



**CBCN
RCCS**

Canadian Breast Cancer Network
Réseau canadien du cancer du sein

2017 - 2018 ANNUAL REPORT

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LETTER FROM THE CHAIR



Another year has passed; a year full of growth and progress at CBCN. We've continued to deliver on the important work our community has come to expect while increasing resources that are vital to those of us affected by breast cancer. Yet again, I am so encouraged to see how much we've grown and how our work has impacted Canadians.

CBCN's involvement in research opportunities has been something that I am most excited about! Having a personal interest in research for breast cancer, I was honoured to sit on the steering committee for this year's Canadian Cancer Research Conference hosted by the Canadian Cancer Research Alliance as a patient representative. This year's conference held a significant focus on patient engagement, something quite rare to see, particularly in the research setting. In addition, CBCN was a key partner in two noteworthy studies that highlight research priorities for metastatic breast cancer and breast reconstruction. These studies allowed patients to have a say in highlighting the most important research questions not yet answered by science. While there is still work to do in seeing that the patient voice is represented in breast cancer research, I am encouraged to see progress and proud that CBCN has been a part of it!

We've made some exciting changes to our digital presence, allowing our supportive and educational resources to reach more people who need it. Last year, the launch of our brand-new website was the first step in creating a larger, more impactful digital presence. Our new blog, Our Voices, is the next step in our growth. Our Voices, gives patients the space to share their stories and make others feel less alone in the process.

This year, we launched an in-depth patient survey looking at how breast cancer has shaped us individually. Having had breast cancer myself, it is remarkable to see how unique every woman's story can be and yet, how we still feel a connection to what each other has been through. Thank you to the hundreds of women who participated in our survey for sharing your experiences so openly and honestly. Your insights will help shape our programs for years to come!

I'd like to acknowledge and thank our dedicated board of directors and staff for these impressive achievements. And thank you to our many supporters whose donations and sponsorships have allowed us to continue this growth.

Cathy Ammendolea, Board Chair

BY THE NUMBERS

2,500+

NEWLY DIAGNOSED GUIDES
DISTRIBUTED NATIONALLY

4,000+

E-MAIL SUBSCRIBERS

45K+

WEBSITE VISITS

4,500+

FOLLOWERS



WHAT ARE PEOPLE SAYING?

"I appreciated the opportunity to be a part of this meeting and connect with others around the table. It is so helpful to meet others with Stage IV and hear their stories."

Patti – metastatic breast cancer patient

"Thank you for taking the time to send me so much personalized information."

Katie – breast cancer patient

"Thank you for all you do for the MBC (metastatic breast cancer) community. Together we have increased awareness & support, through this very meaningful and thought-provoking campaign!"

Jody – metastatic breast cancer patient

"I would like to thank you for taking the time to listen to me through this difficult time and for your advice. It was greatly appreciated."

Shawn – spouse of a breast cancer patient



GIVING A VOICE TO CANADIANS WITH BREAST CANCER

REPRESENTING THE *PATIENT PERSPECTIVE*

Providing Patient Input to Canadian Health Technology Assessment Bodies

CBCN provided patient input to the pan-Canadian Oncology Drug Review (pCODR) board for ribociclib (Kisqali), a therapy used for hormone receptor positive (HR+), HER2-negative metastatic breast cancer. We also made a submission to Quebec's Institut national d'excellence en santé et en services sociaux (INESSS) for fulvestrant (Faslodex) a metastatic breast cancer treatment for hormone receptor positive (HR+) breast cancers. Finally, CBCN submitted input on pertuzumab (Perjeta) in combination with trastuzumab (Herceptin) for early stage HER2-positive breast cancer to both pCODR and INESSS. These submissions provide critical input on the needs and challenges of women living with breast cancer in Canada and the importance of being able to access essential treatments that can improve quality of life.

Consulting on Improvements to Regulatory Review Process of Drugs and Medical Devices

CBCN is actively participating in a new Health Canada initiative to review and improve the regulatory review process of drugs and medical devices in Canada. Health Canada has engaged CBCN, along with various other stakeholders, to consult on numerous aspects of this project through in-person and online meetings via WebEx, electronic questionnaires or comments on draft regulations. We have had the opportunity to voice the patient perspective specifically around the barriers of accessing new treatments from long wait times to limited transparency on deadlines for decision-making and the inequitable access across the country. CBCN will continue to provide input where necessary on ways to improve transparency and eligibility for accessing life-saving treatments.

REPRESENTING THE *PATIENT PERSPECTIVE*

Providing Input on Proposed Amendments to the Patented Medicines Regulations

In February of 2018, CBCN participated in the Patented Medicine Prices Review Board (PMPRB) consultation on its proposed amendments to the patented medicines regulations. CBCN continued to share key concerns from the patient community regarding how pricing for patented medicines is established in Canada and highlighted the need to ensure that PMPRB continues to balance innovation with affordability to the benefit of Canadian patients.

Providing Perspectives on National Pharmacare

CBCN has done extensive work on the issue of National Pharmacare this past year. We participated and informed the Canada 2020 Policy Lab on National Pharmacare in May 2018. The Policy Lab brought together stakeholders and experts including government, academics, industry and patient groups to share information and resources related to pharmacare. The final report can be found [here](#).

In addition, CBCN had the opportunity to sit on the steering committee for a joint Pharmacare Policy Report produced by the Best Medicines Coalition, Health Charities Coalition of Canada and the Canadian Pharmacists Association which was released in July 2018 and can be found [here](#).

CBCN continues to represent breast cancer patients on the issue of implementing a national pharmacare program specifically focusing on addressing the numerous challenges patients experience with drug access and to ensure that those with unmet needs are provided for.

BUILDING THE *CAPACITY OF PATIENTS*

Patients in the Media

CBCN worked closely with metastatic breast cancer patients to support their work in highlighting the need for access to Palbociclib in British Columbia. We assisted patients in the development of their key messaging and preparation for media interviews and op-eds. We also spoke to media to give background information on metastatic breast cancer and drug access issues in Canada.

BUILDING THE *CAPACITY OF PATIENTS*

Surveying the Needs and Experiences of Breast Cancer Patients

This year, CBCN launched two patient experience surveys, one for early stage breast cancer and one for metastatic breast cancer. The purpose of these surveys was to capture the full lived experience from detection through to survivorship or living with metastatic breast cancer. These surveys gave Canadians an opportunity to voice their experiences and share what they feel is lacking in terms of support, education and access in Canada. Giving individuals the space to voice these important views is essential in creating resources that benefit patients. CBCN will use this new knowledge to help guide our programs and resources, and to champion the needs of breast cancer patients and survivors to decision makers, health care professionals, community organizations and to other health charities.

278 early stage
(stage I – III)
respondents

180
metastatic
(stage IV)
respondents


Patient Perspectives on Research Priorities

CBCN had the pleasure of participating as a partner in two key national projects looking at priorities to guide research in metastatic breast cancer and breast reconstruction. The Metastatic Breast Cancer Priority Setting Partnership, which concluded in May 2018, released 10 key research questions to help guide research priorities for metastatic breast cancer. This project received feedback from over 500 patients, caregivers and clinicians. In April, representatives from each of these groups came together in-person to look at the top 27 questions and narrow it down to 10.

The Post Mastectomy Breast Reconstruction Priority Setting Partnership closed its survey in June of 2018 to begin analyzing data to identify key questions about reconstruction that have not been answered by research. CBCN advised on the creation of the survey for patients, caregivers and physicians as well as disseminating the study within our network. We are looking forward to consulting on these findings to develop a list of 10 key research questions.

CBCN leveraged its patient community to help support the promotion of these research surveys allowing breast cancer patients and caregivers to voice their perspectives on key issues relating to metastatic disease and reconstruction. These patient perspectives will help guide future research in important breast cancer issues.





PROVIDING INFORMATION & EDUCATION

DEVELOPING DIGITAL RESOURCES

Our Voices Blog

This year, CBCN launched a new blog on our website focusing on three main areas: patient stories; education; and CBCN news. Our Voices has helped us achieve a larger reach and has allowed us to dive further into topics that impact Canadians. The “Stories” section shines a light on personal stories from men and women affected by breast cancer, while the “Knowledge” section lets us explore educational topics from side effect management to research. Finally, the “CBCN in Action” section highlights exciting initiatives and projects that CBCN is working on.

The blog has allowed us to discuss certain topics in depth with the use of special series. We launched a Managing Side Effects Series in January 2018 that focused on various common side effects of breast cancer and treatment. We complemented these Knowledge posts with Stories from women who faced these challenges first-hand. In June 2018, we launched a Biosimilars and Breast Cancer Series. We explored important topics relating to biosimilars in six posts. We wrote posts explaining the use of biosimilars, development, drugs that are impacted, the patient perspective and the physician perspective.

30 unique
patient stories
shared

Accounted for
over 50% of
website traffic

DEVELOPING **DIGITAL RESOURCES**

Refreshed Newsletters

In August 2017, we made some big changes to our email newsletter. We wanted to ensure that our readers stay engaged with the latest that CBCN has to offer, from new projects and campaigns to recent blog posts that are relevant and thought-provoking. We create our programs and blog content based on the needs of the patient and our newsletter is a direct way to connect our community with resources that would benefit them. Thus, inspiring a new name: **CBCN CONNECTED**. We cleaned up the design and focused each newsletter on a collection of key items. Since then, we have seen our click-through rate double compared to the year before and have had a significant increase in our subscriptions!

In addition, we launched a new special issue newsletter called **MBC CONNECTED**, focused specifically on metastatic breast cancer. This quarterly newsletter was launched in May 2018 and the inaugural email saw a 48% open rate and a 29% click-through rate!



Surgery Decision Aid

A key finding in our 2017 Patient Survey analysis showed that many women have difficulty when it comes to understanding and making decisions about their surgical options once they are diagnosed with breast cancer. To help with this, CBCN began developing a digital resource focused on explaining all surgical options after a breast cancer diagnosis. The new tool will explain the difference between a mastectomy and a lumpectomy as well as the different options available afterwards. Stay tuned for the launch of this exciting project in the Fall of 2018!

PROVIDING PATIENT NAVIGATION

Financial Navigation

In the Fall of 2017, CBCN was honoured to accept a SPARC Grant from the Union for International Cancer Control (UICC) to develop a metastatic breast cancer Financial Resources Navigation Tool. Through this project, we will ensure that patients across Canada are provided with personalized comprehensive information about what financial assistance is available to them and how to access it. You'll be able to access this vital tool in the Fall of 2018!

Individual Patient Navigation

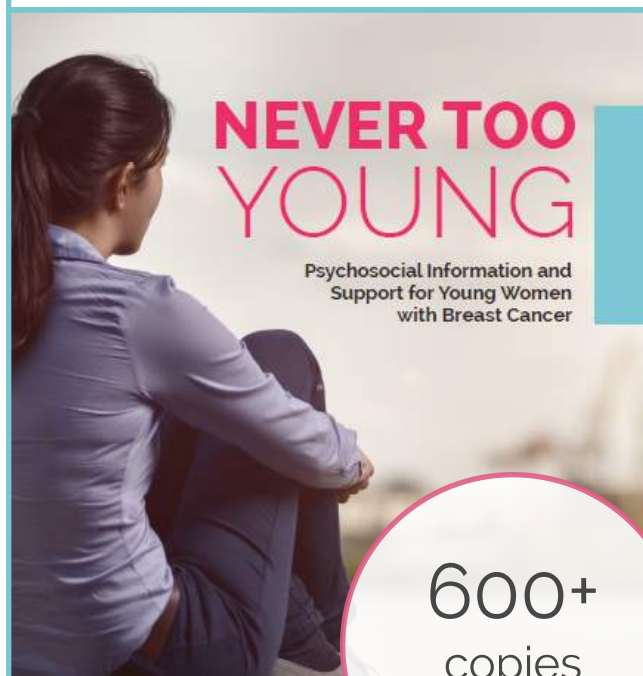
CBCN continues to assist metastatic breast cancer patients and caregivers with individual navigation and advocacy tips for both private insurance and public reimbursement. We provide personalized information to those having trouble accessing treatments in their province. We help to coach patients on strategies to communicate their message to health officials, decision-makers and the media.



OFFERING *EDUCATIONAL OPPORTUNITIES*

Updated Never Too Young

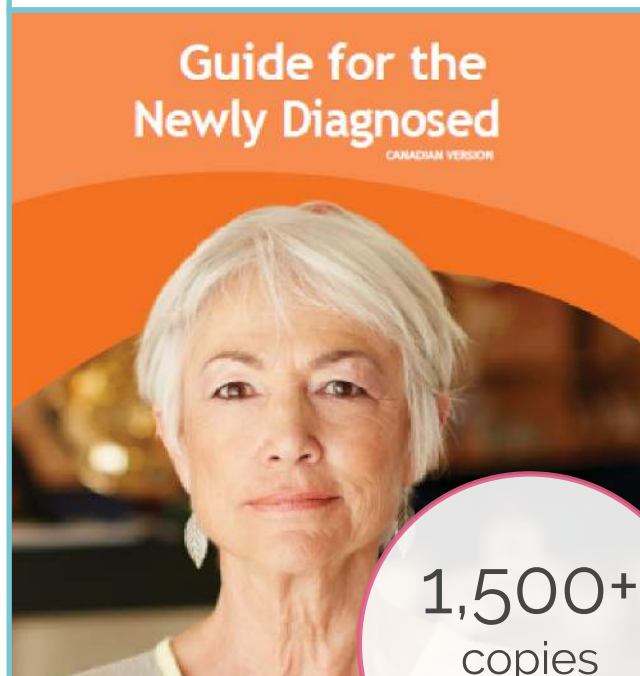
Never Too Young is CBCN's handbook for young women with breast cancer. Developed in 2010, it has been a popular resource for many young women newly diagnosed. We have seen multiple reprints and a steady distribution of this valuable resource over the past eight years. This year, with continued requests and a shrinking supply we decided to give it an update. Thanks to a generous donation from La Vie en Rose through its Roses of Hope Foundation we were able to reprint this refreshed and updated version. We continue to offer this resource free of charge to individuals, cancer centres, community organizations and support groups across Canada.



600+
copies
distributed

The Metastatic Breast Cancer Newly Diagnosed Guide

CBCN was thrilled to partner with Living Beyond Breast Cancer to develop a Canadian version of their popular Newly Diagnosed Guide for metastatic breast cancer. This handbook was adapted with information specific to Canadians in both English and French. We engaged Canadian women living with metastatic breast cancer to help guide its adaption. It gives information and support needed to make informed decisions about treatment and to manage the emotional impact of a metastatic diagnosis. We are pleased to offer this resource free of charge to individuals, cancer centres, community organizations and support groups throughout Canada.



1,500+
copies
distributed

OFFERING *EDUCATIONAL OPPORTUNITIES*

MBC CONNECTED Education Day

In April of 2018 we hosted a special education day focused on information and education for metastatic breast cancer patients in Ottawa, Ontario. This one-day event brought together patients and their caregivers to hear from a variety of community supports. Key speakers at this event included:

- Dr. Sehdev, Medical Oncologist at the Ottawa Hospital, who spoke about new treatments and the latest research for MBC
- Beth Hoag, physiotherapist specializing in cancer, who lead the group in mindfulness exercises for pain management
- Carolyn Andrews, Clinical Manager of the Ottawa Hospital Psychosocial Oncology Program, who spoke about psychosocial resources at the Ottawa Cancer Centre
- Cindy Barka, metastatic breast cancer patient, who promoted the peer support communities available in Ottawa

Webinar on Private Insurance in Canada

We teamed up with the OmbudService for Life & Health Insurance in April to host a webinar about accessing and navigating private insurance and to learn about the appeals process. This one-hour online information session gave individuals:

- A better understanding of private health insurance and life insurance
- How the appeals process works
- What your options are if a medication isn't covered

This webinar is now viewable at our website at www.cbcn.ca/webinar-private-insurance.



CREATING CAMPAIGNS

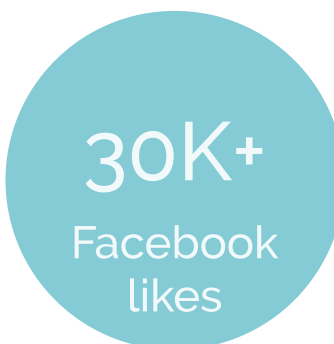


The 2nd It's About MBC Time Campaign

CBCN, in collaboration with the Québec Breast Cancer Foundation, Rethink Breast Cancer and a leading research-based pharmaceutical company in Canada, launched the It's About MBC Time Campaign for its second year in October 2017. This year highlighted the needs of women living with metastatic breast cancer and further helped to bring awareness to a disease that is largely misunderstood.

Nalie Agustin, a well-known blogger and YouTuber who was diagnosed with metastatic breast cancer at age 28, was the face of the campaign where she highlighted her story in a bilingual video that was shared through social and traditional media. The video promotion on social media was followed by text-based stories of various Canadians affected by metastatic breast cancer. Twelve profiles of patients and caregivers were shared across all three organization Facebook pages. Following these profiles, various statistics were shared showcasing the lack of knowledge the average Canadian has about MBC.

CAMPAIGN HIGHLIGHTS:



CREATING CAMPAIGNS

64%

conversion
rate

10k+

video views

2.85%

click-through
rate



Far From Fragile Bone Health & MBC Campaign

Far From Fragile was created to help provide a space for individuals affected by breast cancer to gain insight and understanding about bone health and bone metastases. A digital interactive infographic was created along with a video featuring stories from two women diagnosed with bone metastases. The infographic served as an educational tool to help explain statistics and complications associated with bone metastases. Social media was utilized to help bring awareness to this campaign and its assets.

#MBCNoTime2Wait Drug Access Campaign

The **#MBCNoTime2Wait** campaign took place in September of 2017 and showcased stories from five women living with metastatic breast cancer and why they feel drug access wait times in Canada need to change. This campaign was not supported by paid advertising yet produced a noteworthy reach.

700+

social media
interactions

26k+

social media
impressions

5k+

website
visits

STRENGTHENING PARTNERSHIPS

NATIONAL REPRESENTATION

Canadian Cancer Research Conference

This year, Cathy Ammendolea, CBCN's Board Chair, had the pleasure of participating as a patient representative on the steering committee of the Canadian Cancer Research Conference hosted by the Canadian Cancer Research Alliance. Cathy worked in partnership with clinicians, researchers and other patient group leaders to develop and inform the conference program agenda. She was also given the opportunity to co-moderate the opening plenary session focused on the burden of cancer.

"A key highlight for me was witnessing the genuine commitment of the steering committee members toward ensuring meaningful patient involvement." – Cathy

CBCN also had the chance to offer an advocacy training seminar to patient advocates attending the conference. In partnership with Colorectal Cancer Canada, we presented key strategies for patients to effectively communicate their messages to the government and media.

Finally, CBCN was able to present a poster on MedSearch, our digital navigation tool designed to help metastatic patients in Canada understand what drugs are available in their province and where they sit in the approval process.

This year's conference pioneered a new model for engaging patients and CBCN is looking forward to seeing the expanded contribution of patients at the next conference in 2019.

Representing the Patient Perspective on Biosimilars

CBCN had the opportunity to share insights and discuss the emergence of biosimilar treatments in oncology at various meetings. We presented the patient perspective on biosimilars at the Conference Board of Canada's Healthy Canada Conference. CBCN then had the opportunity to present at the Canadian Association for Health Reimbursement Conference. Finally, we attended the Canadian Association of Medical Oncologists Conference to better understand the perspective of oncologists when it comes to biosimilars.

GLOBAL REPRESENTATION

ABC4: International Consensus Conference for Advanced Breast Cancer

CBCN attended the Advanced Breast Cancer Conference for the second time in November 2017. In addition to learning about the latest research for metastatic breast cancer, we had the opportunity to present two posters on CBCN's accomplishments from the past year. Our first poster presentation focused on our MedSearch digital navigation tool that helps Canadians understand what metastatic drugs are available in each province. Our second post presentation highlighted the work we've done advancing public awareness of metastatic breast cancer. Living Legacy was a three-year social media awareness campaign that brought attention to the needs of Canadians living with this disease and to provide educational resources important to MBC.

ABC4 also saw the launch of the Union for International Cancer Control's SPARC Metastatic Breast Cancer Challenge. CBCN, along with 19 other organizations, were awarded with financial grants to help address the needs of metastatic breast cancer patients worldwide. CBCN is currently developing a financial resources navigation tool to help Canadians find financial assistance.

Breast Cancer Patient Group Forum, Prague

CBCN was invited to attend the Hoffman La Roche Global Breast Cancer Patient Group Forum for the second year in June 2018. The forum was a platform for patient groups to learn from experts and discuss challenges and opportunities for breast cancer organizations. This forum allowed for the strengthening of key relationships between global patient groups and to exchange best practices for achieving effective engagement on the issue of breast cancer. The group discussed various topics including hereditary cancer, access to treatments and screening, and awareness for young women.

OUR CONTINUED PARTICIPATION HAS ALSO INCLUDED:

- Best Medicines Coalition (BMC)
- CanCertainty Campaign
- Quality End of Life Care Coalition of Canada (QELCCC)
- Inuit Cancer Project
- San Antonio Breast Cancer Symposium (SABCS)
- Participation in various global advisory boards

THE TEAM



CBCN's Board of Directors is made up of a dedicated and diverse group of individuals from across Canada who have all personally experienced a breast cancer diagnosis.

This year we lost one of our own, Laurie Kingston, to metastatic breast cancer. Laurie, was a tireless dedicated advocate who was instrumental in guiding much of the work that CBCN has undertaken around metastatic breast cancer. Her perspective and insight helped inform the mBC section of our website, the MedSearch drug navigation tool, our MBC education days, the Newly Diagnosed Guide for Metastatic Breast Cancer Patients, and the survey for Canadians living with mBC. Her legacy continues to live on in so much of the work we do and the work that she's done continues to impact the lives of so many.

Our board members regularly participate in health technology assessments, breast cancer research review panels, meetings with key decision makers and continue to engage with local, provincial, national and global organizations to address priority issues for the breast cancer community. Their dedication and commitment to improving the lives of Canadians affected by breast cancer is the driving force behind CBCN.

- Cathy Ammendolea, Board Chair: Québec
- Sharon Young, Vice Chair: Manitoba
- Diana Ermel, Past Chair: Saskatchewan
- Juliette Inglis: Alberta
- Laurie Kingston: Ontario (In memory)
- Suzanne LeBlanc: New Brunswick
- Judy Donovan Whitty: Prince Edward Island
- Wendy Panagopoulos: Nova Scotia

CBCN staff work closely with the Board of Directors and partners to achieve the organizational goals and priorities to improve the lives of Canadians affected by breast cancer.

- **Jenn Gordon**, Director of Operations
- **Niya Chari**, Director of Public Affairs & Health Policy
- **Rebecca Armstrong**, Coordinator of Programs & Digital Media
- **Wendy Hall**, Publications & Office Coordinator



ABOUT CBCN

CBCN exists to ensure the best quality of life for all Canadians affected by breast cancer. The Canadian Breast Cancer Network (CBCN) is Canada's leading patient-directed organization of individuals concerned about breast cancer. CBCN strives to voice the views and concerns of breast cancer patients through education, advocacy activities, and the promotion of information sharing.

Education and Information – CBCN provides credible breast cancer related information and education to those affected by breast cancer.

Advocacy – CBCN promotes equitable access to support and care throughout the breast cancer experience to ensure best quality of life. CBCN also ensures that the issues affecting breast cancer patients, survivors, and their families inform health care policy and guide research.

National Network – CBCN connects groups and individuals to promote information exchange and collaboration.

OUR SUPPORTERS

CBCN is able to continue our work as leaders in breast cancer patient advocacy and education thanks to the support of many organizations and individuals. Your financial contributions ensure that the lives of Canadians affected by breast cancer are improved through access to the best therapies, information and education. You allow us to continue to work collaboratively with global leaders and engage key decision makers to improve patient outcomes. Thank you for your support, together we're improving the lives of thousands of Canadians.

We gratefully acknowledge the following key funders who have significantly increased CBCN's ability to fulfil our mission:

