Tigerlily Foundation’s (Tigerlily's) MY LIFE (Metastatic, Young, Living in Focus, Empowered) Program is dedicated to sharing the perspectives and the unique challenges facing young women living with metastatic breast cancer (MBC).

MBC changes the life of the young woman diagnosed and everyone around her. Life for a young woman living with MBC means being in treatment for the rest of her life. Many metastatic breast cancer patients often feel isolated and lonely, sometimes even angry about the diagnosis. As a metastatic breast cancer patient, it may be difficult to talk about what you’re going through; and finding people who understand the unique challenges that you face, fears, and living life with uncertainty. This can lead to isolation and loneliness.

Wherever you are in your journey, know that you are not alone. You have friends, advocates and caregivers who hear your voice. Together, we will let everyone know that your stories matter and deserve to be heard.

For anyone who would like to support the MBC community, please consider contributing to our MY LIFE program resources and sharing these resources throughout your networks:

- **MY LIFE Quarterly Newsletter**
- **MY LIFE Guidebook**
- **MY LIFE Blog**
- **MY LIFE Stories**
- **MY LIFE Twitter Chats**
- **MY LIFE Podcasts**

Our MY LIFE Podcasts feature the perspectives of young women living with metastatic breast cancer, giving insight into their needs, challenges, and offering awareness and support to other Metsters. Monthly episodes will be released on the 1st of each month and posted on the My Life Blog and will also be available in the [iTunes Store](https://www.apple.com/itunes/).

- **MY LIFE Facebook Group**

Tigerlily Foundation’s recently launched initiative on Young Women’s Metastatic Breast Cancer Disparities began with a historic listening summit. Our Facebook group provides an opportunity to engage in our Metastatic Breast Cancer Disparities Initiative.

If you would like to take a leadership role in Tigerlily Foundation’s mission, you can apply online on our website. You can also support our mission by becoming an ANGEL (Advocate Now to Grow, Empower and Lead). The ANGEL program provides comprehensive trainings for young women under the age of 45, so that they understand how breast cancer affects younger women, and learn how to get more involved in using their time and voices to make an impact.

Additional ways to help include fundraising for Tigerlily Foundation, participating in social media outreach, Twitter Chats, and webinars, volunteering at local events, sharing your personal story for others through blogs or podcast, and starting your own Tigerlily Foundation chapter in your town or city.
The one thing that I know to be certain is that I will leave this earth one day. Whether it is from metastatic breast cancer, getting hit by a truck, or natural causes, I know that my life will eventually end. I have been blessed to have rotated around the sun 48 times and God willing, 49 times will be here soon. In the days that I have left, I do not sit and worry about when my expiration date will come or how. Every day that God allows me to wake another day, I will LIVE LIFE NOW.

What does living life now mean you ask? To me, in order to Live Life Now means doing what makes me happy daily. If I can stand up and walk, then I Live Life Now. Gone are the days of waiting for people to help contribute to my happiness. If I have to do it alone, so be it. With my faith is in God, I do not worry about my cancer diagnosis. Instead of worrying, I travel, attend concerts, spend time with my family and do whatever else I feel like doing at the moment.

Gone are the days of excessive planning, putting things off because I "have time", waiting until I pay off this or that, waiting for friends or family to do it with me. If it hits me to do it and I have time and can make it work, then off I go. As one of my close friends and I always say "because I can" so I do! I post many pictures of my trips and memories in the hopes that I can inspire someone else to Live Life Now, their way.

I am going to continue to Live Life Now, by my own drumbeat, until the wheels fall off! However, that looks for you, I encourage you to do the same.
Does having stage 4 breast cancer not make me worthy of love?

By Angela "Jersi" Baker

As hard as it is to admit, I have been unsuccessful in finding romantic love in my adult years. Leading up to my adult years, I had no issue in being involved in committed relationships. However, as an adult in my 30s, all that changed for whatever reason, be it the on again, off again relationships, the dating "forever" without a true commitment or the failed relationships, I find myself being single more days than not.

Lately, I have started to wonder if my breast cancer diagnosis is keeping me from being in a committed relationship or of being worthy of love. Does sharing my story scare men off? Do men look at my uno-boob status and fray away? Is my zest for life too much for one to deal with?

When I think back, it has been since 2012 that I have been in a committed relationship. I think I am a loving person; I think that I am capable of attracting love and reciprocating it. In my mind, I often worry if I am worthy enough to have my supporting mate, my equal, my guy, my dude, my protector, my spiritual partner, my person to walk through the storms of life with, my vacation bae. I ponder if I will leave this earth without being in a committed relationship. I know God did not put us on earth to do life alone. I know more single women like myself than I know those in a committed relationship. Is it that men are not interested in committing anymore? Are women too strong, too independent, too set in our ways? I am far from lonely because I am ok with eating alone, but I do long for all the joys of a mate – someone to keep me company, someone to vent to, someone who will let me be me, without judgment.

Is desiring a mate taboo? I honestly do not have any answers to my own questions. I can also admit that I may not be aware of all the dynamics of dating. Should I try a dating site, frequent more clubs, wear a sign that I am single, ask friends to introduce me? Or should I do as I have been doing and wait on God to send me my Boaz?

While I wait, I will continue to Live. As I remind myself daily that I am worthy, I ask that God send me someone who is most worthy and deserving of the love that I have to give.

God please let my worthiness of love speak even when I am silent, let the words of worthiness that slide off my tongue sound like music to someone’s ears. I hope that the love and passion that I have for serving others bounces a bright light to guide my King to this worthy queen.
Metastatic breast cancer drugs that were FDA-approved in 2019

By Anne Loeser

Breast cancer treatments continue to evolve and improve. Last year, several therapeutic options emerged for treating metastatic breast cancer, greatly improving survival rates.

During the first half of 2019, the FDA approved three biosimilars to Herceptin (Trastuzumab). Each one was approved for first-line treatment of HER2-overexpressing MBC in combination with paclitaxel, and as a single agent for treatment of HER2-overexpressing breast cancer patients who have received one or more chemotherapy regimens for metastatic disease: Samsung Bioepis’ SB3 (Ontruzant; trastuzumab-dttb); Pfizer’s Trazimera (trastuzumab-qyyp); and Amgen and Allergan’s Kanjinti (trastuzumab-anns).

In February 2019, the FDA approved Genetech’s Herceptin Hylecta for the treatment of HER2-positive MBC in combination with paclitaxel or alone in patients who have received one or more chemotherapy regimens for metastatic disease. Herceptin Hylecta consists of Herceptin (Trastuzumab) and Hyaluronidase-oysk (Herceptin Hylecta).

In March 2019, the FDA granted accelerated approval for Roche’s Tecentriq (Atezolizumab) in combination with Abraxane (nab-paclitaxel) for the treatment of unresectable locally advanced or metastatic triple negative breast cancer patients whose tumors are PD-L1 positive. This combination therapy is the first FDA-approved immunotherapy regimen for breast cancer.

In April 2019, the FDA expanded the approval of Pfizer’s Ibrance (Palbociclib) with either an Aromatase Inhibitor (Letrozole, Arimidex, Aromasin) or Faslodex (Fulvestrant) to include men with hormone receptor-positive, HER2-negative MBC.

In May 2019, the FDA approved Novartis’ Piqray (Alpelisib), an oral PIK3 inhibitor, in combination with Faslodex (Fulvestrant) for the treatment of postmenopausal women (and men) with hormone receptor-positive, HER2-negative MBC. This treatment is specific for patients with metastatic breast cancer that has PIK3CA mutations and that progressed during or after an endocrine-based treatment regimen. The companion diagnostic test was approved simultaneously to detect the PIK3CA mutation.

In December 2019, the FDA granted accelerated approval to Daiichi Sankyo and AstraZeneca’s Enhertu (fam-Trastuzumab Deruxtecan-nxki, also known as DS-8201) for treating patients with unresectable or metastatic HER2-positive breast cancer who had received two or more prior anti-HER2-based regimens in the metastatic setting.
Clinical Updates for Patients with HER2-Positive MBC

The current standard-of-care treatment for patients with HER2-positive MBC is first-line Herceptin (Trastuzumab) plus Pertuzumab (Perjeta) and a taxane. For patients who have disease progression, the second-line treatment is Trastuzumab Emtansine (T-DM1). The FDA’s recent accelerated approval of Enhertu, and breakthrough therapy designation for Tucatinib are likely to transform the standard-of-care treatment for this population of patients.

Enhertu (Fam-Trastuzumab Deruxtecan-nxki/DS-8201) granted FDA-accelerated approval for treatment of patients with HER-positive MBC: Daiichi Sankyo and AstraZeneca’s international DESTINY-Breast01 Phase II trial evaluated the HER2-directed antibody drug conjugate (ADC) Trastuzumab deruxtecan in 184 HER2-positive MBC patients who had received prior treatment with two or more anti-HER2-based regimens in the metastatic setting. The study results showed a 60.3% confirmed objective response rate, which included a 4.3% complete response rate and a 56.0% partial response rate. Further, with a median follow-up of 11.1 months, the median progression-free survival was 16.4 months. The median duration of response was 14.8 months. The median overall survival has not yet been reached. Given these results, the FDA conferred accelerated approval to Enhertu for the treatment of patients with unresectable or metastatic HER2-positive breast cancer who have received two or more prior anti-HER2 based regimens in the metastatic setting. Read more here.

Addition of Tucatinib (formerly ONT-380) to Herceptin (Trastuzumab) and Xeloda (Capecitabine) chemotherapy improves survival for patients with metastatic HER2-positive breast cancer: Seattle Genetics’ international HER2CLIMB Phase II trial compared the combination treatment of Tucatinib (an oral inhibitor of HER2 tyrosine kinase that crosses the blood brain barrier) + Herceptin + Xeloda to the standard guideline-recommended treatment of Herceptin + Xeloda. The study enrolled 612 HER2-positive MBC patients with or without brain metastases who were previously treated with Herceptin, Perjeta (Pertuzumab), and Trastuzumab Emtansine (TDM-1). The median follow-up for the overall population was 14 months. The results of the study indicated that in the Tucatinib arm, there was a significantly lower risk of progression or death (p<0.00001), and a significantly higher confirmed objective response rate (41% in the Tucatinib arm vs. 23% the control arm; p=0.00008). At 1 year, the PFS was 33.1% in the Tucatinib arm vs. 12.3% in the control arm, and the median PFS was 7.8 months vs. 5.6 months, respectively. At 2 years, the OS was 44.9% in the Tucatinib arm vs. 26.6% in the control arm, and the median OS was 21.9 months vs. 17.4, respectively. Among the 47.5% of study patients with brain metastases (40% of which were untreated, or treated and progressing), the median PFS was 7.6 months in the Tucatinib arm vs. 5.4 months in the control arm, and the PFS at 1 year was 24.9% vs. 0%, respectively. The OS and PFS results were consistent across all pre-specified subgroups based upon age, race, hormone receptor status, geographic location, and other factors. Given these results, FDA granted breakthrough therapy designation for Tucatinib in locally advanced or metastatic HER2-positive breast cancer. Read more here.

Margetuximab shows better progression-free survival compared to Herceptin (Trastuzumab) in patients with HER2-positive MBC: MacroGenics’ SOPHIA Phase III trial enrolled 536 patients with HER2-positive MBC who were previously treated with anti-HER2-targeted therapies. Some of these patients were also hormone receptor positive, and some had brain metastases. The aim of this study was to evaluate the immune-enhancing monoclonal antibody Margetuximab + chemotherapy compared to Herceptin + chemotherapy. The results showed that the objective response rate was significantly higher in the Margetuximab arm compared to the Herceptin arm (25.2% vs. 13.7%, respectively; p=0.0006). The median progression free survival was significantly higher in the Margetuximab arm compared to the Herceptin arm (5.7 months vs. 4.4 months respectively; p = 0.0006). The median overall survival (OS) was 21.6 months in the Margetuximab arm vs. 19.8 months in the Herceptin arm. The subpopulation of patients carrying a CD16A 158F allele represent approximately 85% of the study population and might be more responsive to Margetuximab. In this subpopulation, the median OS was prolonged by 4.3 months in the Margetuximab arm compared to the Herceptin arm (23.7 months vs. 19.4 months). By contrast, for the approximately 15% of patients who were homozygous for the CD16A 158V allele, the Herceptin arm experienced a longer OS than the Margetuximab arm (33.3 months vs. 19.7 months, respectively). Read more here.
SABCS Event Recap

2019 San Antonio Breast Cancer Symposium (SABCS)

By Anne Loeser

SABCS is an annual symposium providing state-of-the-art information regarding the biology, diagnosis, and treatment of all stages of breast cancer to an international audience of physicians, researchers, and patient advocates. Often the results of clinical trials are presented at the conference, and when favorable outcomes are reported from a later-phase study, the experimental drug or combination of drugs may be FDA-approved shortly afterwards. At the 2019 conference, there were several updates on treatment development for metastatic breast cancer. Also, the Tigerlily Foundation launched the well-attended “Young Women’s Metastatic Breast Cancer Disparities Fireside Chat” which provided an open discussion about the disparities in cancer care and outcomes, along with potential solutions regarding these critical issues. This meeting summary includes highlights from the “Young Women’s Metastatic Breast Cancer Disparities Fireside Chat” as well as clinical updates on treatment options for MBC. For additional information, please visit here.

Special thanks to the Metastatic Breast Cancer Alliance (MBCA) for sponsoring my attendance at the symposium, which in turn enabled this document to be compiled for MBC patients worldwide. A major debt of gratitude to Eli Lilly for establishing the Patient Advocate Lounge at SABCS 2019, where patient advocates were able to unwind, enjoy refreshments, and converse with each other in a relaxed setting. A heartfelt congratulation to patient advocates Christine Hodgdon and Julia Maues, and to the many advocates and researchers who participated in the new “GRASP” (Guiding Researchers and Advocates to Scientific Partnerships) Program successfully piloted this year. This initiative brought together patient advocates and scientists for poster walk-throughs designed to enhance joint communication and mutual understanding.
Quotes from SABCS Attendees

"Attending SABCS was a great experience for me. At first, I was skeptical about attending but I'm glad that I went. I learned so much from the other women who are dealing with cancer. The two things that surprised me the most were:

1. Hearing others tell their stories about their doctor visits and me learning that I wasn't the only one who struggled with doctor interactions.

2. Meeting women who are surviving metastatic breast cancer longer than a year. That shocked me but made me so happy. I'm glad I attended. A lot of information was shared that I didn't know."

- Tamekia Powell, Tigerlily Foundation MBC ANGEL Advocate

"It was amazing. To hear the different stories from so many women like yourself was powerful. Just being able to gain so much knowledge and ask questions was everything."

- Keyla Nunny Reece, Tigerlily Foundation MBC ANGEL Advocate

"I learned about the latest research and treatment innovations, participated on panels and made strong networking connections."

- Jamil Rivers, Tigerlily Foundation MBC ANGEL Advocate

"The conference was both inspirational and informative. Learning from doctors, scientists and speaking with MBC, patients gave me additional insight and a larger desire to want to image change in my city."

- Anastasia Stevenson, Tigerlily Foundation MBC ANGEL Advocate
Tigerlily Foundation’s Young Women’s Metastatic Breast Cancer Disparities Fireside Chat was the first-of-its-kind meeting that gave young women of color a “seat at the table” by providing them a platform at the largest global scientific meeting focused on breast cancer – SABCS. This program is part of a broader program, Tigerlily Foundation’s Young Women’s MBC Disparities Initiative, which is aimed at building bridges between women of color, scientists, advocacy groups and industry, as well as increasing engagement in clinical trials and providing a public forum for honest, and sometimes uncomfortable, conversations in a safe space.

The Fireside Chat fostered transformational dialogue, engaging young women in the African American community from 20 cities identified as locations having a high rate of breast cancer diagnosis among women of color. The dialogue was centered on understanding the gaps, misperceptions and barriers within the healthcare system that affect young women of color with MBC. Advocates at the Fireside Chat attended various SABCS presentations, advocacy and poster sessions and the best of SABCS meetings, providing them with additional “seats at the table” and allowing them to work side-by-side with some of the best in breast cancer research and advocacy. Advocates also participated in the pilot GRASP program (Guiding Researchers and Advocates to Scientific Partnerships) for a guided walkthrough of SABCS posters with a researcher provided additional scientific expertise. After the SABCS, the advocates will participate in a one-year cohort program that will offer education, training and immersive experiences in their local community and nationally. Advocates will share their perspectives from these various opportunities via digital content with their local communities.

Maimah Karmo, President, Tigerlily Foundation, shared, “This initiative builds on the landscape-changing work that Tigerlily Foundation has accomplished to work to end disparities of age, stage and color. We look forward to building a table for young women of color at the San Antonio Breast Cancer Symposium; we are excited about launching our cohort with these young women next year, along with a national tour to create change in communities facing disparities. Look forward to amplifying and elevating the conversation around young women of color, metastatic breast cancer, clinical trials and health disparities.”

The Amanda de Fiebre Legacy Travel Grant was generously established to support travel for an additional nine African American patient advocates from underserved areas to attend SABCS and participate in the GRASP program. Amanda de Fiebre, a tireless patient advocate who faithfully attended breast cancer conferences including SABCS, died of MBC this past August.

This event was hosted in partnership with the MBC Alliance; and was generously supported by independent grants from Daiichi Sankyo, Puma Biotechnology, Pfizer, Agenda, Amgen, Genentech, Lilly Oncology, Novartis, Seattle Genetics, Myriad, Paxman Scalp Cooling, Sanofi, Macrogenics, Foundation Medicine, ImmunomedicsPaxman Scalp Cooling, Sanofi Genzyme, Forward4Tobi and the Amanda de Fiebre Legacy Travel Grant; and in partnership with The Iris Collaborative.
Approximately 125 people, most of whom were women of color, all fit in a packed room. Presenters discussed challenging the status quo and not accepting that “it’s too complicated” to provide quality care and support for all breast cancer patients, including underserved populations. Speakers and attendees worked on action items, including pledging that they wouldn’t serve as speakers at medical conferences unless panels included women of color and those who had metastatic breast cancer.

Presenters at the Tigerlily event also highlighted factors that can get in the way of access to care for women of color. For instance, more than three-quarters of African American women are single mothers, which makes navigating cancer treatment even more challenging, noted breast cancer survivor and advocate Ricki Fairley, who works to increase awareness of breast cancer in African American communities as a staff member at the nonprofit organization Sisters Network Inc.

“I was stunned to hear this statistic,” said another panelist, Tatiana M. Prowell, a medical oncologist at the Johns Hopkins Kimmel Cancer Center in Baltimore and a breast cancer scientific liaison to the FDA’s Oncology Center of Excellence.

— Marci A. Landsmann, Cancer Today Magazine Read more of the article here.

All Tigerlily Foundation MY LIFE Newsletter readers are offered to subscribe to Cancer Today Magazine for FREE. Published quarterly by the American Association for Cancer Research, Cancer Today is the authoritative resource for cancer patients, survivors and their family members and friends. In every issue, Cancer Today offers information and inspiration as readers face the challenges of diagnosis, treatment, survivorship or caregiving. To apply for a new FREE subscription click here.

“The thing to know is that we need to make sure that we understand that there’s still gaps in survival, that even though we’ve done so much, we have come so far, there is a difference between breast cancer in white women and black women and that we need more research to know why.”

— Dr. Lori Wilson

“Shawn Johnson, a student at Harvard Medical School also noted the way in which black women have been excluded from breast cancer clinical trials, which play a key role in advancing treatment of the disease and provide those who have already been diagnosed with earlier access to promising treatments. He called up information from one clinical trial that included about 4,000 people, only 20 of whom were black women.”

— Lauren Caruba, San Antonio Express News Read of the article here.
The MBC ANGEL Program consists of 8 education modules that are informed by the young women of color in our program and the communities we aim to collectively empower. This curriculum addresses issues of systemic barriers, social determinants of health, cultural competency, mistrust and mobilizes young women of color in outreach to represent and impact the communities with the greatest MBC disparities.

1. Introduction
2. Disparities & MBC
3. Guidelines
4. Clinical Trials & Genetic Testing
5. Mobilization
6. Healthy Behaviours
7. Patient Empowerment
8. Health Lifestyle Habits

The MBC ANGEL advocates will participate in a variety of activations including:

- 60 Local MBC Education & Outreach Activities
- 20 MBC Advocates attend scientific conferences
- 8 MBC advocate modules & training sessions
- 12 MBC social media resources

Tigerlily Foundation Winter 2019/2020 MY LIFE Newsletter
Tigerlily Foundation Winter 2019/2020 MY LIFE Newsletter

Young Women’s MBC Disparities Initiative
Defining Impact: 3 Phases. 1 Focus.

**LISTEN**

Listen to identify needs, priorities, barriers, partners & methods

**CREATE**

Create a metastatic breast cancer disparities advocacy, education & outreach campaign

**MOBILIZE**

Mobilize young women of color to lower African-American breast cancer mortality rates

**FOCUS**

Tigerlily will listen to gather insights to create a metastatic breast cancer disparities advocacy, education and outreach campaign to mobilize young women of color to build a global platform that will end breast cancer disparities among young women of color in our lifetime.

-Launched at MBC Disparities Listening Summit
  Washington, DC
  March 2019

-Launched at Young Women’s Breast Health Day on the Hill
  Washington, DC
  November 2019

-Launched at San Antonio Breast Cancer Symposium
  December 2019

**20 CITIES. 20 ADVOCATES.**
**OUR AREAS OF IMPACT**

Memphis
St. Louis
Dallas-Fort Worth
Los Angeles
Virginia Beach
Atlanta
Chicago
Houston
Washington, DC
Philadelphia
Baltimore
Detroit
Cleveland
Miami
Charlotte
Oakland
New York
New Orleans
Jackson, MI
Camden, NJ

#ListenUpMBC Together, MBC ANGEL Advocates Will:

**COMMIT**
Commit to advocacy program to learn, share, grow, host events & other outreach activities to educate your community.

**ATTEND**
Attend and actively participate in all Tigerlily Advocate trainings and at least 1 to 2 conferences with travel support.

**AMPLIFY**
Amplify the conversation on social media via Facebook, Instagram, Twitter, Linkedin, and blogging.

**HOST**
Host at least 3 Tigerlily supported educational or outreach events to engage and educate community members.

**PARTICIPATE**
Participate in monthly Advocate calls for training, updates, partnerships, and opportunities.

**ACTIVATIONS**

+60 Local MBC Education & Outreach Activities
+20 MBC Advocates Attend Scientific Conferences
8 MBC Advocate Modules & Training Sessions
+12 MBC Advocate Social Media Resources

Follow @TigerlilyCares and share using #ListenUpMBC | Learn more at tigerlilyfoundation.org or email: ANGELs@tigerlilyfoundation.org
Unity Offers 24/7 Prayer Line

Tigerlily Foundation and Unity have a 24/7 Prayer Line for young women diagnosed with breast cancer. You can speak confidentially with someone at anytime – they are available 24 hours every day. You can be any faith or have no faith tradition. Call 1-888-803-4680. Here is a prayer.

Prayer for Protection

The light of God surrounds us;
I AM light.

The love of God enfolds us;
I AM love.

The power of God protects us;
I AM power.

The presence of God watches over us:
I AM presence.

Wherever we are, God is!
I AM Divine.

Living Beyond Breast Cancer Conference

Living Beyond Breast Cancer (LBBC) is closely monitoring the coronavirus (COVID-19) outbreak. We will provide regular updates on this page about the Conference on Metastatic Breast Cancer: Thriving Together to be held in Philadelphia, PA, April 17-19, 2020. The health and safety of attendees, speakers, and exhibitors remains our top priority as we prepare to host our annual conference.

You can learn about this coronavirus and how to protect yourself and your family at the Centers for Disease Control and Prevention (CDC) the World Health Organization (WHO) website.

Please check this page for regular updates about the Conference on Metastatic Breast Cancer.

American Society of Clinical Oncology

American Society of Clinical Oncology Annual Meeting, ASCO 2020 will be held in Chicago, Illinois, United States between May 29-June 2, 2020. ASCO 2020 is going to be a platform where a lot of essential topics are going to be discussed. Some of these are Medical, Health, Breast Cancer, Oncology, Cancer, Medical Oncology, Cancer Treatment, Immunotherapy, Colorectal Cancer, Skin Cancer, Cancer Prevention, Melanoma, Pediatric Oncology, Gynecologic Cancer and Tumor Biology. Read more here.
We thank all of our sponsors for their generous support. If you would like to sponsor a Tigerlily Foundation event or support our MY LIFE Program, please contact us at info@tigerlilyfoundation.org.