



# 2016 - 2017 CBCN Year in Review



Canadian Breast Cancer Network  
Réseau canadien du cancer du sein



## TABLE OF CONTENTS

03

ADVOCATING FOR CANADIANS  
AFFECTED BY BREAST CANCER

PROVIDING INFORMATION  
AND EDUCATION

06

11

STRENGTHENING PARTNERSHIPS

THE TEAM

15

16

ABOUT CBCN

SUPPORTERS

17

# LETTER FROM THE CHAIR OF THE BOARD



We've had another eventful year here at CBCN! In addition to our regular work promoting the patient voice and representing the patient perspective with decision-makers and health-care assessment bodies we also embarked on new initiatives. We helped to steer new research priorities and launched a new dynamic website to help support the Canadian breast cancer community.

The launch of our new CBCN website along with a new innovative tool designed to help metastatic breast cancer patients navigate available treatments was our most exciting accomplishment this year! We worked to provide Canadians with needed and easy to understand information about breast cancer while MedSearch helps to answer questions people have about what treatment drugs are available to them.

We also continued to leverage our

findings from last year's *Waiting for Treatment* report and highlight the importance of timely access to treatments for Canadians at national and global conferences throughout the year. Being able to continue this critical work was of great concern to us and we look forward to an ongoing discussion.

I continue to be proud of the work we have been able to accomplish each year. Looking forward, we will work hard to continue these discussions and to provide much-needed information, education and support for the breast cancer community so they can have the best quality of life.

A handwritten signature in cursive script that reads "Cathy Ammendolea".

Cathy Ammendolea, Board Chair





## ADVOCATING FOR CANADIANS AFFECTED BY BREAST CANCER

### REPRESENTING THE PATIENT PERSPECTIVE AND PROVIDING INPUT TO CANADIAN HEALTH TECHNOLOGY ASSESSMENT BODIES

#### **Providing Patient Input to the pan-Canadian Oncology Drug Review body and the pan-Canadian Pharmaceutical Alliance**

CBCN provided a patient input resubmission to the pan-Canadian Oncology Drug Review (pCODR) for Ibrance (palbociclib) in July 2016 which is intended for the treatment of postmenopausal women with ER-positive, HER2-negative advanced breast cancer. CBCN also drafted a letter to the pan-Canadian Pharmaceutical Alliance (PCPA) to highlight the need for patients to have access to new therapies for metastatic breast cancer. These submissions provided critical input on the needs and challenges of women living with metastatic breast cancer and the importance of being able to access essential treatments that can improve quality of life. CBCN's goal through these submissions is to raise awareness about the challenges facing and treating metastatic breast cancer and to ensure that patient experiences are being included in an informed decision-making process.

#### **Championing Access to Treatments Through Consultation of New pan-Canadian Cancer Drug Funding Sustainability Initiative**

In March of 2017, CBCN participated in a special consultation in Toronto by the Canadian Association of Provincial Cancer Agencies (CAPCA) to discuss its new pan-Canadian Cancer Drug Funding Sustainability Initiative. This new initiative has the potential to dramatically change the way provinces decide to fund cancer drugs and could impact the treatment options available to Canadian patients. In addition to our attendance at the consultation, CBCN provided a submission to this process and our goal is to communicate the importance for timely access to life-saving treatments for patients and to ensure that Canadian's affected by breast cancer have access to the best care.



### **Providing Input in PMPRB Consultation on the Guidelines Modernization Discussion Paper**

In October of 2016, CBCN participated in the Patented Medicine Prices Review Board (PMPRB) consultation on its Guidelines Modernization Discussion Paper. CBCN shared 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 Critical Input to CADTH on Proposed Revisions to Patient Input Template**

In October of 2016, CBCN provided critical feedback to the Canadian Agency for Drugs and Technologies in Health regarding proposed revisions to their patient input template. CBCN highlighted the need to ensure that patient input submissions are accurately capturing the patient perspective to inform healthcare decision making. CBCN will continue to engage CADTH in discussions around the incorporation of patient values in drug reviews.

## **BUILDING THE CAPACITY OF PATIENTS THROUGH ADVOCACY TRAININGS**

CBCN hosted an advocacy training workshop in Toronto in November of 2016 for women living with metastatic breast cancer. This workshop focused on the unique issues affecting the metastatic community and helped the women develop their skills advocating for more awareness, research and access to treatments. The session accomplished this by teaching the participants how to:

- Navigate the Canadian political landscape and engage elected representatives
- Engage the public and media on issues of interest regarding metastatic breast cancer issues
- Effectively communicate key messages about breast cancer to public officials

We continue to connect with these advocates regularly and engage this network as we move forward with our own advocacy initiatives.



# ENGAGING PARLIAMENTARIANS ON ISSUES AFFECTING CANADIANS LIVING WITH METASTATIC BREAST CANCER

On November 30, 2016, CBCN met with key parliamentarians regarding the issues affecting Canadians living with metastatic breast cancer. Our goal for these meetings was to help raise awareness about this disease and ask for support advancing a designation of October 13th as a National Day of Awareness for Metastatic Breast Cancer. We also requested a letter of support for a national mandate to provincial cancer agencies to collect statistics on breast cancer recurrence and de novo diagnosis of mBC to be sent to the Minister of Health.

## PROVIDING PATIENTS WITH OPPORTUNITIES TO GIVE INPUT ON RESEARCH PRIORITIES FOR METASTATIC BREAST CANCER

The goal of the Metastatic Breast Cancer Priority Setting Partnership (PSP) was to identify key research priorities for metastatic breast cancer. CBCN advised on the creation of a survey for patients, caregivers and physicians to identify where they feel priorities need to be made to advance change in this field of research. We helped to disseminate the survey within our network through social media, our website and our monthly newsletter. We continue to work closely with all partners in this project and will consult on the findings once the survey has closed.



## PROVIDING INFORMATION AND EDUCATION

### DEVELOPING DIGITAL EDUCATIONAL RESOURCES

CBCN continued to develop key digital resources for the breast cancer community in 2016 and 2017. Our Fall 2016 and Spring 2017 issues of Network News focused on information relevant to our subscribers. Our Fall 2016 issues provided information on hormone receptor positive (HR+) breast cancer, returning to work after treatment, febrile neutropenia, immunotherapy and radiosurgery. Our Spring 2017 issue focused on triple negative breast cancer and managing the fear of recurrence. It also featured information on lymphedema and adjusting to life after treatment ends. Both issues had patient stories from women who are advocating for and living with breast cancer.

CBCN's monthly e-newsletter, Outreach continued to help promote local educational opportunities and resources for breast cancer patients and survivors. Our digital communications continue to help connect individuals with local resources and programs as well as useful information for coping with breast cancer.



## New CBCN Website

In the spring of 2017 CBCN was pleased to launch a dynamic new website complete with up-to-date information for people living with breast cancer and metastatic breast cancer as well as information to help a person newly diagnosed with the disease. As part of this website launch we continue to share educational events, our advocacy initiatives and stories from patients and survivors to help others.

Giving Voice to Canadians Concerned About Breast Cancer

[Home](#) | [About CBCN](#) | [Media](#) | [Contact](#)

[EN](#) [FR](#)



Canadian Breast Cancer Network  
Réseau canadien du cancer du sein

[INFORMATION](#)

[EDUCATION](#)

[ACTION](#)

[DONATE NOW](#)



SHARING OUR LIFE

# STORIES

**PROVIDING PATIENT  
NAVIGATION**

### Individual Patient Navigation

CBCN continues to provide patient navigation for individual metastatic breast cancer patients and caregivers experiencing difficulties accessing treatments in their province. CBCN helps to coach patients on advocacy strategies and tips to communicate their message to health officials, decision-makers and the media. Patients are also given educational resources on possible avenues of financial support.



## MedSearch

In addition to launching a new website in early 2017, CBCN also launched an innovative online resource to help people with metastatic breast cancer determine what treatments are available to them. CBCN determined in our *2015 Waiting for Treatment: timely equitable access to drugs for metastatic breast cancer* report that not all life-saving treatments are publicly funded by every province and that patients should have a transparent way of identifying what they have access to in comparison to people in other provinces. MedSearch helps address that gap by allowing patients to see what treatments are publicly funded in each province and territory across Canada.

The database allows you to search for a specific drug by name or filter out drugs by province and/or sub-type. Each drug profile gives up-to-date information on:

- the type of therapy
- the provinces that fund it
- the provinces that do not fund it
- what stage it sits in the drug approval process
- navigation to resources to access drugs that aren't publicly funded

## PROVIDING EDUCATION TO THE METASTATIC COMMUNITY

CBCN was pleased to host an Educational Forum in Calgary at the Tom Baker Cancer Centre in September of 2016. This free interactive session was attended by people living with metastatic breast cancer and their caregivers. Tom Baker's own Medical Director, Dr. Sunil Verma, MD, MSc, FRCPC, shared the latest updates and held a Q & A session with participants. Dr. Michael Specia, Psy.D, R. Psyc., a Clinical Psychologist at the Tom Baker Cancer Centre spoke about practical mindfulness skills for improving well being. CBCN was pleased to partner again with Dr. Verma to offer this session and give participants a chance to hear about ways they can live better with metastatic breast cancer. CBCN will continue to offer this beneficial program in other cities across Canada.

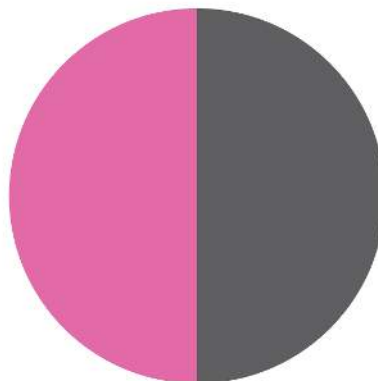
# CREATING CAMPAIGNS TO RAISE AWARENESS OF MBC

## The 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 *mBC Time Campaign* in October of 2016. This campaign was created to raise awareness of metastatic breast cancer with Canadians and media across the country. Starting on October 13th, Metastatic Breast Cancer Awareness Day, and running for 13 days CBCN shared content on our Facebook and Instagram page's. Included was a moving English-speaking video featuring well-known writer and artist Teva Harrison, a corresponding French-speaking video featuring Louise Portal, known for a successful film and music career in Québec, as well as 12 profiles of patients and caregivers facing an mBC diagnosis. The videos and profiles garnered well-deserved attention from the Canadian public on the challenges women living with the disease face. In addition to the social media, traditional media and street teams were also utilized to create support and awareness.

### Some campaign highlights include:

- 134 traditional media stories
- 832,900 + video views
- 10,000 awareness buttons and info cards were distributed between Montreal, Toronto and Vancouver





## The Living Legacy Campaign

In May of 2017, CBCN launched its third iteration of *The Living Legacy* metastatic breast cancer awareness campaign. This digital campaign has allowed Canadians to share their lived experience through a series of videos. These videos honour Canadian women living with mBC and demonstrate that their lives and legacies are much more than a cancer diagnosis. This multi-year campaign has helped galvanize the voice of this patient community and has raised awareness about this form of breast cancer.



The third year has increased the focus of understanding the sub-types of metastatic breast cancer and how this impacts the treatment options for a patient. Four women shared their sub-type of breast cancer and what this means. Educational postcards and graphics about the various sub-types were created to help provide information about the importance of knowing your type. These postcards were printed and continue to be distributed at all mBC related conferences and events that CBCN attends.

CBCN had the opportunity to share these Living Legacy resources at a patient forum hosted by the Québec Breast Cancer

Foundation. This educational day brought together patients from across Québec to learn about the advances in breast cancer care and living well after a breast cancer diagnosis. We were able to further the discussion on knowing your sub-type and we were thrilled to be joined by Mei-Lin Yee, who has been featured in all three years of the Living Legacy campaign.

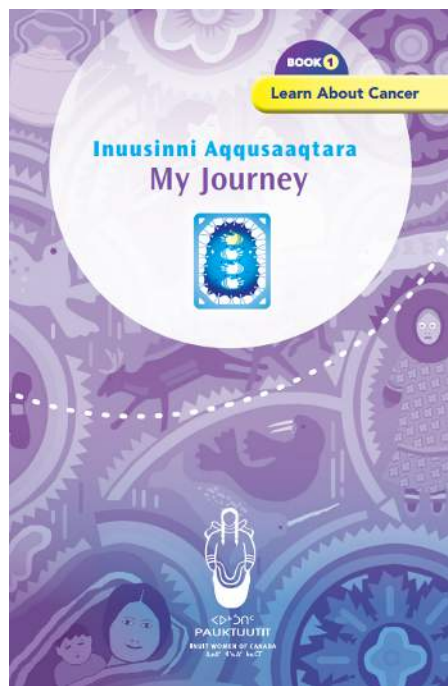
### **The Living Legacy campaign has had the following reach over 3 years:**

- 5,300+ views of the Living Legacy videos
- 180+ media stories
- 24 million + media impressions



## STRENGTHENING PARTNERSHIPS

### THE INUIT CANCER PROJECT



CBCN continued its work as a key partner on the Pauktuutit Inuit Women of Canada's Inuit Cancer Project. The project produced and developed newly diagnosed guides called "Inuusinni Aqqusaaqtara - My Journey" with a specific focus of increasing awareness and understanding of cancer among the Inuit population receiving cancer treatment. These guides included two booklets that can be accessed digitally on their website (<http://pauktuutit.ca/cancerpartnering/resources/>) and were translated into three dialects of Inuktitut – North Baffin, Nunavik and Inuinnaqtun. They were printed and distributed to cancer centres in Edmonton, Winnipeg, Ottawa, Montreal and St. John's that host treatment for those coming from Northern communities. CBCN was pleased to be able to advise on the development of these useful and much-needed resources and we are honoured to be a part of this devoted group of community members and organizations.



ᐱᐸᐸᐸᐸ  
ᐱᐸᐸᐸᐸ ᐱᐸᐸᐸᐸ  
**PAUKTUUTIT**  
**INUIT WOMEN OF CANADA**



# REPRESENTING THE PERSPECTIVES OF PEOPLE LIVING WITH BREAST CANCER AND MBC AT THE NATIONAL LEVEL

## CPAC Conference on Optimal Approaches to Cancer Care in Canada

CBCN had the opportunity to present findings from its 2015 *Waiting for Treatment: timely equitable access to drugs for metastatic breast cancer* report at the Canadian Partnership Against Cancer's (CPAC) Conference on Optimal Approaches to Cancer Care in Canada in April of 2017. This gave us a great opportunity to further discuss the gaps in coverage by public health insurance agencies to cover basic life-extending treatments for metastatic breast cancer. Our poster presentation was part of the "Economics of High-Quality Care" theme which explored the cost of care and the economic factors that have lead to increases in health care costs. Part of the discussion centred on how we determine value for money and translate clinical trial results into real world data that can inform effectiveness. It also explored how cancer control programs can maintain system quality and innovation while maintaining sustainability. CBCN was pleased to be able to contribute to this important discussion and continue to ensure that the voice of patients is represented and considered when discussing the health care system.

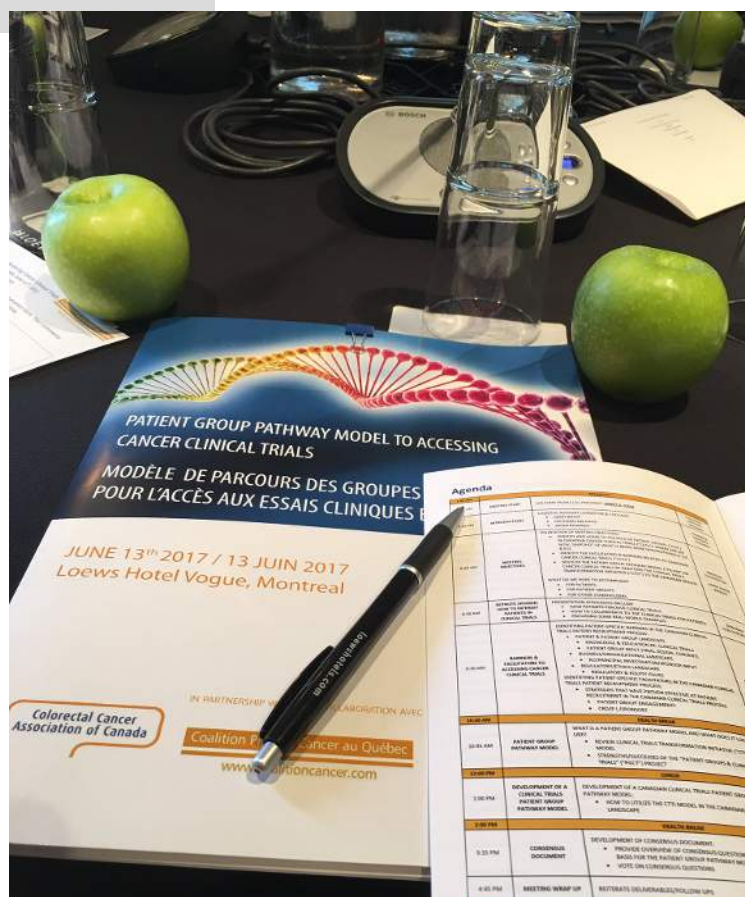
### OUR CONTINUED PARTICIPATION HAS ALSO INCLUDED:

- Best Medicines Coalition (BMC)
- CanCertainty Campaign
- Quality End of Life Care Coalition of Canada (QELCCC)

## Colorectal Cancer Association of Canada meeting: Patient Group Pathway Model to Accessing Cancer Clinical Trials

CBCN was pleased to participate in the Colorectal Cancer Association of Canada's meeting in Montreal June of 2017. The Clinical Trials meeting was very well organized and had great attendance from patient groups, industry and clinical trial centres.

The purpose of the meeting was to look at adopting the US based Clinical Trials Transformative Initiative (CTTI) into a Canadian model and to develop a consensus document on clinical trials to lead to the development of a comprehensive cancer patient group pathway model to accessing cancer clinical trials. The Colorectal Association plans to publish the consensus statements and model as well.



# REPRESENTING THE PERSPECTIVES OF CANADIANS LIVING WITH BREAST CANCER AND MBC AT GLOBAL FORUMS

## World Cancer Congress, Paris


CBCN had the opportunity to present key findings from its *2015 Waiting for Treatment: timely equitable access to drugs for metastatic breast cancer report* at the World Cancer Congress in November of 2016. We presented these findings in a rapid-fire panel session on Practice, Policy and Advocacy Reports. This gave us an opportunity to participate in an important discussion on access and availability to innovative and life-extending treatments globally.

## San Antonio Breast Cancer Symposium, Texas

From December 6 to 10, 2016, CBCN had the pleasure of participating in the 2016 San Antonio Breast Cancer Symposium (SABCS) in Texas. Joined by key researchers, industry leaders and patient advocates from around the world we discussed new and emerging research for breast cancer. As a part of this conference, CBCN presented a poster on the *2015 Waiting for Treatment: timely equitable access to drugs for metastatic breast cancer report* and contributed to a growing conversation on availability to emerging treatments. CBCN used this platform to spearhead global discussions on the treatment and care of metastatic breast cancer patients and their families.

**WAITING  
FOR  
TREATMENT:**

TIMELY EQUITABLE ACCESS TO DRUGS  
FOR METASTATIC BREAST CANCER





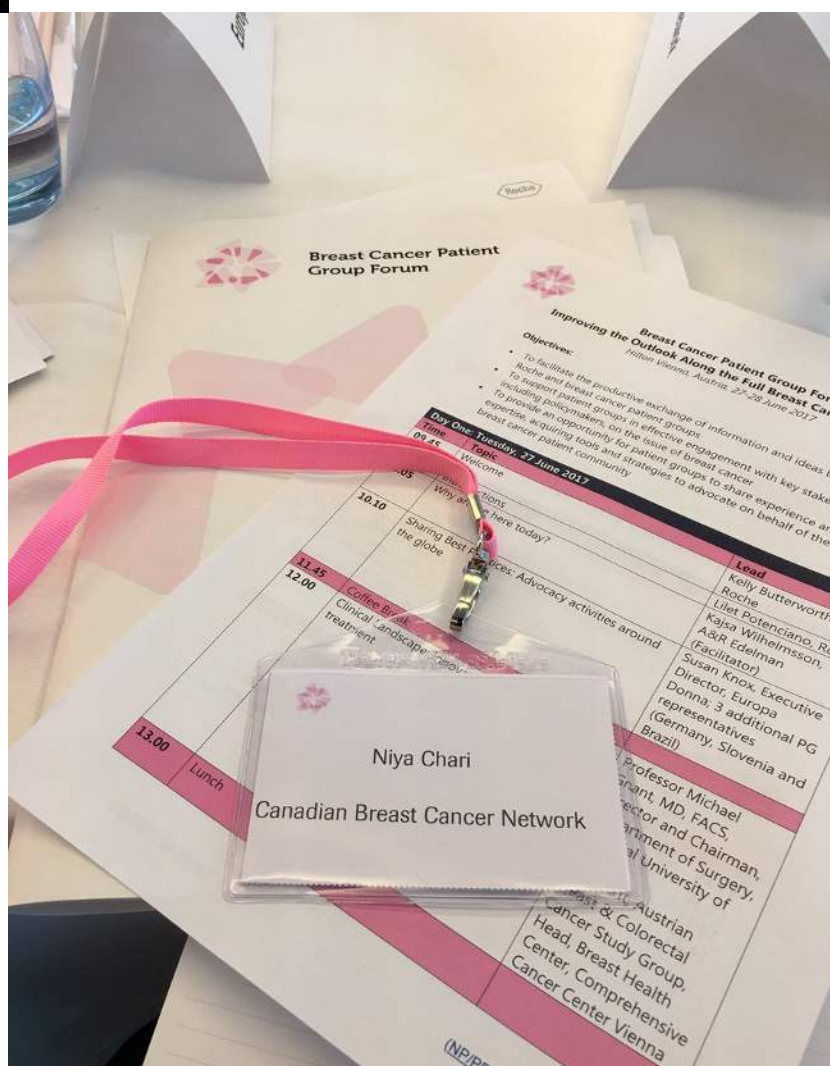


## Europa Donna Metastatic Breast Cancer Advocacy Conference, Italy

CBCN was given the opportunity to attend and speak at Europa Donna's first Metastatic Breast Cancer Advocacy Conference in Italy in June 2017. The Chair of the Board, Cathy Ammendolea, spoke on a panel discussion about advocacy strategies while CBCN also had the opportunity to present on "Successful mBC Advocacy Strategies and Best Practices in Canada." Our participation at this conference led to fruitful discussions with other patient organizations and allowed us to represent Canadian patients and ensure that the patient voice is heard and considered.

## Breast Cancer Patient Group Forum, Vienna

Also in June of 2017, CBCN attended the Breast Cancer Patient Group Forum in Vienna, Austria to discuss the value of patient input in the healthcare system. CBCN joined delegates from breast cancer organizations in Europe, the United States and Brazil to share information, exchange ideas and discuss how patient groups like CBCN, can be more meaningfully engaged in decision-making on health. The conversations included clinical trial designs, earlier detection of breast cancer and the patient experience within the health care system.





## 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. 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
- Bev Jacobs: Ontario
- 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 live 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





## 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.





## SUPPORTERS

**AMGEN**<sup>®</sup>



NOVARTIS  
ONCOLOGY



**Oncology**

UNITED  
**AWARENESS**  
GROUP

AstraZeneca 

*Healthy  
Cravings*



**Full Circle**  
Foundation for **Wellness**

