LBBC RESOURCES FOR LIVING WITH METASTATIC BREAST CANCER

People with metastatic breast cancer—cancer that has spread beyond the breast and nearby lymph nodes, also known as stage IV disease—have unique experiences and needs. Living Beyond Breast Cancer is committed to helping people with MBC and their loved ones find the information, community and support they need to shape their own lives and advocate for change. LBBC’s resources include:

The Metastatic Breast Cancer Series: Guides to Understanding
LBBC’s library of free guides covers a diverse range of topics to provide you with medical and psychosocial information, advice, and tips on where and how to find support. Available in print or for download on lbbc.org.

Guide for the Newly Diagnosed, Available in 5 Languages
To better reach all people living with metastatic disease, LBBC’s Metastatic Breast Cancer: Guide for the Newly Diagnosed has been translated into four languages: Spanish, Chinese, Vietnamese, and Tagalog, and is available online or in print. A French Canadian version is available online only.

LBBC hosted the first national Metastatic Breast Cancer Conference in 2006, and since then, the event has brought its invaluable information to a larger audience each year. Sessions and workshops at this annual conference help people with stage IV disease and their caregivers learn more about diagnosis, treatment, disease management and well-being, and additional activities allow them to connect with hundreds of others who understand their experience and form networks of support. The 2018 Conference on Metastatic Breast Cancer will be held in Philadelphia April 20–22.

LBBC’s Peer Helpline
The Breast Cancer Helpline connects you to trained volunteers who have been diagnosed with breast cancer for emotional support, guidance and hope. Whether recently diagnosed, in treatment, years beyond treatment, living with metastatic breast cancer, or caring for a loved one – LBBC volunteers are available to help. You can either complete an online match form at lbbc.org/helpline or call (888) 753-5222.
Advocacy Training: Hear My Voice
The Hear My Voice: Outreach Volunteer Program, founded in 2015, trains volunteer advocates with metastatic breast cancer to educate the public about MBC and connect others living with the disease to information and resources. Since its founding, the program has enrolled 135 volunteers from across the nation, helping them raise their voices to make a difference in their physical and digital communities. Dedication and unique skills have connected more than 100,000 people to education about MBC.

Silent Voices: A Psychosocial Research Investigation
In 2005, Living Beyond Breast Cancer commissioned Silent Voices, the first nationwide assessment of the psychosocial needs of women living with metastatic breast cancer. With public attention focused on prevention and screening, the metastatic community was underserved. The survey found that women diagnosed with stage IV breast cancer were looking for detailed, trustworthy information about their diagnosis, new and upcoming treatments, and side effects, and that they sought out programs and networks of support.

Count Me!
An estimated 20–30 percent of people diagnosed with early-stage breast cancer eventually receive a diagnosis of metastatic disease—yet we don’t know for sure how many because our national databases record only an initial diagnosis, not breast cancer that becomes metastatic. This crucial gap blunts research and political advocacy efforts around MBC. At its Metastatic Breast Cancer Conference in 2017, LBBC used the theme “Count Me!” to publicize a petition started by the Metastatic Breast Cancer Alliance (MBCA), of which LBBC is a founding member, calling on the NCI to properly count metastatic recurrence in its SEER database. The petition met its 10,000-person goal. The NCI is now funding research to determine a protocol for collecting these data.

Blog and Social Media @LivingBeyondBreastCancer
LBBC often publishes blog entries from Hear My Voice volunteers and others living with stage IV breast cancer, facilitates Twitter chats, and hosts extensive online resources on topics from coping with stress and anxiety, to managing finances, to sorting through treatment options.

If you or a loved one are living with metastatic breast cancer, you can find these resources and more at http://www.lbbc.org/i-am-living-with-metastatic-breast-cancer.

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