

ANNUAL REPORT

2021



Canadian Breast Cancer Network
Réseau canadien du cancer du sein



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ABOUT CBCN

The Canadian Breast Cancer Network (CBCN) exists to ensure the best quality of life for all Canadians 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 **National Network** connects patients, caregivers, health care professionals, researchers, public health agencies and industry stakeholders to improve knowledge translation and promote optimal health outcomes for Canadians with breast cancer.

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



By the Numbers

396K+

Website users

4.5K+

Newly diagnosed guides
distributed and accessed
online

637K+

Website pageviews

2K+

New email
subscribers

7.1K+

Social media
followers

5.2K+

Navigational tool
visits

421K+

Blog visits

IMPROVING DRUG ACCESS

CBCN is dedicated to ensuring that Canadians affected by breast cancer have fair and equitable access to essential treatments, focusing our advocacy efforts on access and coverage. **MedSearch**, our navigation tool that provides general information about the various treatments for breast cancer, was created so that patients can track breast cancer drugs available in Canada and funded in their province or territory.



In 2021, MedSearch was updated with



We were also engaged in the following efforts related to breast cancer drug access for Canadians in 2021:

- Connected 10 people living with HER2+ metastatic breast cancer with AstraZeneca to participate in a patient advisory board to help inform their launch of trastuzumab deruxtecan (Enhertu) in Canada
- Connected with L'INESSS about the restricted access to palbociclib (Ibrance)
- Wrote letters to the Ministry of Health in Quebec, advocating for access to a new mBC therapy not listed on the provincial formulary
- Provided patient submissions to Canadian health technology assessment agencies for 4 breast cancer treatments

ADDRESSING FINANCIAL EQUITY

CBCN acknowledges that those affected by breast cancer come from diverse cultural, linguistic, social, economic, geographic, and family backgrounds. One of the ways that we address financial diversity, the economic disparities across Canada, and the financial burden that comes with a breast cancer diagnosis is through **FinancialNavigator**. FinancialNavigator is our navigation tool that can help patients and their families find sources of financial assistance to offset the financial burden of a cancer diagnosis.



In 2021, we updated FinancialNavigator with the following financial assistance programs:

- Nerlynx Patient Support Program from Knight Therapeutics Inc.
- Trastuzumab (Ogivri) Patient Support Program from Mylan Pharmaceuticals
- Compassion Fund from Lymphedema Association of Ontario
- Karen J. Wiederkehr Memorial Fund from Whitehorse General Hospital
- Kingston Financial Assistance Program from Breast Cancer Action Kingston

ENGAGING THE PATIENT VOICE

The voice and perspective of breast cancer patients are central to the work that CBCN does. We do this by empowering patients to find their voice and by creating resources that are informed by the patient voice.

PATIENTPATH

In 2021, CBCN began putting together **PatientPath**, our newest navigation tool that will walk patients through what to expect and the standard of care depending on where they are in their breast cancer diagnosis. Since the patient voice and perspective is important to include in the work that we do, we created a Patient Advisory Board to inform PatientPath. Doing so ensures that the resources we develop reflect the lived experiences of breast cancer patients across Canada.

DIGITAL ADVOCACY AND STORYTELLING TOOLKIT



Our ***Digital Advocacy and Storytelling Toolkit*** was launched this year as a toolkit that provides patients and their families, as well as caregivers, with the resources and guidance needed to advocate for causes that are important to them. This toolkit helps patients identify their issue, craft how to advocate for their issue via telling their story and helps them determine the appropriate avenue to tell their story as well as the actions to take as the next steps.

OUR VOICES

Our Voices is our online blog that provides patients with a platform to share their experiences in their own words and to inspire others who may have gone through or may be going through something similar.

23

Stories shared from patients about various parts of their breast cancer experience



Our most read English blog post was a patient story:
Why Tamoxifen is a Pain in my Ass and Other Bodily Infractions



26K+

Views

EDUCATING PATIENTS

CBCN provides current, credible, and accessible breast cancer resources that are delivered through digital platforms, navigation tools, print materials, and patient-centered events.



CBCN's ADVOCACY GUIDES

CBCN's Advocacy Guides 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 breast cancer care team. We published two new advocacy guides, ***Accessing Genetic Testing in Canada*** and ***Accessing Genomic Testing in Canada*** that help patients understand the differences between these tests and how to advocate to access them.

PRECISION ONCOLOGY AND BREAST CANCER

To help understand the different perspectives and values on precision oncology in breast cancer and the role of testing and data, we hosted national virtual roundtables with individuals diagnosed with different types and stages of breast cancer and with oncologists. Our newest health policy paper, ***Precision Oncology and Breast Cancer: Considering Canada's Approach in an Evolving Landscape*** shares observations, key takeaways, and recommendations based on insights collected from these two conversations.



OUR VOICES

Outside of stories from patients, we also published blog posts that provide critical and timely information that are relevant to breast cancer patients, regardless of what stage they are in their diagnosis. CBCN also published various blog posts that teach patients about self-advocacy, finding their voice, and becoming part of their healthcare team.

Our most read French blog post provided information about the COVID-19 vaccines:

Des oncologues vous informent au sujet des vaccins contre la COVID-19



32K+

Views

DIGITAL PATIENT MAGAZINES

Our patient magazines are themed digital magazines that focus on topics of interest to breast cancer patients. In 2021, we published **Talking Palliative Care** which focuses on topics such as pain management, grief, and hospice care. We also put together **COVID-19 and Breast Cancer: Patient Voices, Expert Knowledge** which highlights patient experiences with navigating breast cancer during a worldwide pandemic along with information on COVID-19 for cancer patients from healthcare professionals and experts.



BREAST CANCER CONNECTION

We launched **Breast Cancer Connection**, an informative, conversation-based podcast designed for patients and caregivers alike. Breast Cancer Connection breaks down complex terms and topics through meaningful discussion with expert voices.

Episode 1

Breast Cancer Stages and Types Explained

Episode 2

Recurrence: Terms, Risks, and Steps for Prevention

Episode 3

Breast Cancer and Personalized Care: What You Need To Know

Episode 4

Working With Your Healthcare Team: Tips and Guidance

Episode 5

Coping with Breast Cancer: Through Diagnosis, Treatment, and Beyond



"Very informative podcast. There is not a doubt in my mind that Dr. [Gelmon] saved my life. Thank you." – *Podcast listener on episode 2*

"I'm one year into my journey with breast cancer. I've listened to two of the podcasts. This is the most incredibly helpful resource I've discovered. Thank you." – *Podcast listener*

"Excellent! Well done! We need this!" – *Podcast listener*

"I am so pleased that CBCN can offer important information to patients in a podcast format. The experts that joined us are some of the most knowledgeable professionals in Canada and so freely shared their expertise with us in all of the episodes" – *Cathy Ammendolea, podcast host and Chair of the Board of CBCN*

Q&E: QUESTIONS AND EXPERTS

A breast cancer diagnosis comes with many questions, and there never seems to be enough time at appointments to have some of these questions answered. To address this, CBCN developed a **Q&E: Questions and Experts** virtual series which allows participants to ask any questions they have on the featured topic.

A Medical Oncologist Answers Your Questions About HER2+ Breast Cancer with Dr. Karen Gelmon, MD, FRCPC

A Medical Oncologist Answers Your Questions About HR+ Breast Cancer with Dr. Sandeep Sehdev, MD, FRCPC

A Surgical Oncologist Answers Your Questions About Breast Surgery with Dr. Mark Basik, MD, FRCPC

A Naturopathic Doctor Answers Your Questions About Complementary Therapies with Dr. Dugald Seely, ND

A Drug Access Navigator Answers Your Questions About Accessing Breast Cancer Drugs with Michele MacDonald, RPhT

A Medical Oncologist Answers Your Questions About Triple Negative Breast Cancer with Dr. David Cescon, MD, FRCPC

600+

Session registrations

800+

On-demand video streams

90%

Of survey respondents strongly or somewhat agreed that they have more knowledge about the given topic than they did before the session

68%

Of survey respondents strongly or somewhat agreed that they will use information from this session to inform their treatment decisions

INFORMING OUR WORK

In order to educate breast cancer patients, it is important that we also educate ourselves and that we stay up-to-date on what is happening in oncology, health research, and more. This allows us to be aware of what healthcare professionals are up to and what is coming down the pipelines.



This year, we attended and/or participated in various virtual conferences, including:

- *2021 CADTH Symposium*
- *Advance Breast Cancer Conference (ABC6)*
- *American Society Of Clinical Oncology Congress*
- *BioCanRX Summit*
- *Canadian Association of Nurses in Oncology*
- *Canadian Cancer Research Conference*
- *Cancer Clinical Trials Conference*
- *European School of Medical Oncology Symposium*
- *San Antonio Breast Cancer Symposium*

OUR TEAM

BOARD OF DIRECTORS

Cathy Ammendolea, *Board Chair*, Québec

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Diana Ermel, *Past Chair*, Saskatchewan

Judy Donovan Whitty, Prince Edward Island

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Rebecca Armstrong, *Manager of Patient Education Programs*

Bukun Adegbembo, *Coordinator of Health Policy and Digital Communications*

Wendy Hall, *Publications and Office Coordinator*

MEDICAL ADVISORY BOARD

Dr. Mark Basik, *MD FRCPC* Surgical Oncology

Dr. David Cescon, *MD PhD FRCPC*, Medical Oncology

Dr. Karen Gelmon, *MD FRCPC*, Medical Oncology

Dr. Sandeep Sehdev, *MD FRCPC*, Medical Oncology

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