

COLORECTAL
CANCER
CANADA



CANCER
COLORECTAL
CANADA



2021

ANNUAL REPORT



WELCOME TO THE 2021 COLORECTAL CANCER CANADA ANNUAL IMPACT REPORT.

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INTRODUCTION

WELCOME TO THE 2021 COLORECTAL CANCER CANADA (CCC) ANNUAL IMPACT REPORT! THIS REPORT HIGHLIGHTS CCC'S KEY ACTIVITIES BETWEEN JULY 01, 2020 AND JUNE 30, 2021.

It comes as no surprise that Covid-19 continued to impact CCC's activities throughout the year—as it has impacted the lives of the many individuals we serve. Whether as a patient, survivor, caregiver, or member of the public, no one escaped the disruption of the pandemic, including CCC.

However, while the pandemic disrupted our traditional in-person activities and outreach, going into the second year of Covid we were much better prepared to respond to the new environment, planning our programs and activities accordingly. Although we were presented with unique challenges, we also experienced unexpected benefits including the development of our programming in new and exciting directions with the growth of our digital initiatives, including our website, social media, and conference platforms, plus further engagement with the Canadian cancer community on a broader level.

Below are highlights to exemplify the new opportunities CCC embraced this year:

Our Patient Support Program is a hallmark of CCC, through which we continue our essential work of direct patient support. We fielded emails, phone calls, and digital support groups for colorectal cancer patients in greater numbers than ever before to help patients and their caregivers navigate the cancer care system and treatment plans. As a patient organization, this is the first priority for the entire CCC team, as everything we do has the patient and caregiver in mind.

Awareness and education programs are essential for Canadians to be able to prevent and better treat colorectal cancer (CRC). This year, CCC focused our outreach through social media, newsletters, clinical trial research reports, publications, conference presentations, abstracts, and posters. These efforts were supplemented by advertisements and fundraising events to ensure that

Canadians receive information on the latest advances in colorectal cancer. Moreover, this year's presentations at national and international patient and scientific conferences were extremely well received.

Our awareness and education efforts continued to pivot to digital infrastructure, and we focused on developing and professionalizing CCC's website and social media presence, including launching a monthly newsletter that now has over 16,000 subscribers.

CCC organized our first-ever *Colorectal Cancer Community Conference*, a two-day virtual event that united colorectal cancer patients, family members, physicians, and researchers as well as other stakeholders. These are people who, while connected through work or lived experience, are rarely afforded the chance to interact in a common space to learn and foster relationships.

CCC continues to work tirelessly throughout the regulatory approval and health technology process to do everything possible to ensure patients have access to new and effective cancer therapies and their companion diagnostics. CCC gathers patient input for the evaluation of new cancer drugs to be reimbursed by Canada's health technology assessment review panels: The Canadian Agency for Drugs and Technologies in Health (CADTH) and the Institut national d'excellence en santé et services sociaux (INESSS) in Quebec.

CCC's *Patient Values and Preferences* in health technology assessment research is being conducted in partnership with the University of Calgary and six cancer centers across the country. Its goal is to better understand CRC patients' preferences in drugs and their values so that CCC can better inform expert committees in the reimbursement of cancer drugs when providing input to CADTH and INESSS.

This year we were able to conduct three patient group input submissions on behalf of patients for drugs that will now be recommended for reimbursement, opening doors for patient access to new precision medicines and an immunotherapy drug that will prolong and increase the quality of patients' lives.

Additionally, as the incidence of colorectal cancer rises among young Canadians, we focused on expanding our early-age onset program, *Never Too Young*, and we continued to enhance our young adult-oriented awareness and support programs. This year, we published a comprehensive patient toolkit for newly diagnosed early-onset colorectal cancer patients to provide a trusted resource to support patients and their families as they face the challenges of the disease at a young age.

CCC held the fourth annual *Patient Group Pathways to Cancer Clinical Trials and Real-World Evidence Conference* with an emphasis on precision medicines. Holding the conference virtually allowed access to an expanded complement of world-class experts across North America and Europe. With an eye on improving cancer clinical trials, CCC and our expert clinical trials working group, finalized and published *Canadian Cancer Clinical Trials Stakeholder Charter in Current Oncology*. The document serves to ensure patient-centricity in cancer clinical trials and governs the relationship between a trial's sponsor and a participating patient group. By having cancer researchers work together with patients and patient groups, we can improve trial design, ensure trials meet the endpoints most important to patients, improve awareness of clinical trials, and patient participation in them.

Ensuring that the right person receives the right treatment at the right time is at the core of personalized treatment, and the foundation of our *Get Personal Program*. In colorectal cancer, new precision medicines continue to enter the clinical practice and CCC is working to seek approval and reimbursement of

these new medicines, and to ensure that all patients can access molecular profiling.

This year, we surveyed our patient population and cancer centers across the country to understand access to molecular profiling, and better advocate for its growth. We are pleased to say this work is being submitted for scientific publication and has been accepted for presentation at the international conference of the European Society of Medical Oncology.

As a complement to our work with biomarkers, our *Immunotherapy Awareness Program* now includes a program plan and ongoing social media and web campaigns. We also facilitated an extensive patient survey of CRC and other cancer patients for input on reimbursement of an immunotherapy treatment for CRC patients in Canada.

As more people survive colorectal cancer, CCC is developing a survivorship program, *Cope Thrive Survive*. This program includes an initiative covering reentry to the workforce following cancer. Working with leading researchers from across Canada, we are in the process of expanding our work in this area.

As we previously confirmed in our *May 2020 Survey Report on Colorectal Cancer and Covid-19*, the pandemic had severe impacts across healthcare. For cancer patients, this manifested as delays in screening, diagnosis, surgery, and access to treatment and clinical trials. In addressing the impact of Covid-19 on CRC patients, we joined the work of building healthcare system resiliency to avoid future interruptions in cancer care for patients. CCC's program *Ready For The Next Round* is a continuation of that work as we seek to find solutions for the public and for colorectal cancer patients as they navigate and strengthen the healthcare system.

From an organizational perspective, we continue to pursue the implementation of our strategic plan while further developing innovative new programs and our capacity for results reporting, fundraising, and talent growth. This document is arranged according to the strategic plan, with projects meeting specific goals. CCC's audited financial information for prior fiscal years is available on our website.



THE CCC MODEL

THE CHALLENGE WE ADDRESS:

Colorectal cancer is preventable, beatable and treatable. Yet, it is among the deadliest cancers in Canada.

In 2021, colorectal cancer was the third-most diagnosed cancer in Canada and was the second-leading cause of cancer death. While CRC is highly preventable, over 24,800 Canadians will be diagnosed with the disease this year, and due to late diagnosis more than 50 per cent of cases will be detected at advanced stages when cancer is harder to treat and cure.

While CRC mortality rates have been steadily declining since 2011, and the five-year survival rate is about 65 per cent, it is estimated that nevertheless approximately 9,600 Canadians will die from the disease in Canada this year. Initial modelling by researchers indicates that the Covid-19 pandemic has had and will continue to have a severe impact on CRC screening, diagnostics, treatment, care, and ultimately patient outcomes.

Although the pre-Covid trend was positive, as more patients are surviving the illness, Canadians younger than 50 are seeing dramatic increases in colorectal and rectal cancers for unexplained reasons. Compared to Canadians born in 1950, Canadians born after 1990 face as much as double the risk of colon cancer and quadruple the risk of rectal cancer.

This is the landscape in which we operate. As a patient led organization with deep connections to the patient population, colorectal medical practitioners, institutional stakeholders, government, and industry, CCC is poised to address patient and caregiver perspectives that lie outside of standard cancer care with empathy and lived experience. We are guided by three interconnected strategic priorities:

- Awareness and education of colorectal cancer among Canadians, providing educational tools and opportunities to understand the risks, benefits, and impact of the disease.
- Support for colorectal cancer patients and their caregivers through support groups, individual direct support, resource cultivation, and clinical developments.
- Advocacy for and on behalf of colorectal cancer patients and caregivers in areas such as equal access to diagnostics, effective treatments and clinical trials, primary prevention including healthy lifestyles, and colorectal cancer screening.

Funds for our programs are sourced broadly. General donations and major community-oriented events like the Push for Your Tush 5k/10k Walk/Run, which connect the colorectal cancer community with donors while raising awareness in the community, serve as major sources. Individual projects, conferences, and programs are funded through industry sponsorships and educational grants. CCC also works with researchers across Canada who are funded with grants from entities such as The Canadian Institutes of Health Research. This support is further supplemented by generous private donors.

CCC is a national not-for-profit patient organization incorporated under the Canada Not For Profit Act and is a registered charity with the Canada Revenue Agency, charitable registration #86657-2423-RR0001. CCC offices are in Montreal and Toronto. Our programs and services are available in both official languages.



CORE VALUES, STRATEGIC OBJECTIVES AND GOALS

As always, CCC stands by three core values:

- CCC is dedicated to increasing Canadians' awareness and education of colorectal cancer, providing critical support for patients and their families and advocating on their behalf.
- CCC advocates for population-based colorectal cancer screening programs across Canada and primary prevention through healthy lifestyles, including regular exercise and diet.
- CCC believes in the fundamental rights of patients to have equal and timely access to effective treatments to improve their health outcomes.

These values guide our work through the organizational goals outlined in the following section.

Strategic plan structure:

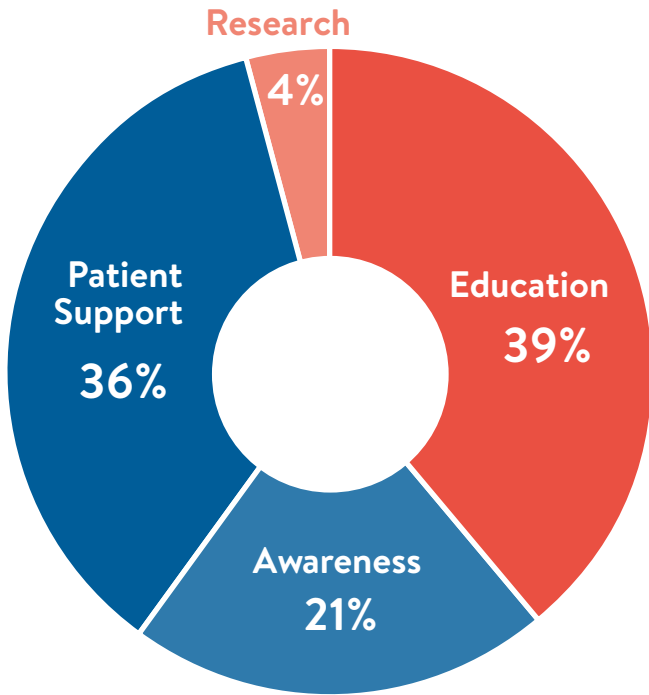
The material in this report follows the structure of our 2019-2022 Strategic Plan; programs and initiatives are framed as working towards accomplishing the articulated goals and their subordinate objectives.

GOALS

1. Raise awareness of the disease and educate Canadians to prevent colorectal cancer.
2. Promote access to effective treatments and care and provide patients with education, support, resources, and access to networks of health care professionals.
3. Increase the national presence of CCC and foster a resilient and sustainable organization and national network of ambassadors and supporters to advocate on behalf of patients and caregivers.

PROGRAMS

The graphs below indicate our funding allocation by organizational goal. These figures are drawn from the audited financial statements for the 2021 fiscal year being July 1, 2020 to June 30, 2021.



Fiscal Year 2021 Program Expenditures

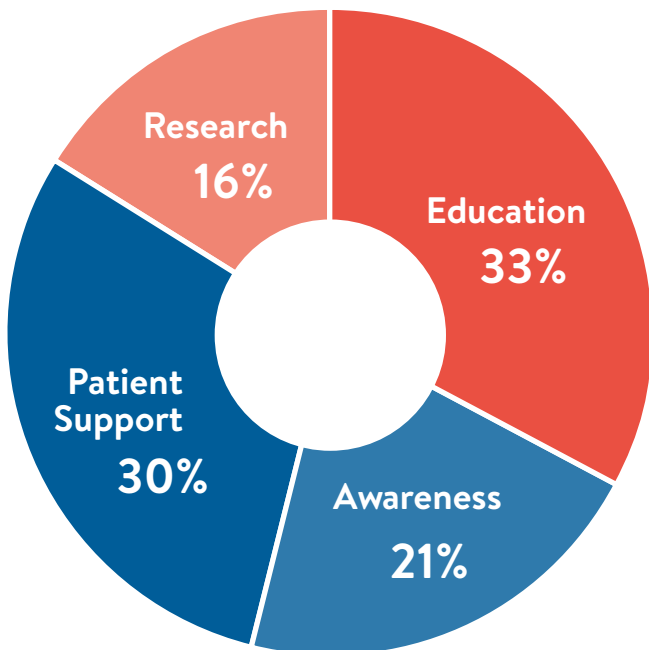
Total: \$998,480

Education: 39%

Patient Support: 36%

Awareness: 21%

Research: 4%



Fiscal Year 2020 Program Expenditures

Total: \$1,021,984

Education: 33%

Patient Support: 30%

Awareness: 21%

Research: 16%



RAISING AWARENESS AND EDUCATING CANADIANS TO PREVENT AND SCREEN FOR COLORECTAL CANCER

Twin goals that unite many of CCC's initiatives are raising awareness and educating Canadians with the aim of preventing and early detection of colorectal cancer. If Canadians are aware of the disease's symptoms, the importance of screening, and the opportunities for personalized treatment, they will be more willing and able to get screened, seek care in a timely manner and consequently improve patient outcomes.

Primary prevention and colorectal cancer screening programs highlighted in this section are for the population at large, who have no signs or symptoms of the disease. It is important to note that colorectal cancer rates are rising rapidly in adults under the age of 50; consequently, CCC has prioritized awareness programs targeting younger Canadians as well as family physicians.

NEWSLETTER

Launched in September 2020, and with over 16,000 subscribers, CCC's new bilingual digital monthly newsletter has been an effective method of proactively sharing our resources, stories, and services with members of the colorectal cancer community across Canada.

Curated to connect current CCC programs and events with educational information and research in an informative and engaging tone, this tool is especially useful for reaching community members who may not be on social media or actively visiting the CCC website. As such, the newsletter is an exciting and versatile vector for education and awareness.



SEPTEMBER 2020
NEWSLETTER



SOCIAL MEDIA

After instituting a social media strategy at the beginning of the year, the CCC pages across all platforms have grown, and are able to reach more people more effectively.

A valuable information resource for patients and caregivers, the purpose of social media for CCC is to provide educational information and expand access and awareness to our resources, projects, and fundraisers. The growth of these social media pages has demonstrably helped to connect and educate the colorectal cancer community.

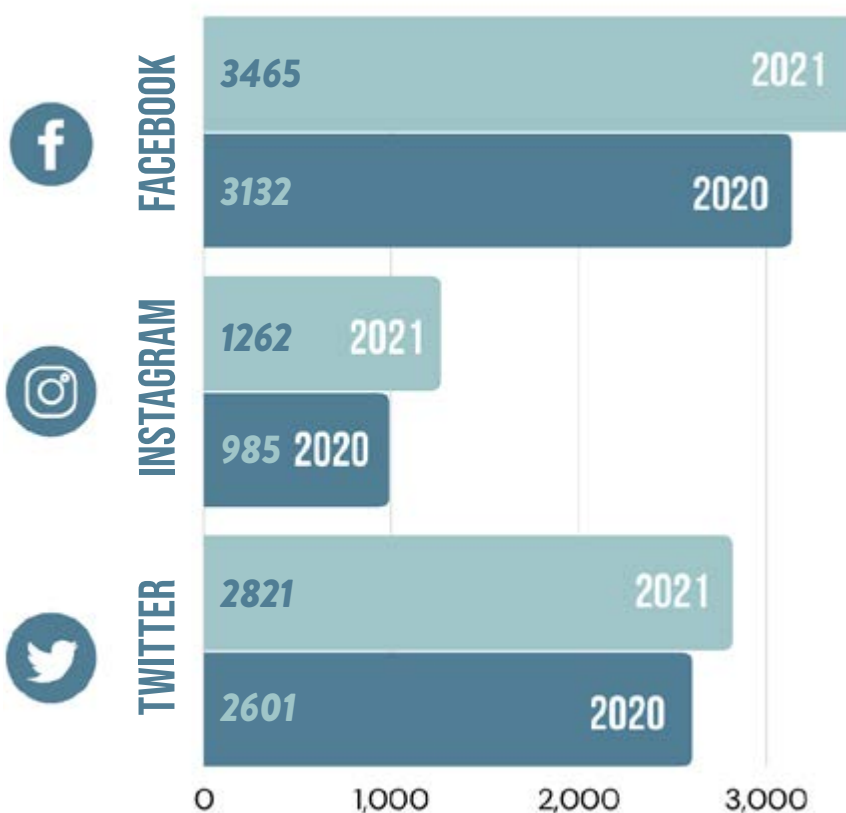
CCC also runs specialized pages for more targeted resource sharing in line with the awareness portions of broader projects like *Never Too Young* and *Foods That Fight Cancer*.

FOODS THAT FIGHT CANCER

The *Foods That Fight Cancer* program was developed in response to research that indicates gastrointestinal cancers like colorectal cancer are highly susceptible to environmental factors and diet. While the program was initiated two years ago, the published information, developed with biochemist Dr. Richard Béliveau, remains relevant and useful for patients, their families, and caregivers.

The recipe book and website remain accessible as resources, as do the social media pages for the program where recipes and tips are shared. The program also provides nutritional tips for patients undergoing cancer treatment. It has its own website and social media apart from CCC to reach a broader audience for cancer prevention.

IMPACT



**COLORECTAL CANCER RATES
ARE RISING RAPIDLY IN
ADULTS UNDER THE AGE OF
50; CONSEQUENTLY, CCC HAS
PRIORITIZED AWARENESS
PROGRAMS TARGETING
YOUNGER CANADIANS AS WELL
AS FAMILY PHYSICIANS.**





INCIDENCE AMONG CANADIANS UNDER 50 IS RISING SIGNIFICANTLY. INDIVIDUALS BORN AFTER 1990 HAVE TWICE THE RISK OF COLON CANCER AND FOUR TIMES THE RISK OF RECTAL CANCER COMPARED TO PEOPLE BORN AROUND 1950

NEVER TOO YOUNG



A major focus in developing awareness programs for CCC is to reach Canadians under the age of 50. The initial push of this project was to develop material to educate

younger Canadians about the importance of getting tested for colorectal cancer; colorectal cancer is eminently treatable if caught early, and the main risks for younger people are that the disease will go undiagnosed or misdiagnosed under the assumption they're "too young" for the disease. Soliciting stories from community members and encouraging social engagement from early-age-onset survivors has the additional goal of reducing the isolation often felt by younger cancer patients.

This year, CCC issued a National Survey on Early-Age Onset colorectal cancer to better understand the needs of younger patients touched by colorectal cancer. Information obtained from the survey was used to develop and publish an Early Age Onset Patient Toolkit, with extensive information and resources for young patients and their caregivers.



IMPACT

- Completed the patient toolkit for early age onset colorectal cancer, available for free on our site and at key distribution points
- Recruited two new volunteer ambassadors for outreach and communication
- Completed N2Y survey of young Canadians
- Posted compelling personal narratives to the website



IMMUNOTHERAPY AWARENESS PROGRAM

Immunotherapy is a novel approach for treating cancer if traditional treatments from a chemical, radiation, or surgical perspective aren't effective or advisable. Some types of colorectal cancers have been shown to respond well to Immunotherapy, a practice of priming the natural immune defenses to recognize, target, and destroy cancer cells effectively. This is particularly important in contexts where a cancer has spread through the body.

The *Immunotherapy Awareness Program* involves educating Canadians about this treatment

with two aims: reaching patients, so they can access the treatment for themselves or participate in clinical trials; and reaching medical practitioners, so the treatment can advance and become more broadly accessible.

As this treatment is entirely dependent on molecular analysis of the colorectal cancer tumours, the *Immunotherapy Awareness Program* is intrinsically connected to the *Get Personal* biomarkers program in patient care.

This year, we developed the program brief, as well as an ongoing social

media and web campaign, and a survey that facilitated the approval of a new immunotherapy drug (see in this report: *pCODR*).

A patient guide to immunotherapy is in development.



IMPACT

- Program brief completed, patient guide in development
- Completed survey as part of pCODR

PROMOTE THE HIGHEST QUALITY OF TREATMENT AND CARE AND PROVIDE PATIENTS WITH EDUCATION, SUPPORT

PATIENT SUPPORT

CCC offers high-impact personalized support that makes a world of difference to an individual's or caregiver's cancer experience. Trained CCC team members who are also colorectal cancer survivors offer an ear to patients and can guide them and their caregivers through common issues, direct them to specific resources, help them make difficult decisions, and put them in touch with peers in individual contexts or group settings.

The personal attention and human connection that one-on-one support provides, be it over Zoom

meetings, phone, or email, was extremely important during the Covid-19 pandemic as many Canadians were facing isolation and fear. For cancer patients in treatment, those concerns were compounded, as our May 2020 survey indicated, highlighting the importance and value of our patient and caregiver support. Throughout the year, we provided direct, ongoing assistance to well over 100 Canadians.

Separately, CCC support groups offer a reliable, safe, and comforting space for patients to bond over shared experiences, discover ways

of coping with their diseases, and honestly discuss their concerns in an understanding forum. During the last year and a half, these monthly meetings became a patient lifeline.

This year, CCC started and continues to directly guide a support group in Kingston, Ontario which is being expanded to include patients around the country. CCC also initiated an online support group for Early Age Onset colorectal cancer patients across Canada, who often feel alone and unable to relate to some of their older peers.



MATERIAL DISTRIBUTION

WEB

Following last year's redesign, the CCC website continues to be a robust, dynamic source of information for patients, caregivers and family members, as well as supporters and donors to CCC.

Documents, guides, and information on all our programs can be found on the site, as well as connections to external resources and guides for navigating all steps of the colorectal cancer patient journey from the patient perspective. Research updates relevant to advances in colorectal cancer care are posted monthly, for the curious patient or the medical professional, while the stories of patients, survivors, caregivers, and families are shared on the blog for inspiration, support, and a diverse set of patient-centered perspectives and experiences.

Our aim is for patients to arrive on the website and experience access to reliable information from a trusted partner. This year CCC continued our major effort at bolstering the content on the web site, making it more accessible, relevant, and comprehensive.



IMPACT

166,489

PAGE VIEWS THIS YEAR

Unique users: 70,219

Blog posts: 20

Personal stories: 10

Compared with last year:

103,814 PAGE VIEWS

70,921 USERS



PRINTED PATIENT INFORMATION MATERIALS

Many of the documents offered on the CCC website are also available in printed format, along with print-specific media, which CCC traditionally distributes at in-person events. Unable to do so this year, we continued to send our materials to cancer centres, endoscopy clinics, hospitals, and individual patients.

These focused guides include "Colorectal Cancer and You," a comprehensive 65-page booklet on living with cancer, a journal for taking emotional stock of the cancer journey, and nutritional information from our nutrition programs and partnerships. Since Spring, we have distributed hundreds of copies of these materials to clinics and hospitals across the country who are restocking their inventories as patients return to in-person care, as well as to individuals seeking information.

COPE THRIVE SURVIVE

Still in the early stages of development, this new survivorship program will help colorectal cancer patients, survivors, and caregivers get their lives back on track after their encounter with the disease. The program places a particular emphasis on the shift from active treatment back to everyday life.

The first steps of project development are underway, having assembled an expert advisory board. The next focus of the project is the creation of a toolkit to help guide a patient's return to the workplace with comfort and confidence.



IMPACT

This year we completed the Strategic Plan, Advisory Committee, and Project Brief for this exciting new initiative.

PATIENT VALUES PROJECT

The *Patient Values Project* aims to increase the value of patient input in the health technology assessment evaluative process for the reimbursement of cancer drugs. CCC continually provides patient input to the expert committees of the Pan Canadian Oncology Drug Review (pCODR) for all provinces except for Quebec, and to the Institut national d'excellence en santé et services sociaux (INESSS) in Quebec. As a key patient group, CCC connects with our medical advisors, colorectal cancer patients and caregivers to provide their perspectives on the effects of the disease, side effects, and effectiveness of existing drugs as well as patient input on the drug proposed to be reimbursed.

Spearheaded by CCC and the University of Calgary, the project opens with a study that includes a survey of metastatic patients, non-metastatic patients, caregivers, and the public at large. This year we will move from the pilot stage of the study to the full scope of the survey field to determine patient values. A steering committee composed of national and international experts help guide the research work. The next phase of the research includes recruitment of patients from BCCA in Vancouver, Tom Baker in Calgary, Cancer Care Manitoba in Winnipeg, Sunnybrook cancer center in Toronto, Jewish General Hospital in Montreal, and QEII in Halifax with the assistance of investigators at each center.

The research is being followed by CCC partners in the Global Action for Cancer Patients for possible application for other cancer sites internationally.



IMPACT

- Began pilot survey, nearing completion.

PARTNER CANCER CENTRES:

University of British Columbia/BC Cancer Agency (BC site)

Tom Baker Cancer Centre (AB site)

University of Manitoba/Cancer Care Manitoba (MB site)

Sunnybrook Hospital (ON site)

Jewish General Hospital (QC site)

Nova Scotia Health Authority/ QEII Hospital Halifax (NS site)

GLOBAL ACTION FOR CANCER PATIENTS:

Ovarian Cancer Canada,
Prevent Cancer Foundation, USA,
Lithuanian Cancer Patient Coalition,
Women Against Lung Cancer In Europe, Italy,
Association of Patients with Brain Tumours, Spain,
Instituto Oncoguia, Brasil,
Fundacion ACIAPO, Argentina,
ICANSERVE, Philippines,
Pan CAN, Japan,
Unicorn Foundation, Australia



GET PERSONAL CAMPAIGN

The *Get Personal Campaign* aims to increase access to molecular profiling (biomarker testing) of cancer tumours to increase access to precision medicines and immunotherapies. The goal is to ensure the right person receives the right treatment at the right time. Molecular profiling is the process of identifying the genomic characteristics of a given cancer tumour. Once the biomarker is assessed a decision can be made if a specific precision medicine or immunotherapy is appropriate for the individual.

Following our research in the area it is imperative that patients be better informed about molecular profiling and precision medicines. To address this need, CCC developed and published an information package for patients on what biomarkers are and how they can help in their fight against cancer. We have developed a regular posting schedule of information and videos on CCC social media to help educate patients and increase awareness.

Additionally, with the help of a team of 42 medical advisors, CCC surveyed medical practitioners in 26 cancer centers across Canada on the availability and accessibility of these treatments in their centers, to determine where barriers exist, and where to focus our efforts to increase knowledge and access to testing. Subsequently, CCC also surveyed patients and caregivers.

CCC presented its survey findings at the Global Colon Cancer Association Congress 2021, to pharmaceutical, biotech, and diagnostic companies, and also shared its results with coalition partners to advocate for better access across Canada. CCC will also present our findings at the European Society of Medical Oncology conference.



IMPACT

- Presented on the project at the Global Colon Cancer Association
- Produced a robust patient guide and an overview of biomarkers' role in care
- Conducted a survey of clinicians, patients with important findings for developing the program

INCREASE THE NATIONAL PRESENCE OF CCC, FOSTER A RESILIENT AND SUSTAINABLE ORGANIZATION WITH THE SUPPORT OF A NATIONAL NETWORK OF AMBASSADORS AND SUPPORTERS TO ADVOCATE ON BEHALF OF CRC PATIENTS AND CAREGIVERS.

PARTNERSHIP

CCC maintains numerous board-level, consultative, and advisory partnerships with governmental, corporate, and non-governmental organizations across the country. This network facilitates advocacy for the patient perspective, accelerates internal program development, and keeps CCC abreast of headwinds in the industries which affect the lives of the colorectal cancer patients we serve. For the list of partners, see appendix: Partner Organizations.

DRUG REIMBURSEMENT

This year, CCC submitted patient group input on several cancer drugs under consideration by CADTH and INESSS for public reimbursement.

These bodies—pCODR for all provinces and Territories other than Quebec, and INESSS for Quebec—assess new oncology drugs and make funding recommendations after reviewing clinical evidence, cost-effectiveness, patient perspectives and adoption feasibility. CCC presented the patient perspective of why these drugs would be beneficial to receive reimbursement approval, as well as facilitating medical advisor input, resulting in greater access for Canadians.



IMPACT

- **POSITIVE:** Encorafenib in combination with cetuximab, for the treatment of patients with metastatic colorectal cancer (mCRC) with a BRAF V600E mutation, after prior therapy.
- **POSITIVE:** Pembrolizumab (immunotherapy) for the first line treatment of adult patients with unresectable or metastatic microsatellite instability-high (MSI-H) or mismatch repair deficient (dMMR) colorectal cancer.
- **POSITIVE:** Larotrectinib for the treatment of adult and pediatric TRK gene fusion positive cancers.

FUNDRAISING EVENTS

PUSH FOR YOUR TUSH

CCC's largest fundraiser by participation and dollars raised, Push For Your Tush 5km/10km Walk/Run is traditionally a friendly, celebratory, in-person event held across 12 Canadian cities. It is an opportunity to show support for patients and caregivers within their communities, as well as to educate attendees and participants about colorectal cancer and CCC.

This year's version was once again a virtual event due to safety considerations imposed by the pandemic. Learning from last year, this year's online event took advantage of the format to begin sign-up and activities earlier, and to use additional digital tools like social media and a newsletter for awareness, engagement, and community.

We will consider taking these lessons into future PFYT events, even as life returns to normal after the pandemic, to increase accessibility and flexibility for participants.

PFYT began in 1996, founded by CCC's co-founder Bunnie Schwartz. To date, the event has raised over \$6.4 million to support patient awareness and support programs.



 **IMPACT**

| | |
|------------------------------|------------------------------|
| 2021: | 2020: |
| 43 teams | 62 teams |
| 226 participants | 267 participants |
| 1,568 donors | 1,450 donors |
| OVER \$140,000 RAISED | OVER \$178,530 RAISED |

OTHER: GOLF AND OTHER THIRD-PARTY EVENTS

After cancelling last year's Kick Ass Golf Tournament for participant safety, CCC is thrilled to once again host its annual fundraising golf tournament during the 2021 calendar year.

The tournament provides an opportunity for solidarity with cancer patients and a chance for patients, survivors, caregivers, and allies to unite and be supported in a lively atmosphere while educating the public and raising funds.

An unexpected and exciting third-party fundraising event was held by volunteer Ambassador Greg Capello. Inspired by and in support of our work: Mille Mile Cent Mille \$ Cancer Challenge, a month-long cycling challenge organized by Greg Capello in the fall of 2020. We are deeply grateful for Greg's commitment to CCC and our programs, which raised \$10,960.

PATIENT GROUP PATHWAYS TO CANCER CLINICAL TRIALS AND REAL-WORLD EVIDENCE CONFERENCE AND THE CANADIAN CANCER CLINICAL TRIALS STAKEHOLDER CHARTER



IMPACT

- Charter finalized and published in *Current Oncology*.
- CT Conference:
 - 148 experts and stakeholders attended across disciplines and groups.
 - A post-conference survey saw great feedback with almost 80% ranking the event 8/10 or higher, and 80% saying we achieved our goals.

Clinical trials are a vital step in the development of new treatments for colorectal cancer patients, and an opportunity for patients to have access to certain treatments earlier than otherwise possible. However, the number of cancer patients enrolled in clinical trials in Canada has for the past few years hovered between two and six percent, despite regular and recurring interest from patients. Low participation can sink trials, delaying the approval of potentially life-saving drugs.

Recognizing this important gap in Canada, CCC has hosted four annual clinical trials conferences to bring relevant stakeholders together. The goal is to develop a Canadian clinical trials transformation initiative that includes the patient voice in the process.

At this year's conference, having multidisciplinary expert stakeholders and patient groups present allowed for rich exchange of knowledge and research. We focused on faster approval of drugs through international collaboration with the FDA and other jurisdictions, precision medicine, molecular profiling, artificial intelligence, and value-based agreements.

To govern the relationship between trial sponsors and patients and patient groups, CCC and its clinical trial working group developed the Canadian Clinical Trials Stakeholder Charter. A manuscript describing the methodology and the Charter was published in *Current Oncology*.

Next steps include: overseeing the adoption of the Charter by those involved, ensuring it accomplishes its goal of making clinical trials accessible to all patients, including the patient voice in the ideation of clinical trials, improving their design and implementation to benefit patients, expanding recruitment and retention of patients, and further advancing cancer research and treatment.

COLORECTAL CANCER COMMUNITY CONFERENCE



We were joined by 150 guests for the first annual *Colorectal Cancer Community Conference*, held virtually over two days in May. This conference was the first of its kind for CCC: a gathering of stakeholders of all types in the colorectal cancer community to speak, listen, share, and learn across disciplines, experiences, and demographics.

Attendees included patients, early age onset patients, caregivers, medical professionals, researchers, survivors, and industry representatives. One of the positive impacts of the shift to online organizing has been the possibility to reach more patients and caregivers from across Canada.

Over the course of 7 main sessions and 4 branching exploratory periods, topics covered included:

- Patient self-advocacy
- Early-age onset CRC
- The emotional impact of CRC on the patient, caregiver, and family
- Nutrition throughout cancer treatment
- New advances in CRC treatment
- Managing side effects of treatment
- Survivorship
- Clinical trials
- Building a resilient healthcare system
- Integrative medicine
- And other participant-led breakout sessions in small groups

Each session concluded with a question and answer period, allowing for a diversity of voices and perspectives to be heard. All sessions were recorded in English and French and are available to view on our website.

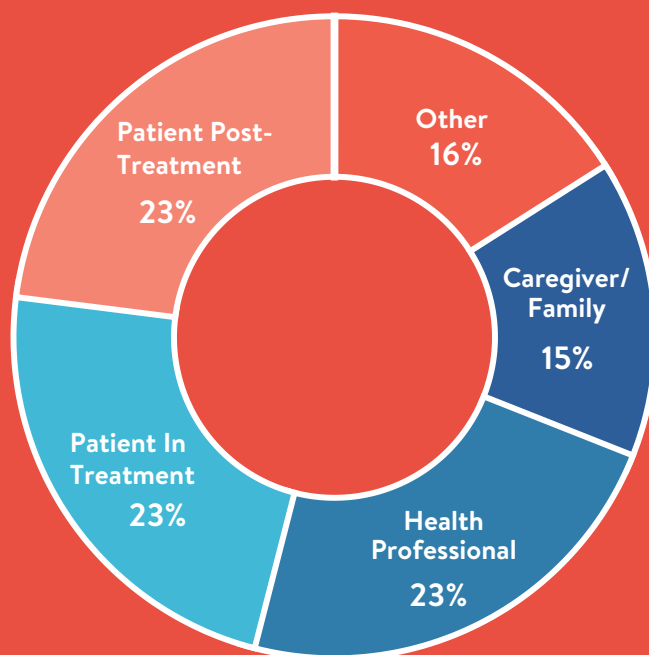


IMPACT

In the post-event survey, 89% were either very or extremely satisfied with the conference!

- 11 videos available on the website
- 150 participants
- **VALUE:** Comments from people who wished they had known about the information shared earlier in their cancer journey
- Accomplished our goal of bringing diverse stakeholders together, see chart:

TYPE OF REGISTRANT





**A RECENT STUDY BY
CANADIAN AND UK
RESEARCHERS SUGGESTS
THAT FOR EVERY MONTH
THAT CANCER TREATMENT
IS DELAYED, MORTALITY CAN
INCREASE BY 10 PER CENT**

READY FOR THE NEXT ROUND

Our 2019 Covid survey, and broader reports, indicated the cancellation or delay of medical treatment increased stress and danger to cancer patients. Cancer screening delays lead to worse patient outcomes. In response to interruptions in cancer care delivery, CCC developed the Ready for the Next Round campaign to advocate for greater resilience in the cancer care system, and to ensure that future crises do not interrupt essential care.

With a program plan in place until 2023, we launched the campaign in conjunction with Colorectal Cancer Awareness Month this past March, sharing an impactful video on social media and through paid placements in the *National Post* and other Postmedia digital properties.

CCC will hold four Thought Leader Roundtables with patients, researchers, healthcare system experts, and physicians to gather information, suggestions, and input on system change. We will publish a report on these roundtables, and expand the campaign to propose tangible policy changes with health ministries, healthcare administrators and health professionals.



FINANCES

At a glance, our revenue for the fiscal year ending June 2021 was \$ 1,273,476 and our expenses were \$ 1,168,821. This is a decrease from FY 2020, with revenues of \$ 1,749,657 and expenses of \$ 1,773,332

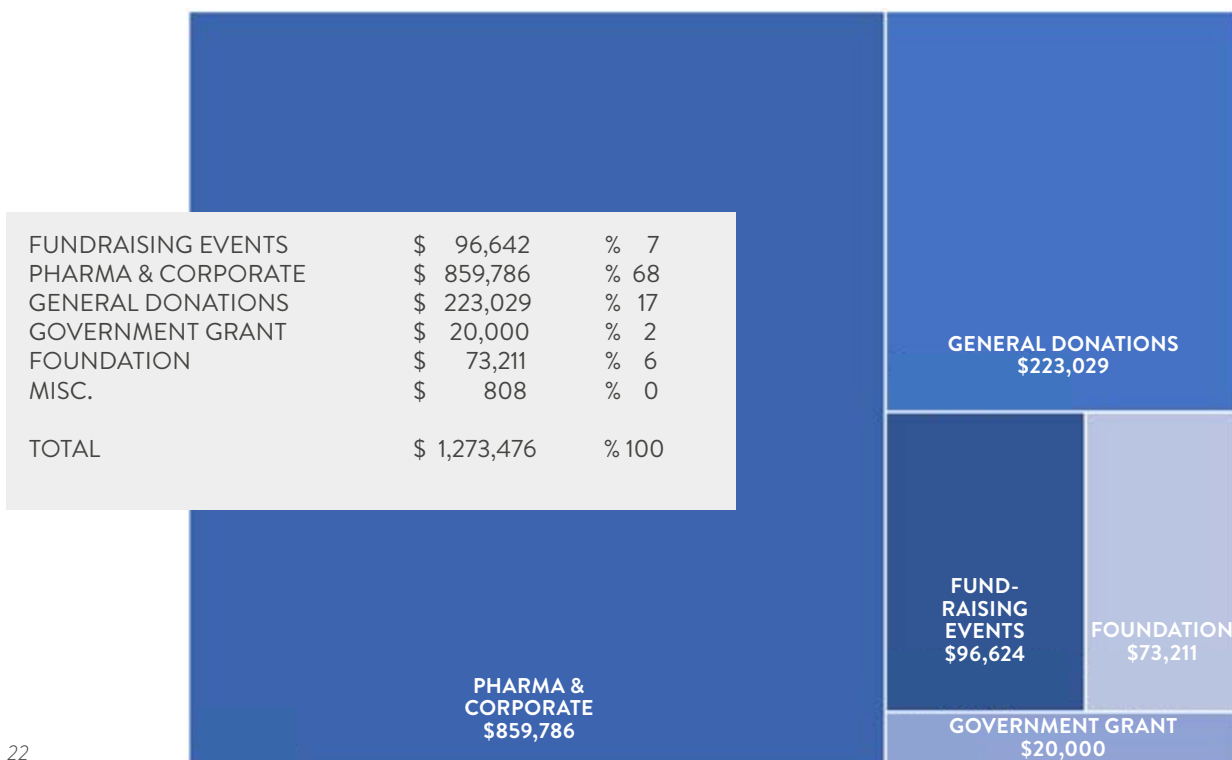
This follows the reduced activities in programming and fundraising brought on by COVID. For the full audited financial statements for 2020 and 2021, please refer to our website.

TOTAL EXPENDITURES BY ACTIVITIES FOR YEAR ENDED JUNE 30, 2021

| | Total Expenditures | Management & General | Programs | Fundraising |
|------------------------------------|---------------------|----------------------|----------------|---------------|
| Salaries & benefits | \$ 398,576 | 14,898 | 362,331 | 21,347 |
| Rent | \$ 80,108 | 3,228 | 76,880 | 0 |
| Office & general | \$ 92,857 | 40,187 | 46,174 | 6,496 |
| Program materials | \$ 239,581 | 0 | 239,581 | 0 |
| Fundraising | \$ 15,965 | 0 | 0 | 15,965 |
| Purchase services | \$ 317,465 | 43,952 | 273,513 | 0 |
| Professional fees | \$ 24,268 | 24,268 | 0 | 0 |
| Board & volunteer development | \$ 0 | 0 | 0 | 0 |
| Total expenses | \$ 1,168,821 | 126,533 | 998,480 | 43,808 |
| % to the total expenditures | 100% | 11% | 85% | 4% |

*Program expenditures include management and other CCC personnel directly involved in the development, planning and implementation of program activities.

TOTAL REVENUE BY SOURCE FOR YEAR ENDED JUNE 30, 2021

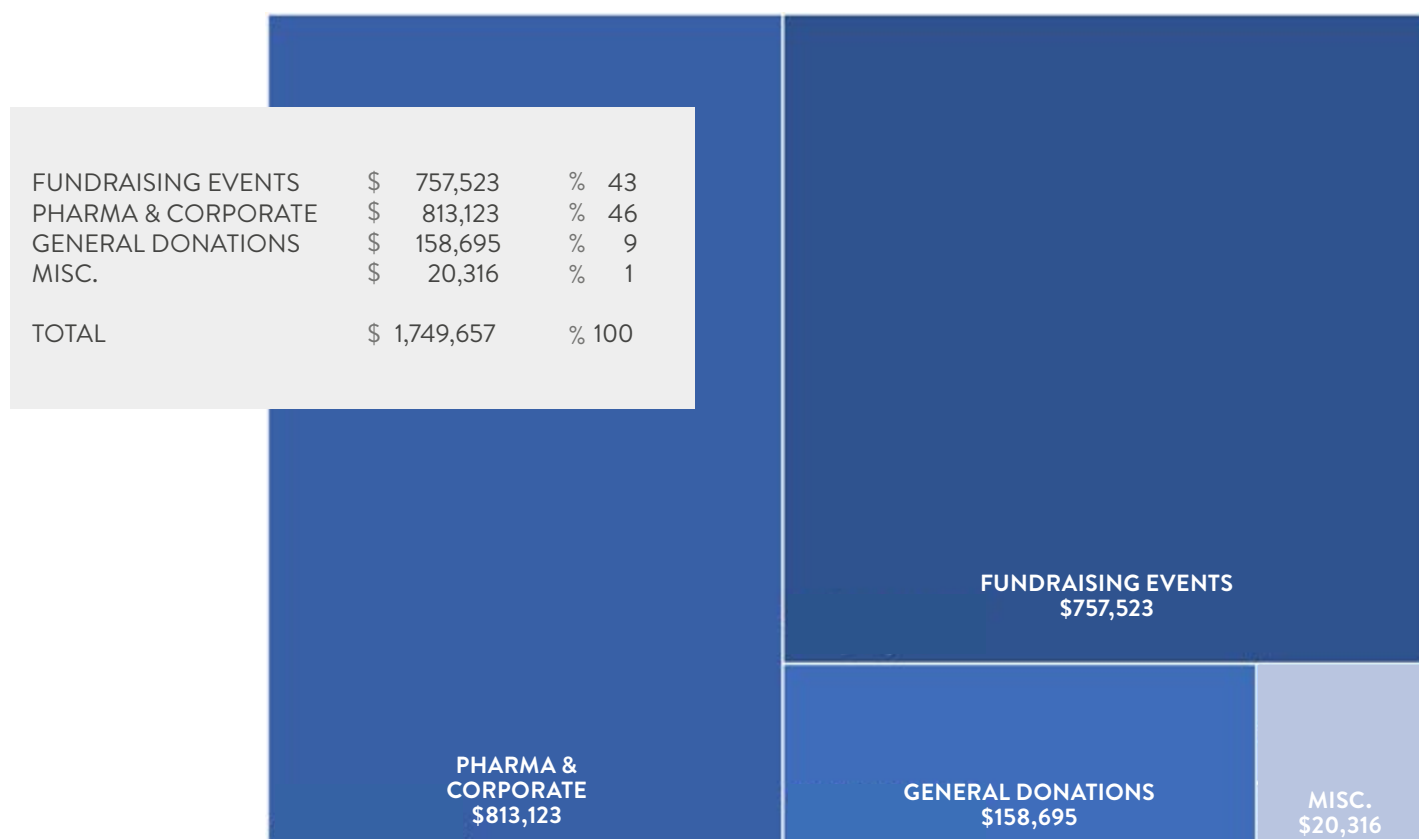


TOTAL EXPENDITURES BY ACTIVITIES FOR YEAR ENDED JUNE 30, 2020

| | Total Expenditures | Management & General | Programs | Fundraising |
|------------------------------------|---------------------|----------------------|------------------|----------------|
| Salaries & benefits | \$ 408,921 | 72,903 | 310,373 | 25,645 |
| Rent | \$ 123,112 | 15,391 | 107,721 | 0 |
| Office & general | \$ 112,523 | 47,748 | 64,551 | 224 |
| Program materials | \$ 285,575 | 3,330 | 265,826 | 16,419 |
| Fundraising | \$ 496,226 | 0 | 0 | 496,226 |
| Purchase services | \$ 318,810 | 45,297 | 273,513 | 0 |
| Professional fees | \$ 28,165 | 28,165 | 0 | 0 |
| Board & volunteer development | \$ 0 | 0 | 0 | 0 |
| Total expenses | \$ 1,773,332 | 212,834 | 1,021,984 | 538,514 |
| % to the total expenditures | 100% | 12% | 58% | 30% |

*Program expenditures include management and other CCC personnel directly involved in the development, planning and implementation of program activities.

TOTAL REVENUE BY SOURCE FOR YEAR ENDED JUNE 30, 2020



APPENDICES

ORGANIZATIONAL STRUCTURE

Colorectal Cancer Canada is led by a volunteer Board of Directors. Our board includes colorectal cancer survivors and caregivers, business professionals, lawyers, researchers and a communications expert. All members of our Board of Directors reside in Canada.

The CCC team is a dynamic group representing diverse experiences and expertise with backgrounds in law, management, medical research, communications, social work, science and public health. Our team is able to respond to multifarious needs and develop robust programs across vital areas of importance to colorectal cancer patients. Many are themselves cancer survivors or caregivers, with a keen understanding of the importance of the work CCC pursues. Each year, CCC staff also mentor a number of student and recent-graduate interns across different fields and programs.



TEAM

BARRY D. STEIN
President

BUNNIE SCHWARTZ
Co-Founder

CAROLE BROHMAN
Executive Director

MARIA EL BIZRI
Program Manager

MAGDA FIELD
Social Media/Administrative Coordinator

CHANA COHEN
Patient Support Specialist

LOUISE WARDROP
Manager, Marketing Events

ELIYA FARAH
Program Manager

IRIS KARRY
Research Analyst

MAY KARRY
Comptroller

BOARD OF DIRECTORS

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President & CEO

Garry Sears
Secretary

Sarita Benchimol

Martin Gosselin

Ellen Walker-Matthews

Melvin Mogil

Alan Peters

Vito Curalli

Elaine Gallagher

MEDICAL ADVISORY BOARD

The CCC Medical Advisory Board ensures our programs are in line with the best available science from development through to deployment, and serve as a vital connection between our patient oriented work and the medical community.

Dr. Pierre Major
Medical Oncologist and Chair of
CCC Medical Advisory Board,
Hamilton Regional Cancer
Center, Hamilton, ON

Dr. David Armstrong
Gastroenterologist, McMaster
University Medical Centre,
Hamilton, ON

Dr. Shady Ashamalla
Surgical Oncologist, Sunnybrook
Health Sciences Centre,
Toronto, ON

Dr. Oliver Bathe
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Charbonneau Cancer Institute,
Calgary, AB

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General Hospital, Montreal, QC

Dr. Sylvie Bourque
Medical Oncologist, Fraser
Valley Cancer Centre,
Surrey, BC

Dr. Robin Boushey
Surgical Oncologist, The Ottawa
Hospital Regional Cancer
Centre, Ottawa, ON

Dr. Christine Brezden-Masley
Medical Oncologist, St.
Michael's Hospital, Toronto, ON

Dr. Ron Bridges
Researcher, University of
Calgary, Gastrointestinal
Research Group, Calgary, AB

Dr. Margot Burnel
Medical Oncologist, Saint John
Regional Hospital,
Saint John, NB

Dr. Sami Chadi
Surgical Oncologist, Princess
Margaret Cancer Center,
Toronto, ON

Dr. Eric Chen
Medical Oncologist, Princess
Margaret Cancer Centre,
Toronto, ON

Dr. Zane Cohen
Director of Zane Cohen Centre
for Digestive Diseases, Mount
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Dr. Bruce Colwell
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Sciences Centre, Halifax, NS

Dr. Christine Cripps
Medical Oncologist, The Ottawa
Hospital Regional Cancer
Centre, Ottawa, ON

Dr. Robert Dinniwell
Radiation Oncologist, Princess
Margaret Cancer Centre,
Toronto, ON

Dr. Sam Elfassy
Gastroenterologist, St. Joseph's
Health Centre, Toronto, ON

Dr. Mary Jane Esplen
Psychosocial Oncologist,
Princess Margaret Cancer
Centre, Toronto, ON

Dr. Margaret Fitch
Clinical Epidemiologist,
Sunnybrook Health Sciences
Centre, Toronto, ON

Dr. William Foulkes
Geneticist, Jewish General
Hospital, Montreal, QC

Dr. Steven Gallinger
Surgical Oncologist, Mount Sinai
Hospital, Toronto, ON

Dr. Carman Giacomantonio
Surgical Oncologist, QEII Health
Sciences Centre, Halifax, NS

Dr. Sharlene Gill
Medical Oncologist, BC Cancer
Agency, Vancouver, BC

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Physician, Charleswood Medical
Clinic, Winnipeg, MB

Dr. Robert Hilsden
Researcher, Southern Alberta
Cancer Research Institute,
Calgary, AB

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Surgical Oncologist, Sunnybrook
Health Sciences Centre,
Toronto, ON

Dr. Yoo Joung Ko
Medical Oncologist, Sunnybrook
Health Sciences Centre,
Toronto, ON

Dr. Michael Kolber
Physician, Edmonton, AB

Dr. Monika Krzyzanowska
Medical Oncologist, Princess
Margaret Cancer Centre,
Toronto, ON

Dr. Calvin Law
Surgical Oncologist, Sunnybrook
Health Sciences Centre,
Toronto, ON

Dr. Becky Lee
Naturopathic Physician,
Marsden Centre, Vaughn, ON

Dr. Sender Liberman
Surgical Oncologist, Montreal
General Hospital, Montreal, QC

Dr. Eric Marsden
Naturopathic Physician,
Marsden Clinic, Vaughn, ON

Ms. Celestina Martopullo
Psychosocial Oncologist, Tom
Baker Cancer Centre,
Calgary, AB

Dr. Andrea McCart
Surgical Oncologist, Mount Sinai
Hospital, Toronto, ON

Dr. David Mulder, Thoracic
Surgeon, Montreal General
Hospital, Montreal, QC

Ms. Fiona O'Shea
Palliative Medicine Physician, Dr.
H. Bliss Murphy Cancer Centre,
St. John's, NL

Dr. Terry Phang
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Hospital, Vancouver, BC

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Sciences Centre, Halifax, NS

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Sciences Centre, Halifax, NS

Dr. Carole Richard
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Hôpital Saint-Luc, Montreal, QC

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Medical Oncologist, North York
General Hospital, Toronto, ON

Dr. Andrew Scarfe
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Cancer Institute, Edmonton, AB

Dr. Lucas Sideris
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Maisonnette-Rosemont,
Montreal, QC

Dr. Andrew Smith
Surgical Oncologist, Sunnybrook
Regional Cancer Centre,
Toronto, ON

Dr. Stephanie Snow
Surgical Oncologist, QEII
Hospital, Halifax, NS

Dr. Jennifer Spratlin
Medical Oncologist, Cross
Cancer Institute, Edmonton, AB

Dr. John Srigley
Pathologist, Credit Valley
Hospital, Mississauga, ON

Dr. Deborah Terespolsky
Geneticist, Credit Valley
Hospital, Mississauga, ON

Dr. Jean-Luc C. Urbain
Radiologist, Wake Forest
University Baptist Medical
Center, Winston Salem, NC

Dr. Ramses Wassef
Surgeon, CHUM-Hôpital Saint-
Luc, Montreal, QC

Dr. Petra Wildgoose
Family Physician, Sunnybrook
Hospital, Toronto ON

Dr. Clarence Wong
Gastroenterologist, Royal
Alexandra Hospital,
Edmonton, AB

Dr. Rebecca Wong
Radiation Oncologist, Princess
Margaret Cancer Centre,
Toronto, ON

Dr. Huiming Yang
Healthy Living and Medical
Director, Screening, Alberta
Health Services, Calgary, AB

Dr. Rami Younan
Surgical Oncologist, Hotel Dieu,
Montreal, QC



INSTITUTIONAL SPONSORS

These corporate and institutional funders enable many of the CCC programs and goals, and we want to take this opportunity to recognize and thank them.

AbbVie Corporation

Amgen Canada Inc.

AstraZeneca Canada Inc.

Bayer Inc.

BiocanRx

Boehringer Ingelheim (Canada) Ltd.

Bristol-Myers Squibb Canada Inc.

Canexia

Eli Lilly Canada Inc

GlaxoSmithKline

Hoffmann-La Roche Ltd.

Innovative Medicines Canada

Janssen Inc.

LifeLabs

Merck Canada Inc

Novartis Pharmaceuticals Canada Inc.

Pendopharm

Pfizer Canada Inc.

Taiho Pharma Canada Inc.

ThermoFisher

THANK YOU!

PARTNER ORGANIZATIONS

1. Biomarking/molecular profiling - The Beat Cancer Coalition.
2. Biosimilars- CCC collaboration with the Education Committee of the pan Canadian Oncology Biosimilars Initiative with Cancer Care Ontario (pCOBI) and with the Quebec Ministry of Health on Biosimilars (MSSS).
3. Drug reimbursement - CCC regularly provides input to CADTH (pCODR) and INESSS providing the patient perspective to expert committees' evaluating new cancer treatments for reimbursement and well as treatment algorithms.
4. Health policy in cancer prevention and screening - CCC was a founding member of and sits on the Canadian Partnership against Cancer's (CPAC) National Colorectal Cancer Screening Network (NCCSN).
5. Access to data – IQVIA advisory panels and providing input on BIG Data and other issues to improve the health of Canadians.
6. Quebec Government Panels (PQC) - CCC works with the Comité national des milieux communautaires en cancérologie to provide insights to the Quebec government Programme Québécois Cancérologie.
7. Transforming Healthcare in Canada Providing insight on a Board level to the Canadian Personalized Healthcare Innovation Network (CPHIN) that visions a healthcare system enabled by data and innovation to improve health outcomes for Canadians.
8. Participant in Canada Health 2030 Visioning the future of health care in Canada.
9. Clinical Trials Networks - Provides insight on the Board of Directors of clinical trial networks such as Exactis Innovation.
10. Consortium de recherche en oncologie clinique du Québec (Q-CROC) and brings the patient perspective to Quebec Clinical Trials and helped to create the Quebec CRC Community of Practice in Clinical Trials.
11. Participates as a Patient advisor to the Terry Fox Marathon of Hope patient committee.
12. Patient Stakeholder Group with BioCanRX.
13. Cancer Research Projects - Provides the patient perspective as collaborators and often as investigators in many Canadian Institutes of Health Research (CIHR) funded cancer research projects.
14. Health Technology Assessment - Provides insights on patient preferences and other patient perspectives to international health technology assessment bodies such as the International Society for Pharmacoeconomic and Outcomes Research (ISPOR) and Health Technology Assessment International (HTAi) as part of its Patient and Citizen Involvement Group (PCIG)
15. Coalitions - CCC takes a leading role in various cancer group coalitions such as the Coalition Priorité cancer au Québec in Quebec and CONECTed across Canada and internationally in the Global Action for Cancer Patients (GACP) and the Global Colon Cancer Association (GCCA) as well as the US based GI Alliance and partners with numerous other colorectal/bowel cancer associations internationally.
16. Industry Panels - Provides patient group insights on Health Policy in Canada to Innovative Medicines Canada and other Industry Panels both in Canada and Globally.
17. Resiliency in Healthcare Systems – Member of the Steering Committee of the Resilient HealthCare Coalition.
18. Canadian Health Research Forum, founding member of representing cancer patients with multiple leading cancer research organizations and institutes to advance cancer research in Canada.
19. Value Based HealthCare – Member of the Advisory Committee Meeting for VBHC Canada Colorectal Cancer Demonstration Project Initiative in Colorectal Cancer.
20. Patient advisor to the International Grand Challenge CRC Research on the Microbiome (OPTIMISTICCC.org) Cancer Research UK (CRUK).