

Canadian Breast Cancer Network Réseau canadien du cancer du sein



Annual Report 2024

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About CBCN

The Canadian Breast Cancer Network (CBCN) exists to ensure the best quality of life for people in Canada diagnosed with breast cancer.

CBCN is Canada's leading patient-directed breast cancer health charity that voices the views and concerns of breast cancer patients through the promotion of information sharing, education, and advocacy activities.

Our **Patient Education** provides current, credible, and accessible breast cancer resources that are delivered through digital platforms, navigation tools, print materials, and patient centered events.

Our **Patient Advocacy** ensures that the patient experience, values and perspectives inform policy and guide research.

Our **National Network** connects patients, caregivers, healthcare professionals, researchers, public health agencies, and industry stakeholders to improve knowledge translation and promote optimal health outcomes for Canadians with breast cancer.



By the Numbers

Website Users

238,863

Blog Visits

180,522

Newsletter Subscribers

6,154

Social Media Followers



Website Pageviews

447,589

Individuals We Provided Direct Navigation Support To

68

CBCN Network Support Group Members

581

2024 Priorities



CBCN's 2024 priorities were to:

Promote the Patient Voice: Ensure the lived experiences of patients informed policy decisions, resource development, and educational programming for patients.

Health Equity: Address the needs of vulnerable populations through community capacity building and community specific resources.

Shared Decision-Making: Support patients in understanding their diagnosis, treatment options, and advocacy mechanisms to enable them to participate in shared decision-making with healthcare providers.

Health Policy: Ensure the lived experience of patients is considered and informs drug regulators, health technology assessment agencies, and policy.

Treatment Access: Ensure patients have equitable access to appropriate therapies that are available in Canada as new treatments emerge.

These priorities were supported and addressed through our Patient Education, Patient Advocacy, and National Network pillars.

Our Patient Education

Priorities addressed: Promoting the Patient Voice; Shared Decision-Making

Knowledge Translation

CBCN educated breast cancer patients and their caregivers about breast cancer to help address their educational needs. These resources helped to remove knowledge barriers and enable shared decision-making so that patients have access to optimal care.

Breast Cancer Connection

Breast Cancer Connection is our informative, conversation-based podcast that breaks down complex terms and topics through meaningful discussion with expert voices.

1,286 listens in 2024

7,499 total streams



Our Voices

We developed and published original content relevant to breast cancer patients on Our Voices, CBCN's online blog.

20,952 blog views

Digital Patient Magazines

Our digital patient magazines are curated from articles published on Our Voices and incorporate education, advocacy, and the patient perspective on specific topics of interest for the breast cancer community. In 2024, we published two new digital patient magazines:

Faces of Hope: Navigating Life with TNBC

Redefining Beauty and Appearance After a Breast Cancer Diagnosis

Newly Diagnosed Guides

CBCN Canadian Breast Cancer

CONSIDERATIONS

A guide for older adults with breast

cancer and their

In 2024, we continued to promote and mass-distribute CBCN-developed guides and handbooks to help patients navigate diagnosis, treatment, living with breast cancer, post-treatment, and survivorship. These guides are available online and were also sent to patients and their caregivers, cancer centres, healthcare professionals, and patient educators across Canada in both official languages.



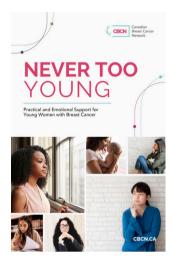
Considerations of Care: A guide for older adults with breast cancer and their caregivers – Newly developed in 2024, this guide offers unique considerations for older adults, and the people that help to care for them, when diagnosed with breast cancer. It includes checklists, questions to guide conversations with healthcare providers, tips on speaking to family and friends about breast cancer, advice for caregivers, and more.

166 digital copies acessed

Breast Cancer and You: A guide for people living with breast cancer, Seventh Edition – This guide is aimed to work as a handbook that can be used by patients and their healthcare team as a personal resource. It includes information on breast cancer staging, diagnostic tests, recommended treatments for each cancer stage, side effects and side effect management, breast reconstruction options, and more.

3,428 physical and digital copies accessed

Never Too Young: Practical and Emotional Support for Young Women with Breast Cancer – Updated in 2024, this resource is CBCN's comprehensive handbook designed to provide the guidance and information needed to support a young woman's emotional wellbeing. It helps young patients navigate conversations with family and friends, maintain a healthy lifestyle, address fertility concerns, access practical resources for support, and more.



1,074 physical and digital copies accessed

Metastatic Breast Cancer Handbook: A guide for individuals living with stage IV breast cancer - This guide explains stage IV breast cancer, existing and upcoming treatment options and their side effects, clinical trials, and complementary therapies to relieve stress and anxiety. It teaches patients how to speak effectively about their concerns with their healthcare providers and helps them understand their diagnosis so that they can be actively involved in their treatment and care.

974 physical and digital copies accessed

Digital Navigation Tools

CBCN's educational navigation tools are digital-only resources that guides breast cancer patients and their caregivers through aspects of their diagnosis, treatment, and care to support informed and shared decisionmaking. In 2024, we continued to promote these tools to ensure patients' education needs were met.

PatientPath – PatientPath is CBCN's most recently launched digital patient navigation tool, and it provides patient-friendly information at critical decision-making points on the patient journey.



"I wish I had this 18 years ago." – Breast cancer patient on CBCN's PatientPath

SurgeryGuide – SurgeryGuide is CBCN's decision aid that is meant to navigate patients through the various surgery and post-surgery options and provide them with the information that they need to make treatment and care decisions with their doctor.

1,238 digital views

Information Sharing

In 2024, we continued our commitment to educate the breast cancer patient community about innovative therapies, the latest research, and relevant breast cancer-related news to keep them informed with up-to-date information about the latest treatments, research, and breast cancer-related news. We updated the breast cancer patient community through our bilingual website, our social media channels, our monthly newsletters, and another resources and platforms.

Clinical Trials Connected



Breast cancer clinical trials play a large role in the discovery of new treatments for breast cancer. The results from them can help to determine the safety and effectiveness of potential new treatments compared to the current standard-of-care, leading to more optimal cancer care. Unfortunately, it has been reported that less than 5% of adult cancer patients enroll in clinical trials, whether due to lack of awareness, lack of understanding about clinical trials, or fears. Similarly, patients might not be aware of all the latest research and data coming from innovative clinical trials and studies.

To address these gaps, in 2024 we launched Clinical Trials Connected, our newsletter that broadly disseminates information on innovative breast research, as well as breast cancer trials that are recruiting across Canada. This new resource increase patients' knowledge of oncology research, supports knowledge translation, enables shared decision-making, encourages clinical trial enrollment, and helps patients be part of their healthcare team.

Virtual Education Sessions

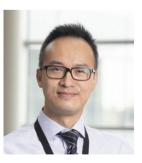
In 2024, we hosted virtual education sessions on a variety of topics relevant to breast cancer patients and their caregivers.

"Patients are finding [the webinars] so useful." - Clinician in Ottawa

Education Webinars – CBCN hosts several Education Webinars each year to help address the educational needs of patients and caregivers. The purpose of these sessions is to allow participants to connect with, and access the knowledge of, leading healthcare experts to help inform their own treatment decisions and the overall management of their breast cancer diagnosis. In 2024, we hosted the following sessions:



Advancements in care and treatment for earlystage breast cancer with Dr. Nancy Nixon, MD FRCPC



Advancements in care and treatment for triple negative breast cancer with Dr. Terry Ng, MD FRCPC

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"As a triple negative, stage 3 [patient] having had chemo, surgery, and radiation almost 4 years later, the information is of great interest and very important." – Advancements in care and treatment for TNBC webinar attendee



Advancements in care and treatment for metastatic breast cancer with Dr. Mita Manna, MD FRCPC



Understanding Your Diagnosis Workshops: Understanding a pathology report with Dr. Jason Wasserman, MD FRCPC and Deconstructing clinical trials with Dr. Jan-Willem Henning, MD FRCPC



Tough Topics in Cancer: Sexual health and intimacy with Dr. Melanie Atlas, MD FRCSC; Onco-fertility with Dr. Jeffrey Roberts, MD FRCSC; Genetic testing with Dawn Siciliano, MSc CCGC

640 Total registrations for all virtual education sessions



Total on-demand views for all virtual education sessions

Questions and Experts Series – A breast cancer diagnosis comes with many questions and patients may not have enough time at appointments to have some of these questions answered. To help address this, CBCN developed a Q&E: Questions and Experts series. During these sessions, the expert guest speaker uses the entire session to answer questions submitted in advance and asked live. In 2024, we hosted the following sessions:



Dr. Kasia Jerzak, MD FRCPC answered questions about metastatic breast cancer



Dr. Joy McCarthy, MD FRCPC and Scott Edwards, PharmD, MSc (Oncology) answered questions about navigating side effects from systemic treatment

193 Total registrations for all Q&E sessions

153

Total on-demand views for all Q&E sessions

MedSearch

We updated MedSearch as needed to ensure patients and caregivers had the latest information on breast cancer treatments available in Canada. MedSearch is our digital navigation tool that allows individuals to easily find information about which breast cancer drugs are available in Canada, which are publicly funded, which provinces and territories fund them, and more.

1,916 digital views

Our Patient Advocacy

Priorities addressed: Promoting the Patient Voice; Health Equity; Health Policy; Treatment Access

Engaging the Patient Voice

CBCN involved the experience and voice of breast cancer patients in the inputs and submissions we put together to inform health policy reforms and other relevant inputs. Our overall work in this space was to ensure patient access to innovative therapies and adequate healthcare, as well as to ensure that patient values and priorities were part of decision-making process of government officials, health technology assessment agencies, and other regulatory bodies. In 2024, we:

- Submitted over 13 inputs to the Canadian Drug Agency (CDA), L'Institut national d'excellence en sante et en service sociaux (INESSS), Health Canada, the Patented Medicine Prices Review Board (PMPRB), and other stakeholders.
- Wrote over 20 letters to government officials as part of our efforts to address and enhance equitable access to breast cancer drugs.



Other health policy and health equity initiatives we achieved in 2024 included:

- inputs to Health Canada, through Clinical Trials Ontario (CTO), on decentralized clinical trials and on expanded access to clinical trials
- input to PMPRB, through Best Medicines Coalition (BMC), on PMPRB's discussion guide
- a position statement, through BMC, on national pharmacare
- input to CDA on their funding algorithm procedure
- connecting patients to Cancer Action Now Alliance (CANA)'s Waiting to be a Priority campaign

Sharing the Patient Voice

We also used our online blog, Our Voices, as a platform to share patient and caregiver stories to show the varied experiences and impacts of a breast cancer diagnosis.





The top five most viewed patient stories published in 2024 were:



Dense Breast Tissue and Lobular Cancer - Doubly Hard to Diagnose by Karin



Can You Do the Tamoxifen Time? and The Must-Know Info About Early-Stage Breast Cancer both by Adriana Ermter



For Lorraine's Sake by Chrisanne Pennimpede



Why Stopping Cancer Treatment Can Be About Living, Not Dying by Kitt Ritchie

Addressing Health Equity

At CBCN, we recognize that there are vast inequities in cancer care that impact some groups more than others. In 2024, we continued our ongoing efforts of advocating for equitable access to innovate therapies to ensure that patients, regardless of where they live in Canada, have access to the same level of adequate care. We also addressed the needs of individuals diagnosed with triple negative breast cancer (TNBC), raised awareness about the less known facts about breast, and supporting individuals who might be facing negative financial impacts from their diagnosis.

TNBC Awareness Campaign

In 2021, CBCN began an initiative to better understand the unique needs of people diagnosed with TNBC. The overall project, with a specific focus on the findings from the survey, was published in an executive summary report. In 2023, CBCN began broadly disseminating the report and its findings to raise awareness of the unique needs of individuals diagnosed with TNBC. In 2024, we continued our outreach and work in this space. Here's what we achieved in 2024 for this campaign:

- Shared the report with 150+ stakeholders
- Had 25+ meetings with stakeholders
- Published 2 op-eds on the needs of the TNBC population



- Presented 2 posters at conferences using data from the original survey
- Sent letters calling for advocacy and increased education to government officials in three provinces

Following input from individuals diagnosed with TNBC, we created a TNBC hub on our website to make finding quality resources on TNBC easier and we were honored that following our meeting with MP Zarrillo, she delivered a statement about breast cancer awareness and TNBC in the House of Commons during Breast Cancer Awareness Month.

Breast Cancer 102 Campaign



While breast cancer awareness month (BCAM) is usually associated with raising awareness around prevention, early detection, and treatment, we began our Breast Cancer 102 campaign in October 2024, and it explores the lesser-known aspects and far-reaching impacts of a breast cancer diagnosis that often go unnoticed. Our Breast Cancer 102 goes beyond the basics, shedding light on the complexities,

from the emotional toll to the financial burden, and the barriers to equitable care for marginalized groups. Throughout BCAM 2024, we shared stories, insights, and facts about breast cancer, and we invited others to join the conversation.



"As a breast cancer patient[,] I especially relate to all of the content. It will be such a help to many. Thanks for all your hard work." - Community member

FinancialNavigator

FinancialNavigator is CBCN's navigation tool that helps patients and their caregivers find sources of financial assistance to offset the financial burden of a cancer diagnosis. In 2024 we updated this database with new programs and promoted it to those in our community to keep patients and their caregivers aware of financial supports that may be available to them.

3,182 digital views

Enabling Self-Advocacy

In 2024, CBCN remained dedicated to helping patients become active participants in their care. While we advocate on behalf of all breast cancer patients, we also develop tools to enable patients to advocate for themselves.

Advocacy Guides

Our Advocacy Guides which are short booklets that take a deep dive into a specific topic as a means to provide patients with the knowledge and tools to become part of their healthcare team. In 2024, we published two advocacy guides:

Connected Care - Accessing Your Electronic Health Records

Understanding Breast Density



Our National Network

Priorities addressed: Promoting the Patient Voice, Health Equity, Health Policy, Treatment Access

Collaborating and Engaging with Stakeholders

In 2024, CBCN continued as members of various patient advocacy groups to bring about optimal healthcare reforms. Our involvement with these and other relevant stakeholder groups addressed cancer and overall health equity, as well as enabling timely and equitable access to treatment and care. We also address these concerns by engaging with federal and provincial decision-makers.

Lastly, we connected patients and caregivers in our community with over 20 opportunities with media relations, government, industry partners, researchers, and other relevant stakeholders to share the lived experiences of a cancer diagnosis.

Knowledge Building and Sharing

In order to continue providing the most current information and resources available to the breast cancer community, it is important that we stay engaged with healthcare professionals and stay aware of the latest news, advancements, clinical trials, and research in oncology. In 2024 we attended several local, national and international events to support this work. We also had the privilege of sharing our work at the following events:

Canadian Centre for Applied Research in Cancer Control (ARCC) where we shared a poster titled "Assessing the Availability and Quality of Educational Resources for Canadians Diagnosed with Breast Cancer".

Juravinski Hospital & Cancer Centre's Life After Breast Cancer event where we shared our various resources with individuals who had been diagnosed with breast cancer.

Canadian Association of Nursing Oncology (CANO) where we shared a poster titled "Personalizing Canadian Breast Cancer Patients' Understanding of their Treatment Path".



CCRAN's Early Age of Onset Cancer Symposium where we shared information on our guide for young women diagnosed with breast cancer, Never Too Young: Practical and Emotional Support for Young Women with Breast Cancer.

San Antonio Breast Cancer Symposium where we shared a poster titled "Does Age Impact Patient Involvement in Treatment Decision Making: Results from the Canadian Breast Cancer Network (CBCN) Assessment Project".

Our 30th Anniversary





2024 marked the 30th anniversary of CBCN.

In 1992 the House of Commons published a report entitled Breast Cancer: Unanswered Questions, and one of its recommendations resulted in the National Forum on Breast Cancer, which was held in Montreal in November 1993. With Health Canada support under the leadership of Monique Bégin, the Canadian Breast Cancer Network (CBCN) was facilitated, helping to coordinate a network of smaller organizations into a cohesive group focused on breast cancer advocacy and support. CBCN was officially incorporated and registered as a charitable organization in November 1994.



For the past 30 years, CBCN has been at the forefront of educating, advocating for, and supporting individuals diagnosed with breast cancer in Canada. Guided by a vision to ensure the best quality of life for people affected by breast cancer, CBCN has implemented a wide range of initiatives aimed at amplifying patient voices, enhancing patient education, and influencing health policy and research.

Additionally, having a volunteer board of directors led by those with personal and familial experience with breast cancer ensures that the leadership and direction of CBCN are guided by individuals who have a personal understanding of the challenges faced by those affected by breast cancer.

From foundational support from Health Canada to leadership driven by those with direct experience with breast cancer, CBCN is an organization that remains deeply connected to its roots and mission.

In commemoration of our 30-year anniversary, we highlighted snapshots of our past accomplishments in patient education, advocacy, and networking. These achievements reflect CBCN's dedication to its mission of voicing the views and concerns of breast cancer patients by promoting information sharing, education, and advocacy.

"Truly grateful for the remarkable work that you do supporting those affected by breast cancer. Congratulations on 30 years of supporting this important cause." – Community member

Our Team

Board of Directors

Cathy Ammendolea, Chair Juliette Inglis Suzanne Leblanc Judy Donovan Whitty Quinn Obrigewitch Khalilah Elliott Chhavi Sikri

Patient Ambassadors

Christine McKay Jaclyn Carter Elizabeth Barnes

Medical Advisory Board

Dr. Mark Basik, MD FRCSC Dr. David Cescon, MD PhD FRCPC Dr. Karen Gelmon, MD FRCPC Dr. Sandeep Sehdev, MD FRCPC

Staff

Bukun Adegbembo, Director of Operations Rebecca Armstrong, Director of Patient Education and Engagement Erika Cao, Communications and Administrative Coordinator JK Harris, Health Policy and Advocacy Lead Wendy Hall, Outreach Coordinator

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We also acknowledge and are grateful to all our individual donors, employee donation programs, companies and corporations, and so much more.