



# Using a National Needs Assessment to Direct Programs for Young Women Affected by Breast Cancer

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## Background

Ten percent of breast cancer cases occur in women under age 45, resulting in an estimated 24,000 new diagnoses a year. Younger women are less likely than older women to be diagnosed with breast cancer, but their cancers are more likely to be found at higher stages and have biological characteristics that require aggressive treatment. In addition, young women face unique psychosocial issues. In 2011, Living Beyond Breast Cancer (LBBC) launched the Young Women's Initiative (YWI) to expand and strengthen LBBC programs and services for young women. YWI is funded through a cooperative agreement with the Centers for Disease Control and Prevention.

**YOUNG  
WOMEN'S  
INITIATIVE**



## National Needs Assessment

In 2012, LBBC conducted a national needs assessment of young women and used the findings to set program priorities and direct program expansion. The goal of the needs assessment was to explore the information and support needs of young women affected by breast cancer, examine subgroup differences and identify gaps in programming.

### Needs Assessment Components:

- 1 Key informant interviews with healthcare providers and cancer advocates (N=12)
- 2 Four focus groups with young women (N=33)
- 3 Environmental scan and gap analysis of organizations (N=29)
- 4 National survey of young women (N=1,473)

### Primary Needs Assessment Findings:

- 1 Young women want breast cancer information and emotional support tailored to their age group but many have difficulty finding this information and support.
- 2 Women diagnosed with breast cancer before age 30, African-Americans, Latinas and women living with metastatic breast cancer report different concerns and interests compared to other groups of young women.
- 3 There are limited national educational programs for young women affected by breast cancer. There are even fewer resources for historically underserved subgroups of young women.
- 4 More healthcare providers should discuss the potential impacts of treatment on fertility with premenopausal women prior to cancer treatment.
- 5 All young women should receive genetic counseling when they receive genetic testing.
- 6 Many women diagnosed before age 45 report side effects many years after completing treatment.

## Program Expansion

### ONLINE CONTENT: LBBC.ORG/YOUNGWOMEN

Fifty percent of the survey respondents reported preferring to receive health information in an online format. Based on this finding, LBBC expanded online resources tailored to young women.

- Developed over 100 website articles specific to young women. They include easy-to-read summaries of breast cancer research studies and profiles
- Posted 16 Web content pieces relevant to young women for the "Learn About Breast Cancer and Young Women" section. Topics included advocacy, using social media to find information and support, bone health, sex and intimacy, fertility, early menopause, and communication with healthcare providers



### BREAST CANCER HELPLINE: (888) 753-LBBC (5222)

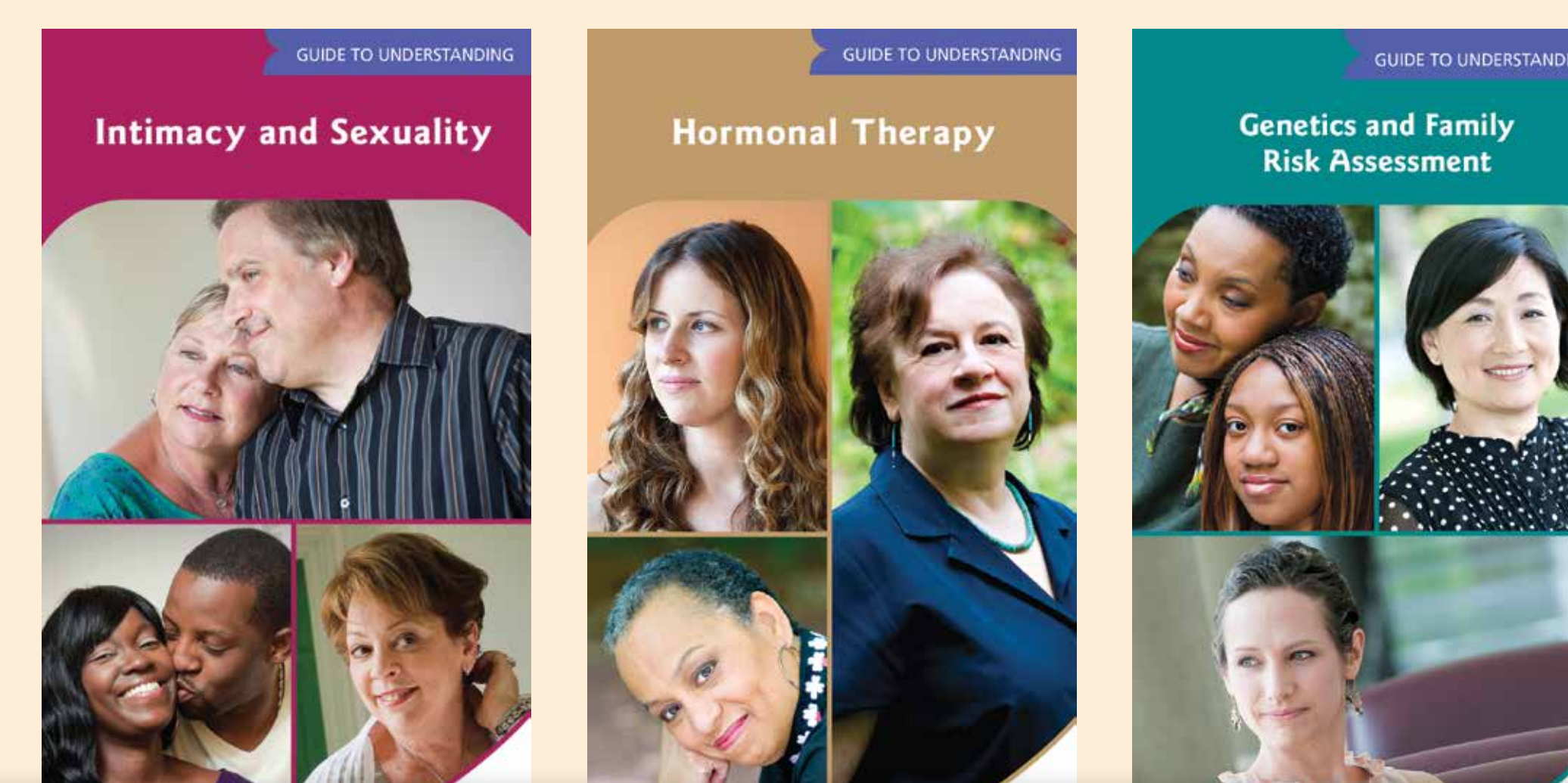
The needs assessment showed that young women want to receive emotional support tailored to their age group. LBBC expanded its Breast Cancer Helpline, a peer support service serviced staffed by trained volunteers, to better meet the needs of young women.

- Trained 35 young women as Helpline volunteers since 2011
- Increased percentage of Helpline volunteers who were diagnosed before age 45 to 40%
- Receive 1,300 calls per year, with an estimated that 15–20% from young women
- Conducted national marketing campaigns for Helpline

### PUBLICATIONS

Psychosocial topics and side effect management were ranked of high interest by survey respondents. LBBC focused efforts on developing print publications on topics of high interest to young women. They included:

- *Guide to Understanding Intimacy and Sexuality*
- *Guide to Understanding Hormonal Therapy*
- *Guide to Understanding Genetics and Family Risk*
- eReader version of *Guide for the Newly Diagnosed*

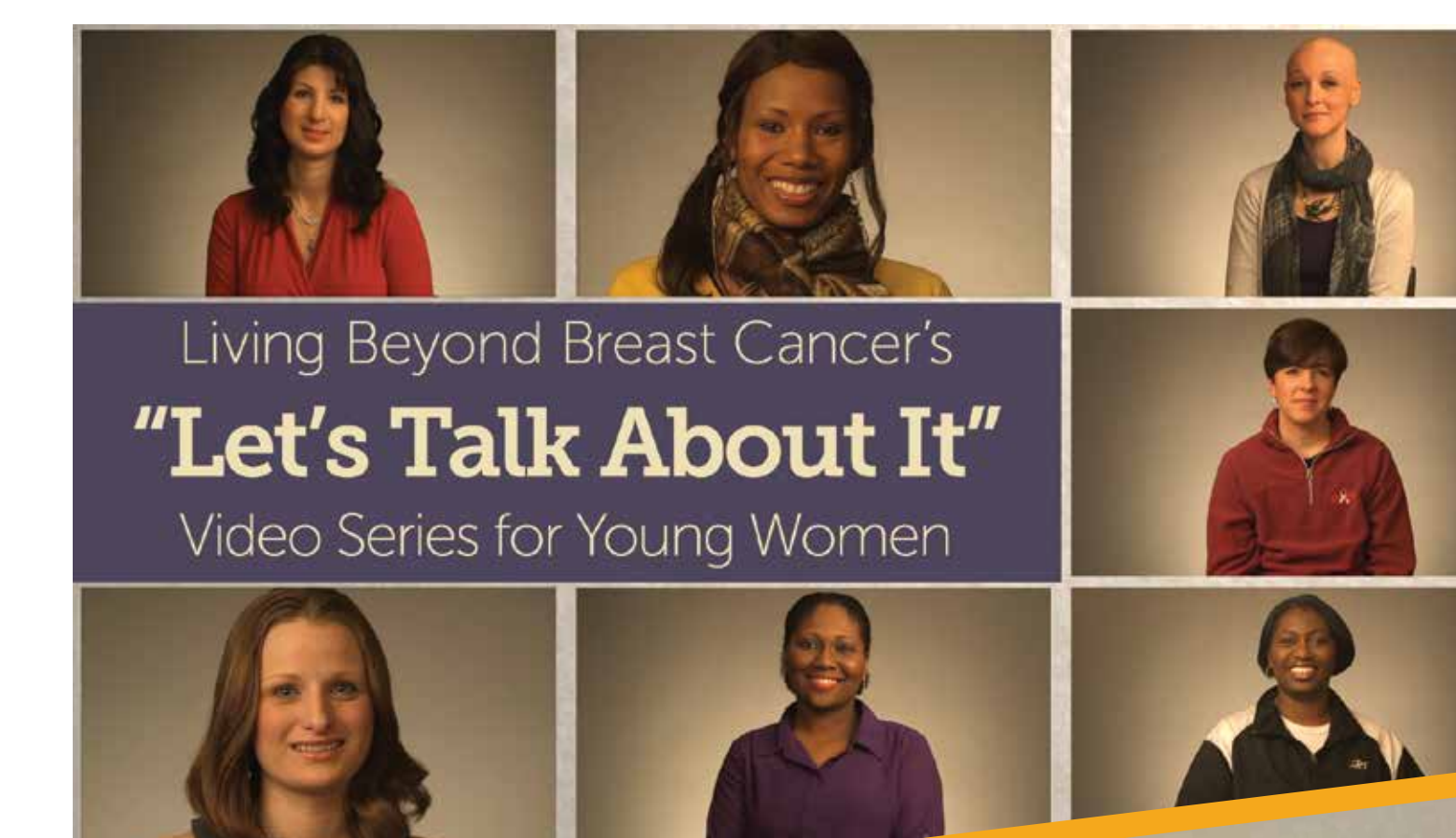


## New Programs

### LET'S TALK ABOUT IT VIDEO SERIES

The needs assessment found that young women prefer to learn from other young women and want interactive online resources. The *Let's Talk About It Video Series* brings together in short online videos the perspectives of young women and healthcare providers on relevant health topics.

- Videos in Series:
  - Let's Talk About Sex (and Breast Cancer)
  - Hear Me: Communicating With Your Healthcare Team
  - What Young Women Should Know About Bone Health
- Over 3,200 combined views
- Three additional videos in development: the financial impact of breast cancer, body image, and communicating with your support system as a young woman living with metastatic breast cancer



### YOUNG ADVOCATE PROGRAM

The Young Advocate Program helps young women harness their personal experience to make a difference in their communities.

- Targets women with incomes at or below 200% of the federal poverty guideline who are within three years of diagnosis or living with metastatic breast cancer
- 8 hour in-person training covers topics on the spectrum of advocacy, breast cancer health disparities and effectively sharing one's personal story of breast cancer
- Participants reported an increase in their knowledge of breast cancer and young women, national advocacy resources, and LBBC as a result of this training
- Program participants are required to complete two advocacy activities and share LBBC's publications with at least one healthcare provider within six months of training
- Trained 29 young women through the program

### HEALTHCARE PROVIDER EDUCATION

Young women reported that standards of care, particularly as they relate to fertility options and genetic counseling, are not being upheld for all young women diagnosed with breast cancer. LBBC developed programs to educate healthcare providers on the unique needs of young women and help them develop the skills needed to address these needs.

- Developed two webinars for healthcare providers, combined participation of more than 500 healthcare providers
- Majority of webinar participants reported an increase in knowledge based on their participation in the program
- Healthcare Provider Symposium held in May 2014 in conjunction with Association of Oncology Social Work Annual Conference

## Challenges

LBBC faced multiple challenges when expanding programs to better meet the needs of young women affected by breast cancer. Some challenges include:

- Measuring impact and outcomes of online content
- Tracking marketing efforts
- Engaging diverse populations
- Reaching young women upon diagnosis
- Find a balance between creating inclusive general programming that meets the needs of young women and creating tailored programs just for young women

## Conclusion

LBBC's national needs assessment of young women affected by breast cancer found that young women have significant information and support needs that are not currently being met. LBBC used the needs assessment findings to expand and develop new programming through its Young Women's Initiative that better meet these needs.

This process demonstrates the benefits of using needs assessments to drive program development. This model can be used for other cancer survivor populations, where knowledge of their needs and program offerings are lacking.

