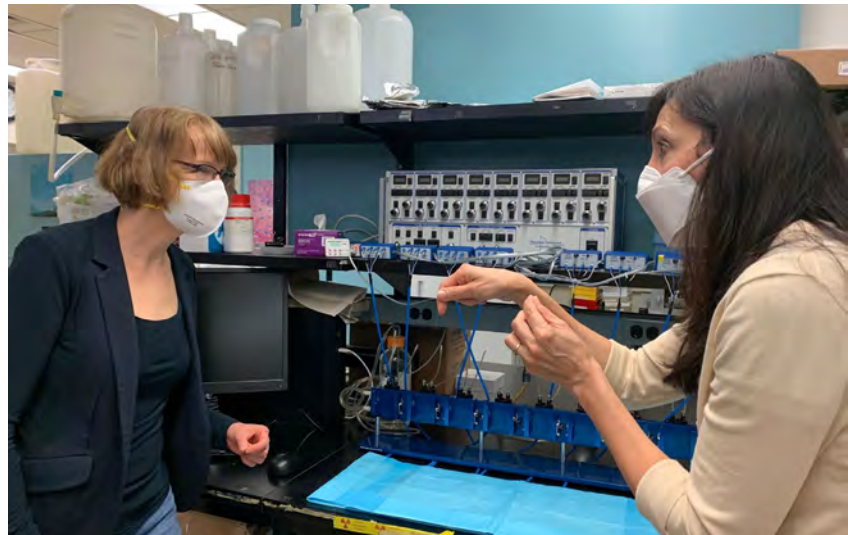
State of Celiac Disease in Canada Health Survey

This year, CCA launched a major comprehensive online survey on the state of celiac disease in Canada. The survey was open for 12 weeks and received a total of 7,491 responses, making it our biggest piece of research to date! The data, which will be released fall 2023, will help highlight any progress made in the past 20 years and continuing challenges surrounding life with this condition. It will help inform initiatives, future education and advocacy efforts and support programs going forward so we can better help our growing community and advance CCA's vision to have every Canadian with celiac disease diagnosed and empowered.

JAC Research Grants.

The James A. Campbell (JAC) Research Fund is the only celiac specific research granting program in Canada. Since its inception, the CCA has distributed just under \$400,000 in grant money to Canadian researchers.

This year, our JAC Young Investigator Research Award winner was Sara Rahmani. Sara is a PhD candidate at the school of Biomedical Engineering at McMaster University. Her research focuses on developing an in vitro epithelium model in the form of organoid monolayers from mice that transgenically express the human HLA-DQ2 or HLA-DQ8 molecules encoded by the necessary genes in celiac disease (CeD). She investigates mechanisms underlying the interaction between gluten and the intestinal epithelium.



Specifically, she will unravel the inflammatory triggers that switch on the expression of DQ2, necessary for antigen presentation, on organoid monolayers and whether the expression of these molecules promotes the activation of CD4+ T cells. She will also explore how other environmental triggers and drivers of celiac disease, such as opportunistic bacterial pathogens, influence these pathways. Her long-term goal is to engineer a high throughput preclinical screening tool for novel drugs in CeD.

Clinical trial recruitment.

CCA continued efforts to support clinical trial recruitment in 2022. Through our partnership with ProventionBio and the University of Alberta, CCA has been instrumental in recruiting qualified participants in Phase 2 and qualitative studies.

**Research is a part of the Strategic Area: Promoting Evidence Based Standards.*

Community



BRINGING TOGETHER THE CELIAC COMMUNITY

The importance of connection is critical.

CCA works to find meaningful and creative ways to connect and unite the gluten-free community across Canada. We focused on online events, programs, and services to bring people together from across the country for virtual TCS run, cooking events, educational webinars and more.



“As an individual with celiac disease, it is important that others are aware of the disease and the impacts it can have on someone. I was only diagnosed three years ago when my dad was, almost completely by chance. It is thanks to CCA that I was able to transition to a gluten-free diet fairly seamlessly. Their advocacy for good labelling laws and information about what is and is not safe continues to be invaluable, as I will be eating gluten-free for the rest of my life.”

**Heather,
Toronto, Ontario**

“
My daughter, who is 5 years old, was recently diagnosed with celiac disease. During this difficult transition to a gluten-free lifestyle, CCA has been an invaluable resource to us. Despite their assistance, there are daily struggles medically, financially, emotionally and socially.”

**Kelly,
Kamloops, BC**

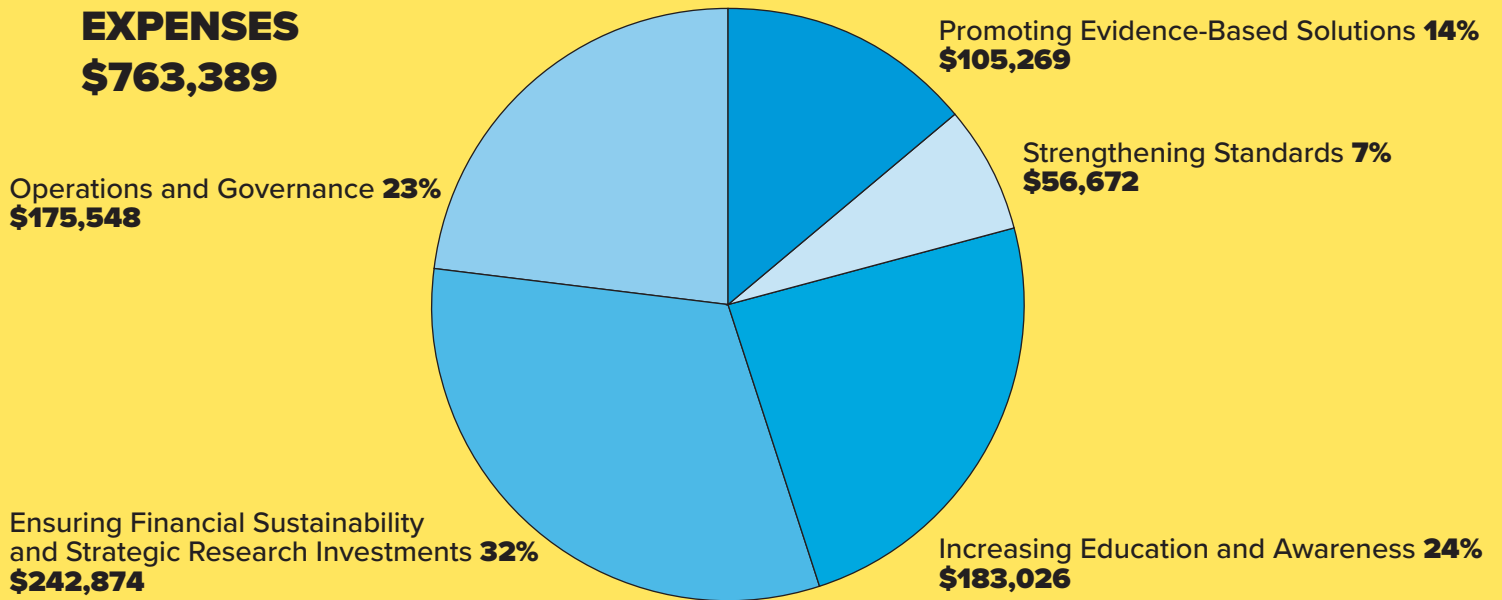


“
My son was diagnosed with celiac disease last year at six years of age. Since then, we have relied on CCA and their resources to guide us in adopting the gluten-free diet for our household, in educating our son’s school/teachers and in advocating for appropriate testing and care from his healthcare providers. Awareness is key!”

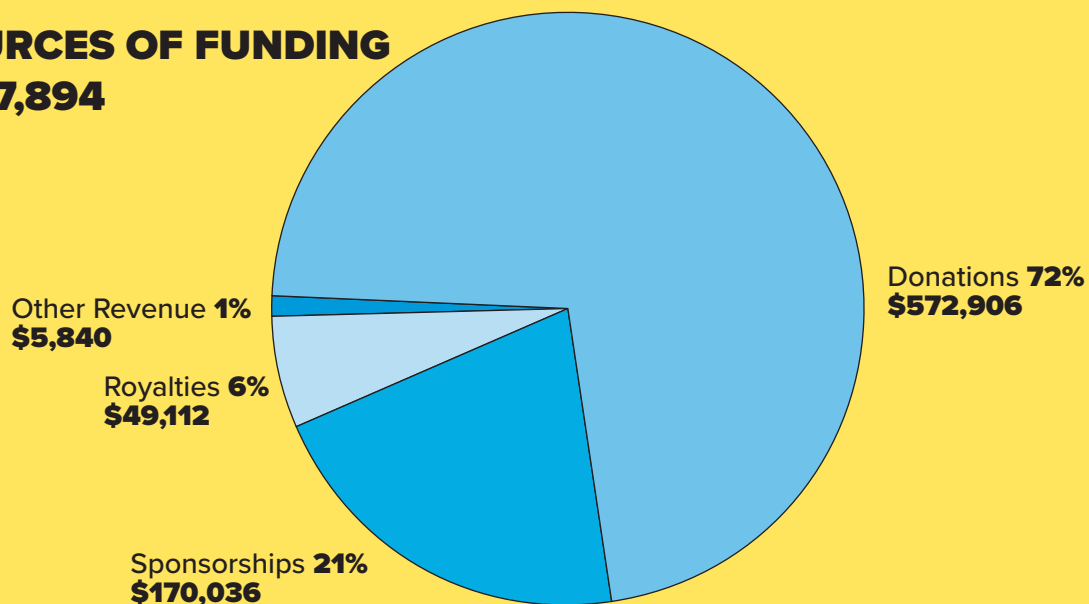
**Allison,
Ontario**

2022 Financials

EXPENSES \$763,389



SOURCES OF FUNDING \$797,894



Thank you CCA Community.

Board of Directors

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President – Jennifer Stebbing
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Secretary – Wanda Walkden

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June 2021 - June 2023
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June 2022 - June 2024
Marsha Hebert
June 2021 - April 2022
Uzair Jalil
June 2021 - June 2023
Rumi Jasavala
June 2022 - June 2024
Steven Poirier
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Carly Willis
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Melissa Secord
CCA National Executive Director

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Nisha Paul
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(August 2022)
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Caleigh McAulay
*Health Promotions and
Research Coordinator*
Kari Rintoul
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Francis Fernandez
Database Administrator
(Contract)

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