



2015-2016
CBCN
Year in Review



Canadian Breast Cancer Network
Réseau canadien du cancer du sein



FROM THE CHAIR OF THE BOARD

We have had another productive year at CBCN as we continue to lead important breast cancer educational and advocacy initiatives for Canadians. From our regular patient advocacy workshops to new learning opportunities online and in person, CBCN has worked to ensure that patients have access to credible information while navigating our complex healthcare system. We have also continued to represent the patient perspective through patient input submissions and discussions with federal review bodies.

Our most exciting accomplishment this year was the launch of our powerful report *Waiting for Treatment* which highlights the need for timely access to treatment drugs for Canadians living with metastatic breast cancer. This report has allowed us to speak extensively on an important issue affecting many women with metastatic disease. I had the privilege of presenting our findings at the third International Consensus Conference for Advanced Breast Cancer (ABC3) in Lisbon, Portugal which lead to dynamic discussions about accessibility and affordability on the global scale.

The transition of our Network News magazine from print to digital was another exciting achievement. This new format allows us to share important and valuable breast cancer information in a more accessible way. We are continuing to offer information on new topics that are often not widely discussed and share unique stories from Canadians concerned about breast cancer.

I am proud of the work we have accomplished thus far and I look forward to continuing our work on these crucial initiatives to ensure Canadians have the best quality of life while facing this disease.



Cathy Ammendolea, Board Chair



IVING A VOICE TO CANADIANS AFFECTED
BY BREAST CANCER

IDENTIFYING INEQUITABLE ACCESS TO TREATMENT FOR WOMEN LIVING WITH METASTATIC BREAST CANCER

On October 13, 2015, Metastatic Breast Cancer Awareness Day, CBCN launched our report **Waiting for Treatment: Timely equitable access to drugs for metastatic breast cancer** which calls for more equitable access to treatments for the thousands of Canadian women living with this disease. Through an online survey, 98 individuals across Canada shared their experiences accessing treatment drugs specific to metastatic breast cancer. The results concluded that there can often be a 2+ year delay from when Health Canada approves the drug for use to when provinces and territories list the drug on their public formularies. CBCN found that women in Québec and Atlantic Canada face some of the longest delays accessing new treatments.

The launch of this critical report resulted in an impressive media campaign with more than **12 million media impressions**. CBCN will continue to present the findings of this report and lead advocacy initiatives with the goal of achieving equitable access to treatment drugs for metastatic breast cancer patients regardless of where they live in Canada.

12.1+
MILLION

MEDIA IMPRESSIONS

112K+

SOCIAL IMPRESSIONS

74

STORIES GENERATED

26

TWEETS



André Picard @picardonhealth · Oct 14

Provinces vary widely on coverage of #breastcancer treatments:

@CBCN, by @MAJ_Robinson on thestar.com/1VRB0oL

@CanCertainty @torontostar

RETWEETS

6

FAVORITES

4



6:04 AM - 14 Oct 2015 - Details

GIVING A VOICE TO CANADIANS AFFECTED BY BREAST CANCER

PROVIDING PATIENT INPUT TO THE PAN-CANADIAN ONCOLOGY DRUG REVIEW

CBCN provided patient input submissions to the pan-Canadian Oncology Drug Review (pCODR) for Ibrance (palbociclib) which is intended for the treatment of postmenopausal women with ER-positive, HER2-negative advanced breast cancer. CBCN's submissions provided critical

input on the needs and challenges of women living with metastatic breast cancer and the impact that access to essential treatments can have to improve the quality of life for women affected by this disease. Through these submissions, CBCN seeks to raise awareness about the challenges associated with treating metastatic breast cancer, and ensure that patient experiences are being leveraged towards more informed decision-making.



In April, CBCN was pleased to represent the patient perspective at the Canadian Agency for Drugs and

REPRESENTING THE PATIENT PERSPECTIVE AT THE CANADIAN AGENCY FOR DRUGS & TECHNOLOGIES IN HEALTH'S SYMPOSIUM

Technologies in Health's (CADTH) Symposium in Ottawa. The theme for the symposium was "Expanding the reach of Health Technology Assessment" and CBCN was invited to present on the panel discussing "The Changing Landscape for Pharmaceutical Funding Decisions in Canada." In our talk, CBCN highlighted the key principles that patients value in pharmaceutical funding decisions and the need to incorporate patient input throughout the decision-making process. This opportunity allowed CBCN to emphasize the need for patient values to inform health decision-making.



A VOICE TO CANADIANS AFFECTED
BY BREAST CANCER

BUILDING THE CAPACITY OF PATIENTS

CBCN hosted two advocacy training workshops this year, one for women living with metastatic breast cancer and their caregivers and the other for women who have experienced early stage breast cancer. The metastatic specific workshop took place in Toronto in September of 2015 and focused on the unique issues affecting this community. The second workshop took place in Vancouver in April 2016 and focused on advocacy to support equitable drug access across Canada. These workshops help provide patients with the knowledge and information needed to navigate the political landscape in Canada. They also give patients the tools and resources to engage decision-makers, the public and the media on issues of concern to the breast cancer community. We continue to connect with these advocates regularly and engage this network as we move forward with our advocacy initiatives.



CBCN's Advocacy Training Workshop in Vancouver, BC, April 2016



"Very grateful and will be very beneficial in my everyday advocacy."

"I enjoyed this training. It really helped me with new ways I can assist and be a caregiver for my wife."

PROMOTING DIALOGUE FOR A NATIONAL PHARMACARE PROGRAM

CBCN is continuing to work actively with the Best Medicines Coalition of Canada (BMC) as a steering group member in the newly formed Pharmacare partnership between BMC, the Health Charities Coalition of Canada and the Canadian Pharmacists Association. CBCN participated in the BMC's collective efforts to promote a national dialogue around Pharmacare, including a specific media campaign focus at the Health Ministers meeting in Vancouver in January 2016, encouraging the Federal Minister of Health to ensure that Pharmacare is featured in discussions around the signing of a new Canada Health Accord in 2016. CBCN will continue working in coalition with other patient and health organizations around the implementation of a Pharmacare program.

PROVIDING INPUT TO REGULATORS ON SUBSEQUENT ENTRY BIOLOGICS (SEB's)

In February 2016, CBCN provided input on Health Canada's Guidance Document: Information and Submission Requirements for Subsequent Entry Biologics (SEB Guidance) for sponsors. CBCN highlighted the need to ensure that the regulation of SEB's continues to offer patients choice, broadens access and above else, ensures patient safety.

CBCN will continue to engage stakeholders and decision-makers on the regulation of Subsequent Entry Biologic products and ensure that the patient perspective is informing health decision-making.



PROVIDING INFORMATION AND EDUCATION

DEVELOPING EDUCATIONAL PUBLICATIONS

CBCN's semi-annual magazine, Network News, was transformed into a digital magazine this year which has allowed it to be more accessible and easily shared. This year's issues provided information on targeted therapies, psychosocial resources, inflammatory breast cancer and continued to share stories of women who have a lived experience dealing with breast cancer. This publication continues to be a resource that helps meet the informational needs of Canadians and provides the community with the opportunity to connect.

CBCN's monthly e-newsletter, Outreach, helped promote local educational opportunities and Canadian resources for breast cancer patients and survivors. This newsletter continues to help connect individuals with local resources and programs.



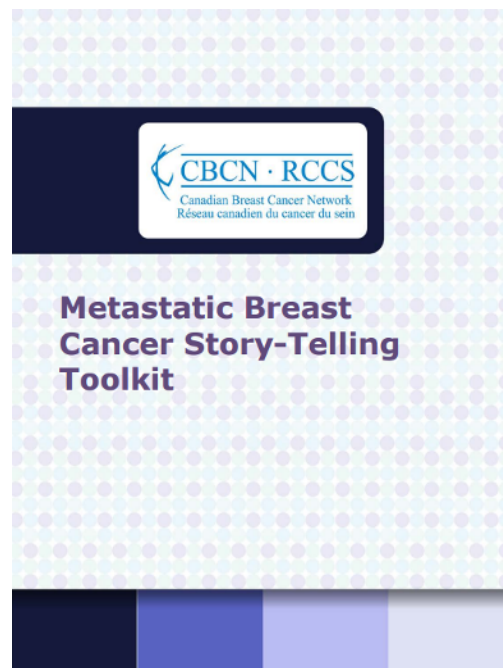
FALL 2016



SPRING 2016

PROVIDING INFORMATION AND EDUCATION

SHARING LIVING LEGACIES AND EMPOWERING OTHERS TO TELL THEIR STORY



>> 2000
ORGANIC VIEWS

In the fall of 2015 CBCN launched the second iteration of the Living Legacy Campaign. We asked nine women from across Canada to share their personal stories, words of support, and advice to others facing this disease and created our second Living Legacy awareness video promoted through Facebook, Outreach and our website. The video quickly became our most viewed video, **reaching 2000 organic views** in the first month of its launch.

CBCN also produced a *Metastatic Breast Cancer Story-Telling Toolkit* that can be downloaded for free on our website to help women share their experience with metastatic breast cancer and detail the unique needs associated with this disease. Within this informative toolkit women can find blog writing tips, how to write a letter to the editor and Members of Parliament as well as a guide for speaking with media.

CBCN seeks to continue future Living Legacy campaigns with additional educational resources to help Canadian women facing metastatic breast cancer.



PROVIDING INFORMATION AND EDUCATION

CREATING AWARENESS CAMPAIGNS TO SUPPORT INFORMED DECISION-MAKING

CBCN lead two successful social media campaigns aimed at creating awareness for a lesser known side effect of chemotherapy, febrile neutropenia. During both 6-8 week campaigns, CBCN promoted a series of Facebook posts that helped educate the public on febrile neutropenia; what it is and how it's treated. In total, CBCN's Facebook posts saw a total **reach to 260,000 people** nationwide.

During the second iteration of this social media campaign, an advocacy component was included asking concerned individuals to send a letter to the Ministers of Health in Ontario and British Columbia to ensure the availability of choice when it comes to a patient's treatment plan. By the end of the campaign, **786 people** sent emails to their health ministers.

CBCN was pleased to host an Educational Forum in Winnipeg for people living with metastatic breast cancer. One of Canada's leading oncologists, Dr. Sunil Verma, shared the latest updates in metastatic breast cancer treatments. Katherine Gottzmann, MSW, RSW, a psychosocial oncology clinician and Lori Santoro, R.N. Con(C), a breast cancer patient educator with Breast Cancer Centre of Hope also spoke on the resources and programs available to provide information and support to patients and families. CBCN was pleased to partner with the CancerCare Manitoba to offer this new session, which was also available through Telehealth, allowing it to reach rural communities throughout the province. This new educational session was received positively by the patients and families in attendance who felt it filled a needed gap in access to patient education. CBCN looks to continue this beneficial program in other cities across Canada moving forward.

PROVIDING EDUCATION SESSIONS FOR THE METASTATIC COMMUNITY

STRENGTHENING PARTNERSHIPS

REPRESENTING THE PERSPECTIVES OF CANADIANS LIVING WITH MBC IN A GLOBAL FORUM



CBCN had the opportunity to participate at the third International Consensus Conference for Advanced Breast Cancer (ABC3) in Lisbon, Portugal. CBCN presented an abstract on the outcomes of our *Waiting for Treatment* report, highlighting inequities in access to new metastatic treatments. The presentation allowed CBCN to initiate great dialogue around the issue of accessibility and affordability of innovative medicines globally. CBCN received recognition as the “Best Presentation in the Patient Advocacy Stream” by the European School of Oncology (ESO) and the conference itself. At ABC3, CBCN had the unique opportunity to lead global discussions around the needs of metastatic breast cancer patients and we look forward to continuing to spearhead global discussions on treatment and care.

PARTNERING ON DEVELOPMENT OF KEY INUIT CANCER RESOURCES

CBCN continued our work as a key partner on the Pauktuutit Inuit Women of Canada's Inuit Cancer Project. Work is underway to develop resources to help Inuit patients when they are first diagnosed with cancer and are looking to start treatment. CBCN was thrilled to be a part of the dedicated group of community members and organizations that has worked on these much-needed resources. We are pleased to continue our work on the advisory committee over the remaining years of the project.

OUR PARTICIPATION

- Best Medicine Coalition Annual Meeting
- Quality End-of-Life Care Coalition of Canada Annual Face to Face Meeting
- San Antonio Breast Cancer Symposium
- Canadian Agency for Drugs and Technologies in Health Symposium
- CanCertainty Campaign
- American Society of Clinical Oncology Annual Meeting



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. 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:
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- Sharon Young, Vice Chair:
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- Diana Ermel, Past Chair:
Saskatchewan
- Juliette Inglis:
Alberta
- Laurie Kingston:
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- Bev Jacobs:
Ontario
- Shirley MacLean:
New Brunswick
- 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.

- **Craig Faucette**, Director of Operations, Development & Strategic Partnerships
- **Jenn Gordon**, Director of Education & Community Engagement
- **Niya Chari**, Director of Government Relations, Policy & Public Engagement
- **Rebecca Wilson**, Coordinator of Programs & Digital Media
- **Wendy Hall**, Publications & Office Coordinator



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 & 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 fulfill our mission:



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