

2018-2019

Annual Report



Canadian Breast Cancer Network
Réseau canadien du cancer du sein

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Letter from the Chair

Another rewarding and impactful year at the Canadian Breast Cancer Network (CBCN) is under our belts. With thanks to our dedicated staff and board of directors, medical advisors and our supporters, CBCN was able to achieve many notable accomplishments! These accomplishments will continue to help those who are affected by breast cancer for many years to come.

Two critical reports were released this past year that focused on issues of great concern to the organization and to patients across the country. Our *Breast Cancer & Biosimilars* whitepaper allowed us to discuss and communicate key take-aways of the emergence of biosimilars into the Canadian oncology treatment landscape. The second report *Breast Cancer: The Lived Experience*, developed directly from patient experiences through two national surveys, showcases the needs and concerns of patients living with both early stage and metastatic breast cancer.

Our digital presence and online resources also continued to grow and expand this year. Our online blog continues to be an essential source of information and support to the breast cancer community. Our two newest online navigation tools, *SurgeryGuide* and the *FinancialNavigator* are also proving to be incredibly beneficial to people living with or newly diagnosed with breast cancer.

Finally, we had the opportunity of attending and presenting our resources and insights at various Canadian and global conferences this year while also furthering our outreach to community stakeholders at conference booths and through direct mail dissemination.

Thank you again to all of our committed stakeholders for joining us in strengthening the voice of the breast cancer community.

Cathy Ammendolea
Chair, Board of Directors



By the Numbers



2,100+ mBC guides distributed



142,000+ Blog visits



277,000+ Website visits



1,500+ Never Too Young books distributed



5,500+ Followers



6,700+ Navigation Tool visits

What are People Saying?

"CBCN's website is one of the most thorough and clear references on the subject of breast cancer that I came across in the last two years (since my diagnosis)." - *Breast cancer patient*

"Having the opportunity to be in a shared space with so many other people going through a "breast cancer" journey of their own. We know others are out there but just bringing us together allows us to put real faces to experiences." - *Breast cancer patient*

"Thank you very much for education on how to manage + better understand about cancer."
- *Breast cancer patient*



Giving Voice to Canadians with Breast Cancer

REPRESENTING THE PATIENT PERSPECTIVE

Breast Cancer: The Lived Experience



In 2017, the CBCN undertook two surveys of Canadians who have experienced a breast cancer diagnosis to better understand the lived experience of patients. The results of these surveys culminated in the report, *Breast Cancer: The Lived Experience* and highlights the challenges faced by Canadians with early stage breast cancer and those living with metastatic breast cancer. It also outlines key recommendations to improve the health outcomes and the quality of life of Canadians who experience a breast cancer diagnosis.

The results of this report were presented at the 2018 San Antonio Breast Cancer Symposium, the 2019 CADTH Symposium, the IPOS World Congress of Psycho-oncology Conference, the Canadian Association of Nurses in Oncology Conference, the Canadian Cancer Research Conference, and the Advanced Breast Cancer 5 Conference. Copies of this report were also disseminated to provincial ministries of health, provincial cancer care agencies and physicians.

Providing Perspectives on National Pharmacare

CBCN has continued its work informing the implementation of a national pharmacare program. CBCN participated in a patient organization consultation with the Advisory Council on the Implementation of National Pharmacare to help communicate the key priorities from the perspectives of breast cancer patients as well as regional consultations across the country. CBCN also contributed to discussions through our membership with the Best Medicines Coalition.

Giving Voice to Canadians with Breast Cancer

REPRESENTING THE PATIENT PERSPECTIVE

Breast Cancer & Biosimilars: Recommendations on Use, Implementation and Patient Communications

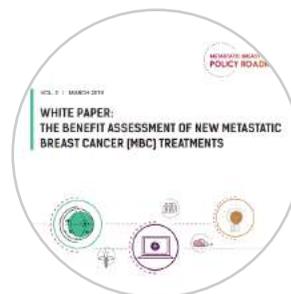


In the fall of 2018, CBCN conducted two national virtual roundtables with breast cancer patients and medical oncologists looking at the different perspectives on the entry of biosimilars into the breast cancer treatment space. It culminated into a whitepaper outlining some key observations and recommendations that was released in April of 2019.

The outcomes of this paper were presented at the CADTH Symposium and copies were sent to all provincial ministries of health and cancer care agencies, private insurance companies, oncologists, Health Technology Assessment Agencies, and industry.

Global and National Whitepapers Focusing on Perspectives of Metastatic Breast Cancer

In collaboration with Eli Lilly, CBCN participated in roundtable discussions with leading medical oncologists examining the importance of individualized care for patients with metastatic breast cancer. From these discussions, a national whitepaper titled, *Individualized care for patients with advanced breast cancer*, and a global whitepaper titled, *The Benefit Assessment of New Metastatic Breast Cancer (MBC) Treatments*.



Giving Voice to Canadians with Breast Cancer

REPRESENTING THE PATIENT PERSPECTIVE



Economic Impact of Breast Cancer: An update to the 2010 Economic Impact and Labour Force Re-Entry Report

In February of 2019, CBCN released an update to our 2010 report. This updated report highlights the financial burden a breast cancer diagnosis can have on patients based on results from a patient survey conducted in 2017. CBCN outlined key recommendations to ease the financial burden of current and future breast cancer patients.

Providing Patient Input to Canadian Health Technology Assessment Bodies

CBCN has provided patient input submissions to the pan-Canadian Oncology Drug Review (pCODR) and L'Institut national d'excellence en santé et en services sociaux (INESSS) for:

- Verzenio (abemaciclib) for metastatic HR+, HER2- breast cancer
- Ibrance (palbociclib) for metastatic HR+, HER2- breast cancer
- Kisqali (ribociclib) for metastatic HR+, HER2- breast cancer
- Neralynx (neratinib) for early stage HER2+ breast cancer
- Kadcyra (T-DM1) for early stage HER2+ breast cancer
- Ogivri (trastuzumab biosimilar) for HER2+ breast cancer
- Tecentriq (atezolizumab) for metastatic triple negative breast cancer

These submissions continue to 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.

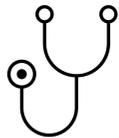


Giving Voice to Canadians with Breast Cancer

BUILDING THE CAPACITY OF PATIENTS

Giving Voice to Patients Concerned about Research for Post-Mastectomy Reconstruction

CBCN continued its partnership in the Post Mastectomy Breast Reconstruction Priority Setting Partnership this year. CBCN advised on the creation of a national survey for patients, caregivers and physicians and facilitated dissemination to our network. We then consulted on guiding the research priorities based on the feedback from this survey. A second survey was created to better narrow down the key priorities of patients on this issue. The completed top 10 list of research priorities for post-mastectomy reconstruction options will be available later this year.



Study of Preferences for Advanced Breast Cancer Treatments in Canada

CBCN, in partnership with Novartis Pharmaceuticals, consulted in the creation and dissemination of a research study regarding preferences for treatment of advanced breast cancer in Canada. This study allowed patients to share their perspectives on common treatment side effects as well as their goals for the treatments they receive. CBCN is looking forward to sharing the results of this survey with our networks.

Clinical Trials Participation in Breast Cancer

In the fall of 2019, CBCN finalized and launched a survey in partnership with The Ottawa Hospital Research Institute and Clinical Trials Ontario focusing on the level of knowledge patients have with participating in clinical trials. Rates of participation in clinical research are often low and the goal of this study is to help to understand the range of factors that people consider when deciding to participate in a clinical trial. CBCN is looking forward to reviewing the results of this important survey.



Providing Information and Education

OFFERING EDUCATIONAL OPPORTUNITIES

Florence Winberg Education Series on Breast Cancer

In June of 2019, CBCN partnered with Sunnybrook Health Sciences Centre to present an education event for patients and families in Toronto. The event consisted of a variety of topics that focused on exercise and weight management, support and educational resources online and in the community, symptom management strategies and updates on breast cancer systemic therapy treatments. This event was attended by 160 patients and caregivers. Overall, the majority of attendees found the topics helped to inform their questions and needs while living with breast cancer.

Our Voices Blog



CBCN's *Our Voices Blog* continues to be the most viewed and shared content on our website. Over 42 blogs were published this past year on a variety of topics including pharmacare, drug access, complementary therapies, palliative care, genetic testing, research updates and more. Our blog also continues to share stories from Canadians living with or directly impacted by breast cancer as well as educational and advocacy information through our three main categories: Stories; Knowledge; and Taking Action.

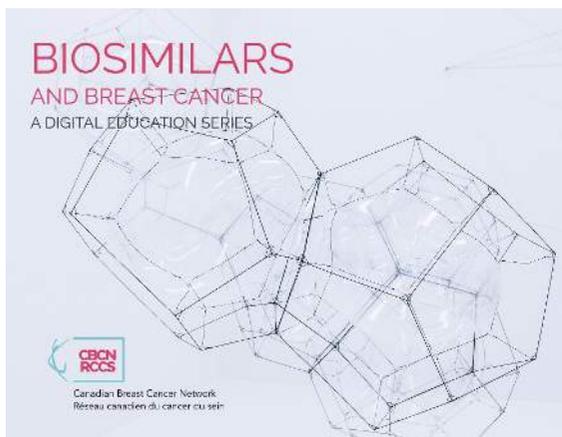


Providing Information and Education

OFFERING EDUCATIONAL OPPORTUNITIES

Digital Patient Magazines

Our new themed digital magazines were launched in the fall of 2018 as an additional resource for people living with breast cancer. Each magazine is a curated selection of articles from Our Voices Blog on specific topics so that the information can be viewed all in one accessible place. Our magazines have credible and easy-to-understand information along with patient and physician perspectives to help patients make informed decisions about their health. This year we have published:



CBCN Connected

CBCN continues to promote our information and resources through our monthly e-newsletter CBCN Connected and quarterly e-newsletter mBC connected, focused specifically on metastatic breast cancer news. In the last year, we've seen 256 new subscribers and we continue to see an above average click through rate of 20+ percent.

Providing Information and Education

OFFERING EDUCATIONAL OPPORTUNITIES

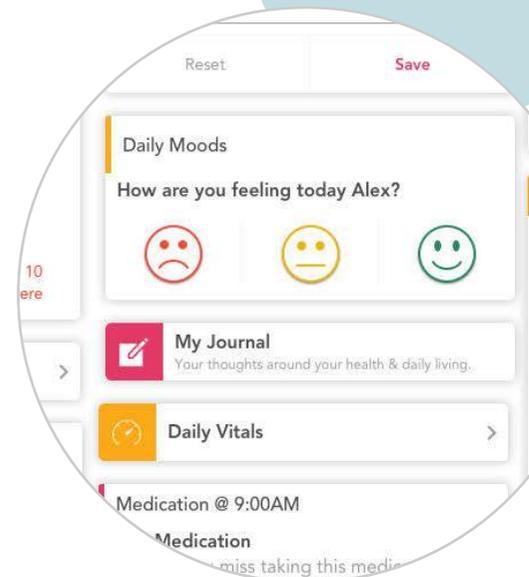
Putting Resources into the Hands that Need Them

CBCN has been working this year to promote our print and online resources for patients through targeted resource dissemination to cancer centres, medical oncologists, surgical oncologists, plastic surgeons and community organizations. As a result, we have sent out over 2,100 *Metastatic Breast Cancer Newly Diagnosed* guides, 1,500 *Never Too Young* handbooks, and over 16,000 information cards about our digital navigation tools.



Health Storylines

This year, CBCN was excited to partner with Self Care Catalysts to launch a breast cancer specific mobile app. This new app can help patients track symptoms, set up medication alerts, track moods and find information that will help them better understand a breast cancer diagnosis and how to manage it. It also offers CBCN's Our Voices blog and our SurgeryGuide decision aid within the app so patients are able to keep up-to-date and informed about CBCN resources.





Providing Information and Education

PROVIDING PATIENT NAVIGATION

SurgeryGuide

In October of 2018, CBCN was excited to launch our online decision aid for breast cancer surgery and reconstruction. SurgeryGuide was developed based on feedback from our 2017 Patient Survey that showed that many women have difficulty understanding and making decisions about their surgical options when newly diagnosed with breast cancer. SurgeryGuide walks patients through the possible options for surgery and the different types of reconstruction procedures, from living flat, to choosing between implant or autologous reconstruction. Additionally, each choice is complimented by real-life stories from women who have gone through these very same decisions. Since its launch, SurgeryGuide has seen over 3,000 visits.



FinancialNavigator

Earlier this year, CBCN launched a new financial resources navigation tool. FinancialNavigator, offers a comprehensive database of grants and programs to help patients struggling with the financial burden of a cancer diagnosis find and access support in their communities. It offers detailed information on government income supplement programs, charitable programs, and even free services such as house cleaning and childcare to help offset this financial burden. In addition, the FinancialNavigator offers detailed information on public and private health insurance benefits, travel, taxes, and end of life financial planning. Since its launch, the FinancialNavigator has seen over 2,200 visits.





Providing Information and Education

PROVIDING PATIENT NAVIGATION

Individual Patient Navigation

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

CREATING CAMPAIGNS

Senseless Surgery Letter Writing Campaign

This past year, CBCN launched a digital letter writing campaign that focused on access to certain medications in British Columbia. Policy stated that in order to access certain medications, women needed to undergo unnecessary oophorectomy surgery instead of taking ovarian suppression medication. Our digital media campaign allowed concerned Canadians to easily send letters to the Ministry of Health in British Columbia urging government to change their policy. Ultimately, the government of British Columbia re-evaluated this policy and agreed to allow the use of ovarian suppression medication.





Strengthening Partnerships

San Antonio Breast Cancer Symposium

Last December, CBCN had the opportunity to attend the annual San Antonio Breast Cancer Symposium to present our poster on the results of our Lived Experience Report. Our poster outlined our recommendations to improve the lived experience for breast cancer patients in Canada.



Canadian Agency for Drugs and Technologies on Health (CADTH) 2019 Symposium



In April of 2019, CBCN was accepted to present at the Canadian Agency for Drugs and Technologies on Health (CADTH) Symposium. CBCN provided an oral presentation on how drug access challenges differ between people living with early stage breast cancer and people living with metastatic breast cancer. We were also given the opportunity to sit on a panel discussing biosimilars where we were able to share our recommendations from our Breast Cancer and Biosimilars Whitepaper.

Canadian Breast Cancer Symposium

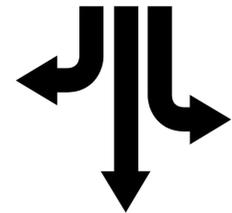
This past June, CBCN participated in the Canadian Breast Cancer Symposium and presented an oral abstract on our SurgeryGuide decision aid at the Surgical Forum. CBCN also participated in the inaugural Patient Program hosted by Rethink Breast Cancer that brought together patients and oncologists from the conference to discuss shared decision making.



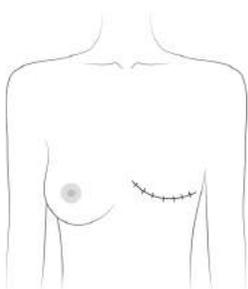
Strengthening Partnerships

IPOS World Congress of Psycho-Oncology Conference

This year CBCN was able to attend the World Congress of Psycho-Oncology Conference hosted jointly by the Canadian Association of Psychosocial Oncology and the International Psycho-Oncology Society. During this conference we were able to present posters on the recommendations from our Lived Experience Report to improve the lived experience for breast cancer patients in Canada as well as information on how a web-based financial resources navigation tool like our FinancialNavigator can help patients manage the financial toxicity of breast cancer. We also had the opportunity to provide a booth of resources for the conference participants to better learn about and share our tools to help breast cancer patients in Canada.



Canadian Association of Nurses in Oncology (CANO)



During the Canadian Association of Nurses in Oncology Conference this October, CBCN presented four posters sharing information about our FinancialNavigator digital tool, the MedSearch online tool, and the recommendations from our Lived Experience Report. We also had the opportunity to provide an oral presentation on how our SurgeryGuide decision aid is supporting breast cancer patients.

Our continued participation has also included:

- Quality End of Life Care Coalition of Canada
- Canadian Partnership Against Cancer
- American Society of Clinical Oncology
- Best Medicines Coalition
- CanCertainty Campaign
- Inuit Cancer Project
- Pan-Canadian Oncology Biosimilars Initiative

The Team

BOARD OF DIRECTORS

- **Cathy Ammendolea**, Board Chair: Québec
- **Sharon Young**, Vice Chair: Manitoba
- **Diana Ermel**, Past Chair: Saskatchewan
- **Juliette Inglis**: Alberta
- **Suzanne LeBlanc**: New Brunswick
- **Judy Donovan Whitty**: Prince Edward Island
- **Wendy Panagopoulos**: Nova Scotia
- **Cathy Hemeon**: Newfoundland & Labrador
- **Jackie Greenham**: Newfoundland & Labrador

STAFF

- **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

