About Our MY LIFE Program

Tigerlily Foundation’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. Metastatic Breast Cancer (MBC) can be a frightening word, as it means that the breast cancer has spread to other areas of the body. Further, life for metastatic breast cancer patients means being in treatment for the rest of their life. With metastatic breast cancer accounting for a small focus of the traditional breast cancer community, many metastatic breast cancer patients often feel isolated and lonely, sometimes even angry about their diagnosis. You may be experiencing this as well.

As a metastatic breast cancer patient, you may find it difficult to talk about the unique challenges that you face, your fears, and living life with uncertainty. As such, you may choose to keep your diagnosis a secret from family and friends, or you may keep your feelings and emotions to yourself. Wherever you are in your journey, keep in mind that you are not alone and you do not need to feel isolated. You have friends, advocates and caregivers who listen to the voices of you and others who are living with metastatic breast cancer. Together, we will let everyone know that your story matters and we will do our very best to ensure that your story is heard. For anyone who would like to connect with or support the metastatic breast cancer 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 Podcasts
MY LIFE Stories
MY LIFE Twitter Chats
MY LIFE Facebook Group "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 with others through blogs or podcasts, and starting your own Tigerlily Foundation chapter in your town or city. 

"Together, we will let everyone know that your stories matter and do our very best to ensure that your stories are heard."
"Every illness is an opportunity to see beyond the uncomfortable physical realities and find a way to adopt a new and larger perspective about one self. It is an imposed 'time out' in which we may find great depth and value. It is certainly a journey that can teach us how to love ourselves unconditionally with honor, respect and high regard. Of course the harsh physical realities of cancer can also make it difficult to navigate the spiritual aspects of the road back to health."  - Fabianna Marie

"I worried briefly, and then remembered the Bible verse I live by. Hebrews 11:1 says, "Faith, the hope for things which are not seen, but true." My faith in God is strong, and I know without a doubt He’s GOT me! Although I am often tired, and have daily aches and pains, my mission and grassroots non-profit keep me busy and remind me of the people I need to help, inspire and support."  - Angela "Jersi" Baker

"I decided to join a clinical trial because I think it’s important for the African American community to see how vital clinical trials are to medical advancement. Without investment into improving trust issues, exclusion, and other barriers to the inclusion of African Americans, such as finances, cultural differences and transportation, there will continue to be a lack of diversity in clinical trials."  - Sheila McGlowin
"Cancer has taken many things from me, but it has not taken my voice so I intend to use for as long as I can! Gratitude is an outlook which brings me such joy, despite all of the BS that life sometimes gives us." - Em Beacon

"As a cancer patient I am still learning that people are always coming in and out of my life. While it is a hard thing to grasp I have to look at the memories I have with that person and smile." - Maggie Kudrika, Bald Ballerina

"It is all about the details, the “micro-changes” we make in the days, the year, our lives that add up and ripple out to make BIG changes." - Tricia Russo

"Living with metastatic breast cancer may be challenging, but I refuse to lose. I smile because God is a Miracle Worker and I believe in MIRACLES. Never, ever allow your situation to take over your life." - Adrian McLeeney

"I know this has made me a stronger person. It's made us a stronger couple. It makes me want to be a better mom, a better wife, a healthier person. It changes your perspective." - Erin Davis
Last night as I was going to sleep, Mike was holding me in his arms as he has almost every night for the past 40 years. That is the place that gives me the most comfort. No matter how I’m feeling, I’m always able to relax and go to sleep when I’m in his arms. As I was thinking about how things are now, the thought came to me about how empty his arms are going to feel when I’m gone and I couldn’t keep the tears from streaming down my face. We were never the kind to sleep in the other room or on the couch because of differences. Touch removes so many walls and softens hearts. The scripture in Proverbs 15:1 says “a soft answer turneth away wrath” and this is so true. Touching and speaking softly - when the two are combined, love happens. So we have been sleeping with him holding me in his arms night after night. This has been especially meaningful lately when I have not felt well. His arms have been my haven. All too soon, they will be the source of his aching, and I wept for him. This morning as I awoke, he was again holding me in his arms and he softly said, “This room will be so empty without you”. I hadn’t told him the thoughts I had about his arms being the source of his aching. I know he feels it too. Oh, that I could take this from him! If I could only spare him the heartache that I know is coming. I know I can’t. Our spirits have become intertwined as we have traveled this path together. I’m glad he is strong and I know he will get through it, but I know it will be hard. I pray for him each night that he will be comforted. When I am gone my dear sisters, please pray for Mike. He will need you.
Patient Perspective

Living with Metastatic Breast Cancer

By Angela “Jersi” Baker

I am a 48-year-old woman who is taking breast cancer on the ride of its life. I am battling this disease for the third time and am now living with metastatic breast cancer. My breast cancer journey started in 2003, when I was diagnosed with a non-invasive form of breast cancer. I had a mastectomy, reconstruction, and took medicine for 5 years. In 2010, I noticed a small bump on my skin on my left breast. It didn’t hurt so I ignored it. A few months later during a routine checkup, I mentioned it to my surgeon. My surgeon immediately started taking pictures and said that she would like to remove it. The pathology report later deemed it was in fact cancerous. In 2012, a visit to urgent care for a cold and a weird feeling in my breast-bone area led to x-rays and a return call to follow up. It was found that the cancer had returned and spread to my chest walls, spine and head as metastatic breast cancer.

Although this disease has changed my life, I refuse to let it own or define my journey in life. In fact, I have made lemonade with my lemons and founded Angel in Disguise, Inc., a non-profit organization. Our mission is to help underserved and uninsured cancer patients “Live Life Now!” by helping with tasks that they are unable or incapable of completing alone. What is unique about Angel in Disguise, Inc. is that it is mainly myself, the Founder, a stage IV breast cancer patient, who drives the patients to their appointments and keeps them company. My dream is to expand Angel in Disguise, Inc. to other cities and to leave this organization as a legacy for my son to continue.
Partner Updates

MacroGenics’ Margetuximab drug shows positive results for HER2-positive metastatic breast cancer patients

MacroGenics is the sponsor of the Phase III SOPHIA study, which compares Margetuximab plus chemotherapy to Trastuzumab plus chemotherapy in 536 patients with HER2-positive metastatic breast cancer. The Food and Drug Administration had previously granted fast track designation to the investigation of Margetuximab for treatment of patients with metastatic or locally advanced HER2 positive breast cancer who have previously been treated with anti-HER2-targeted therapy. Fast Track designation facilitates expedited review of new therapies for serious conditions and unmet medical needs so that if the investigation drug is effective and safe, it will be available faster to the patient population.

In the Phase III SOPHIA study, patients in the Margetuximab group experienced a 24% reduction in the risk of disease progression or death, compared to the patients in the Trastuzumab group. The median progression-free survival of patients treated with Margetuximab and chemotherapy was 5.8 months, compared to 4.9 months in patients treated with Trastuzumab and chemotherapy. This difference in effect between the two groups was statistically significant ($p = 0.033$).

Furthermore, approximately 85% of the patients in the Phase III Sophia study carry the CD16A 158F allele, which was previously shown to reduce clinical response to treatment with Trastuzumab or other antibodies. Among this 85% of patients, those who were treated with Margetuximab experienced an increase in overall survival, and a significant reduction in the risk of disease progression or death for patients, compared to patients treated with Trastuzumab. Specifically, overall survival was increased by 6.8 months among the patients carrying the CD16A 158F allele who were treated with Margetuximab compared to the patients carrying the CD16A 158F allele who were treated Trastuzumab. Also, progression-free survival was prolonged by 1.8 months in the Margetuximab group compared to the Trastuzumab group (6.9 months versus 5.1 months, $p = 0.005$).

Read more about the study [here](https://www.macrogenics.com/newsroom/news-releases/).
Tigerlily Foundation Spring 2019 MY LIFE Newsletter

Partner Updates

Genentech

Genentech’s Herceptin Hyllecta (trastuzumab and hyaluronidase-oysk) drug approved for treatment of HER2-positive breast cancer

The FDA has granted approval for Herceptin Hyllecta as treatment for HER2-positive breast cancer. Herceptin Hyllecta is a combination of trastuzumab, which binds to HER2 on cancer cells to slow down cancer growth, and hyaluronidase-oysk, which is an enzyme that helps deliver trastuzumab under the skin. Approval for Herceptin Hyllecta is based on the results from three clinical studies:

1. The Phase III HannaH study, which compared intravenous Herceptin treatment plus chemotherapy to neoadjuvant (before surgery) treatment with Herceptin Hyllecta and adjuvant (after surgery) plus chemotherapy. The study indicated that treatment with Herceptin Hyllecta resulted in the absence of invasive cancer cells in the breast in 45.4% patients, compared to the absence of invasive cancer cells in the breast in 40.7% patients who were treated with Herceptin.

2. The Phase III SafeHER study of adjuvant Herceptin Hyllecta, which confirmed previous findings about the safety and tolerability profile of Herceptin and Herceptin Hyllecta.

3. The PrefHER patient preference study, in which patients were treated with adjuvant Herceptin Hyllecta followed by intravenous Herceptin, or intravenous Herceptin followed by Herceptin Hyllecta. This study showed that the majority (86%) of people preferred treatment with Herceptin Hyllecta.

Read more here.
Pfizer’s Trazimera drug approved for treatment of HER2-positive breast cancer

The FDA has granted approval for Trazimera, a drug that is biosimilar to Herceptin (trastuzumab), for treating HER2-positive breast cancer patients.

Like Herceptin, Trazimera binds to HER2 on cancer cells to prevent HER2-HER2 receptor interaction, thus reducing cancer growth.

This approval was based on results from the REFLECTIONS B327-02 study, which indicated that there was a high degree of similarity and clinical effectiveness between Trazimera and Herceptin. In the REFLECTIONS study, 707 HER2-positive metastatic breast cancer patients were treated with either Trazimera plus paclitaxel or Herceptin plus paclitaxel. The median progression-free survival was similar in the two treatment groups: 12.16 months for the Trazimera group, and 12.06 months for the Herceptin group.

Similarly, there was no statistical difference between the Trazimera and Herceptin treatment groups for 1-year survival rate (54% vs 51%, respectively). Further, patients in the Trazimera and Herceptin treatment groups had similar safety outcomes and immunogenicity (ability to generate an immune response).

Read more [here](#).

Celgene’s Tecentriq in combination with Abraxane drug approved for treatment of PD-L1-positive metastatic triple negative breast cancer

The FDA has granted accelerated approval for Tecentriq plus Abraxane combination therapy in the treatment of metastatic triple negative breast cancer with tumors that express PD-L1. This combination is the first cancer immunotherapy approved for breast cancer.

Approval for Tecentriq plus Abraxane combination therapy is based on results from Phase III IMpassion130 study. This study showed that among metastatic or unresectable locally advanced triple negative breast cancer patients with tumors that express PD-L1, Tecentriq plus Abraxane therapy significantly reduced risk of disease worsening or death, compared to treatment with Abraxane only.

Specifically, patients treated with Tecentriq plus Abraxane had a median progression-free survival of 7.4 months vs 4.8 months for the patients treated with Abraxane only (p < 0.0001).

Read more [here](#).
Lilly's Verzenio® (abemaciclib) Significantly Extended Life in Women with HR+, HER2- Advanced Breast Cancer in MONARCH 2

E li Lilly and Company announced that Verzenio (abemaciclib) demonstrated a statistically significant improvement in overall survival in the Phase 3 MONARCH 2 clinical trial. These results were from a pre-planned interim analysis and are definitive. MONARCH 2 evaluated Verzenio in combination with fulvestrant for the treatment of women with hormone receptor-positive (HR+), human epidermal growth factor receptor 2-negative (HER2-) advanced or metastatic breast cancer previously treated with endocrine therapy. The study included both pre/peri- and postmenopausal women.

The analysis showed that treatment with Verzenio in combination with fulvestrant met its secondary endpoint of overall survival. The MONARCH 2 study previously demonstrated a statistically significant improvement in progression-free survival, the trial's primary endpoint which served as the basis for its approval of this regimen in more than 50 countries around the world. No new safety signals were observed in this analysis of MONARCH 2, consistent with the established safety profile of Verzenio.

Lilly plans to submit these data to regulatory authorities and present the detailed data at an upcoming medical meeting later this year.

Read more here.
Tigerlily Foundation is excited to share with you an exciting new initiative in our MY LIFE Program, our MBC Disparities Outreach Program. As you know, MBC disproportionately affects the African-American community and younger women. Our 2019 goal is to enhance our current MBC activities to reach healthy young women, underserved communities and those facing disparities. We will work with early stagers, the MBC community, colleges, community leaders, faith-based groups, policy and advocacy partners, to conduct outreach in underserved communities, targeting the African-American community. The goal will be to reach young women of color, a community that is highly impacted by MBC, to increase education of MBC, and understanding of and engagement with clinical trials, and to increase engagement within the breast cancer community.

We began this work by holding the first Young Women’s MBC Disparities Listening Summit in March. This “listening” event engaged young women, women of color, community health influencers and people living in those communities, to better understand the challenges and gaps when it comes to educating healthy young women, women living with MBC and young women of color, on how to better engage when it comes to MBC. At this event, we gathered key insights, which will be used to build an educational campaign focused on young women of color. The campaign will target women of color, designed by women of color, and will educate young women and people in underserved communities of color and empower this community with tools to engage with each other and healthcare providers, while advocating for themselves.

Our next step, based on the recommendations from the MBC Disparities Listening Summit, is to engage young women of color who are usually not “at the table” in advocacy work and at scientific conferences. With this in mind, we will launch this program, by holding an MBC Listening Fireside Chat at the San Antonio Breast Cancer Symposium (SABCS) in December.

One of the key insights gleaned from our MBC Disparities Listening Summit was the need to engage the people we are trying to reach by inviting them to participate at strategic events, giving them a “seat at the table”, and giving them a platform at key scientific meetings, like SABCS. The Tigerlily Foundation MBC Disparities Fireside Chat at SABCS will convene a diverse representation of people from communities of color, impacted by MBC. This event will be the first of its kind historically, bringing together such a diverse range of people at an event like SABCS, to discuss the challenges affecting this community and how to bridge them.
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.

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.

Tigerlily Foundation’s Soul Peace Inner Reality Transformed (SPIRIT)

Tigerlily Foundation’s Soul Peace Inner Reality Transformed (SPIRIT) Program is focused on providing young women diagnosed with breast cancer with transformative spiritual resources, that support holistic healing, provide inner peace, and foster deeper relationship with their Higher Power – and transformation – throughout the breast cancer journey. The SPIRIT program offers young women several initiatives which include our (1) SPIRIT Blog, (2) SPIRIT Retreat and the (3) Tigerlily & Unity 24/7 prayer line.

1 SPIRIT Blog. After a diagnosis of breast cancer, there is an immediate focus on your treatment plan, and often this does not include connecting and supporting the patient’s mind, spirit and soul. Integrating spirituality into your treatment plan addresses every part of you, and can offer many benefits during your treatment. We have created the SPIRIT Blog to provide you with spiritual tips and tools from young women just like you moving through the breast cancer journey.

2 SPIRIT Retreat. Tigerlily Foundation, in partnership with Unity of Fairfax, and Unity World Headquarters bring you the SPIRIT Retreat. If you are facing cancer, know that you are not alone. Your healing journey can become easier when you have spiritual tools or a personal spiritual practice. Tigerlily Foundation and Unity invite you to a peaceful safe haven for a 1-day free retreat, to enjoy the beauty of nature, quiet rejuvenation, and affirming spiritual support tools available to you, your friends and your caregiver(s).

3 24/7 Prayer Line. Tigerlily Foundation has partnered up with Unity have launched a dedicated, 24/7 Prayer Line for young women diagnosed with breast cancer. Call 1(888) 803-4680, any time of the day or night to receive confidential prayer support. Unity prays with people of all faiths or no faith tradition. The 24/7 Prayer line is an initiative of Tigerlily Foundation’s SPIRIT Program, which is focused on providing transformative spiritual resources to young women diagnosed with breast cancer, during treatment, and throughout all stages of breast cancer and survivorship.
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.