Dear Sisters,

We put together this newsletter as a way to provide information to young women with metastatic breast cancer – information about clinical trials, the latest research and programs, stories and resources. We also seek to connect you with other metsters. Mostly, the goal of this newsletter is to focus on YOU.

After connecting with many metsters, one of the resounding things that we heard was that you want more resources just for you. You want to know how and where you can express what you’re going through. We hope that you find this resource helpful, and we want to hear from you on ways to improve it, so that we can give you what you need.

In this newsletter, you’ll read patient perspectives on living with metastatic breast cancer and find information on results from recent clinical studies. You’ll also learn the basics about clinical trials, updates from our partners, and how you can participate in the upcoming MRS/METAvivor MBC Engagement Conference.

I want to give a special recognition to my dear, sweet, strong, fearless friend, Beth Caldwell, who transitioned in November. I don’t know if I’ve ever met anyone like Beth. Do you know how you recognize a soul sister the first minute you see her? That’s how we connected. From the moment I spoke to her in the airport bar as we were headed home after the San Antonio Breast Cancer Symposium, we were sisters. It seems impossible that I have to write about her in the past tense, so I won’t. What Beth taught me was that while a person may not have a long life, what matters is what we do with our time. Beth did more in her lifetime than most. She was a powerful Advocate for Metastatic Breast Cancer. Outspoken. Disruptor. Unforgettable. This is how I will always remember Beth.

Please join us in this movement to create change, get more research, awareness and support for the metastatic cancer community. To join us, email mbc@tigerlilyfoundation.org. We want to hear from you.

Love and blessings,

Maimah Karmo
In Honor of Beth Caldwell

Beth Caldwell, a fearless metastatic breast cancer advocate, transitioned on November 2, 2017. She was diagnosed at age 37 with Metastatic Neuroendocrine Breast Cancer. Beth became a leading voice in advocating for patient access to and insurance coverage for critical medications. She was very vocal about the need for metastatic cancer treatment research. Beth was her own health advocate and partnered with her oncologist when deciding on her course of treatment. She created MET UP, a non-profit organization aimed at increasing funds for metastatic cancer research, and she wrote about her life and advocacy efforts on her blog, The Cult of Perfect Motherhood. Beth organized “die ins” to bring to light the fact that over 100 individuals died from metastatic cancer every day, deaths that are not usually widely publicized. Her testimony before the state legislature helped to pass a bill that supported funding for cancer research. Beth received several accolades including the LBBC Hear My Voice award and the NWMBCC Leadership and Advocacy Breakthrough award. Beth wanted her legacy to be that she “helped change the landscape for metastatic cancers and saved lives.” Beth’s vocal advocacy has contributed to important health policy changes, and what she started will continue to impact the metastatic cancer community. Beth is survived by her husband and two young children.

Patient Perspective

Living with Metastatic Breast Cancer

by Maggie Kurdirka

In 2014, I was living my dream. I had trained to be a ballet dancer since I was four years old. Now, I was dancing with the Joffrey Concert Group in New York City. I was rehearsing and performing six days a week and I was in the best shape of my life. A few weeks before my 23rd birthday, I felt a lump above my left breast while showering. Because of its location, I thought it was a pulled muscle. Then, two weeks later, I felt a sudden pop in my sternum during a back bend in rehearsal. Again, I thought I had pulled a muscle. Later I would learn that this pain was cancer eating away at the bone.

Learning I had incurable metastatic breast cancer (MBC) with a short life expectancy was devastating. I had trained my entire life to become a ballerina. With my MBC diagnosis, I felt that my life’s dream was taken away, and I had no idea how long I would be alive. I was afraid. My old life was gone. Cancer had destroyed it like a tornado flattens a neighborhood. I had to rebuild my life and find a new purpose.

I can say that living with no predictable timeline is one of the hardest things I have experienced. I can’t go more than three weeks without getting an infusion, and I plan my life around those infusion appointments because they are keeping me alive. I hesitate planning more than a few months into the future because my situation could change at any time.

Despite this, I am incredibly grateful to still be alive and except for MBC, I am pretty healthy. The prospect of dying has made me focus on what’s important in life and to appreciate each day because none of us knows what tomorrow will bring. Since my diagnosis, I have treasured each day that I am able to dance. I cherish every performance opportunity because it may be my last.

I have also learned to not be afraid to try new things. You don’t know if you will ever get another chance to try it. I love this inspiring quote from Maya Angelou:

“My mission in life is not merely to survive, but to thrive and to do so with some passion, some compassion, some humor and some style.”

For those of you reading, cherish your family and your friends and tell them how much they mean to you. Overlook small annoyances. Don’t fight battles that don’t matter. Forget gossip. Never take the people you love for granted. This is life – not a reality show. Life can change in the blink of an eye. Learn to say no to things that cause you stress or make you uncomfortable. Saying no does not make you rude, selfish, or unkind. It can help you feel empowered and free instead of resentful or trapped. Whatever you decide, make sure it makes you happy. Always remember, time is more precious than gold because it can never be replaced.
“At times, I don’t want to hear encouraging words . . . I look fine and healthy on the exterior and people don’t think that I have cancer due to the misconception that all those with cancer should be bald or appear terribly ill. This isn’t everyone’s case, and because I appear so well, I feel like my wounds and daily struggles are invisible.”

“Be strong,” “stay encouraged,” and “you can beat this!” These are some of the phrases I often hear but really and truly, I can’t do this every single day for the rest of my life.

My name is Shonte. I am a 33 year-old Army wife and Nurse Practitioner. I am not a mom, but my life is filled with the love of children around me. I am ambitious, but humble. I am alive. I currently live with Stage 4 Invasive Ductal Carcinoma (IDC) Metastatic Breast Cancer (MBC). This cancer has spread throughout my body. It’s in my ribs, my hip, spine, lungs and lymph nodes. I was diagnosed on June 17, 2015. It was self-discovered because since I am so young, there isn’t any screening.

At times, I don’t want to hear encouraging words nor do I want to act upon them. I look fine and healthy on the exterior and people don’t think that I have cancer due to the misconception that all those with cancer should be bald or appear terribly ill. This isn’t everyone’s case, and because I appear so well, I feel like my wounds and daily struggles are invisible. Sometimes, I feel it’s a living torture. I love living my life and being joyful but about ten percent of the time, I feel like giving up. Having Metastatic Breast Cancer is a lifelong condition, so unless a cure is developed, I will never be in remission; I will always remain in treatment and I live and schedule my life around cancer.

Even though ten percent of the time I feel unmotivated, 90% of the time I feel fabulous! Sometimes I even forget that I have cancer. I keep busy, and living a quality life is my goal. I don’t let little things bother me. I don’t let anyone’s perception of how I should feel bother me either. When I was first diagnosed, I was ok with it. People thought I was in denial, but in fact I wasn’t. I took the active commitment to look for this cancer. I found it, and now it’s time to face it. I cannot control this beast. If it takes me tomorrow, I would be perfectly fine because I know I lived joyfully, or in my husband’s words, in “La-La land.”

Below are some of the things I learned while living with MBC. I hope that they will be useful to you:

- Don’t let fear prevent you from living.
- Who cares what others think of you? At the end of the day it doesn’t matter, even from those who have cancer. Cancer is so individualized that comparing your life to someone else’s is a waste of energy.
- Don’t let anyone invalidate your feelings. If you want to be sad, angry, happy, joyful, just do it.
- Eat what you want. I am a foodie, I won’t stop eating sugar, meat, or having a glass of wine or two. Remember what I said, it’s all about quality of life.
- Replace Survivor with Surviving. Many times I am labeled as a “Survivor.” I look at that word as past tense. This cancer isn’t gone so I am Surviving.
- Don’t lose your autonomy just because cancer tries to take your joy and physical capabilities. I tire so easily and so quickly. I ache all day, every day along with a slew of other discomforts. But don’t let that make you lose yourself. I still work, clean, cook, ride a bike, go to the gym, snowboard, read, etc. Do as much as you can while you can.
- Cancer chips away at me daily, but preventing it from making me crumble is a struggle. My glue is my family, friends, husband, mentors, organizations and my dog Leo. This journey is unique and isn’t easy. But I take what I have and keep on going. I focus on what truly matters for today and live beautifully as possible.
The Basics about Clinical Trials

As a breast cancer patient, it is important to know about clinical trials. Not only are clinical trials a critical part of the development of treatments, but your participation in clinical trials help researchers, patients and advocates learn more about breast cancer.

1. What are clinical trials? A clinical trial is a type of medical research study that determines whether an intervention – a new drug, medical device or diagnostic tool – is safe and/or effective. The investigators leading a clinical trial develop a protocol – a detailed document that describes how the study will be performed. A clinical trial recruits volunteer study participants to test the intervention. Clinical trials are conducted by government agencies, universities, hospitals and drug companies.

It takes an average of seven years for a promising intervention to progress through the steps of clinical testing. First, the protocol must be approved by the institutional review board (IRB), and by the Food and Drug Administration (FDA). Following this initial approval, the intervention progresses through a rigorous series of clinical studies. Some interventions that are being tested never complete the testing series. Others complete all of the testing, but they are not approved because they are either not safe or because they are not effective, or both.

2. What are the different types of clinical trials? Clinical trials are categorized into four phases or types.

**Phase I:** Phase I clinical trials are the first time the drug is used by people. For these clinical trials, a small group of healthy volunteers are given the drug to determine the dose range that is tolerated for a single dose or for multiple doses. These studies are also performed to learn if the drug has any side effects.

**Phase II:** If the Phase I studies have demonstrated that the new drug is safe, Phase II clinical trials are conducted on patients with the disease or condition to be treated, diagnosed or prevented. Phase II studies are performed...
to determine if the new drug is safe and effective at treating the disease. Phase II trials may also be performed to determine if drugs that are already on the market can be used for another purpose.

**Phase III:** Phase III clinical trials are done as a final step to gain regulatory approval to market the drug. In Phase III trials, the drug is given to a large group of patients with the disease. For comparison, some of the study participants are given standard treatment, a placebo or both.

**Phase IV:** Phase IV trials, sometimes referred to as post-marketing surveillance, are performed after the drug is available and in use to the general public to provide additional details about the drug’s safety. This may include side effects not observed in the earlier clinical trials. Evaluations may include different formulations, dosages, durations of treatment, and interactions of different medicines. Evaluations may also include new age groups, races and other types of patients. If new side effects are identified that are serious, the use of the drug may be limited or restricted. In some cases, the intervention may be removed from the market.

3. **Why are clinical trials important?**

   Today, people are living longer in part because of the results of clinical trials. Imagine for a minute – aspirin and other common medications and medical devices went through clinical trials before they were approved for public use. Clinical trials also help us learn more about diseases and other health conditions. This includes learning how the condition develops, if there are certain characteristics that make us more likely to get a disease, and which treatment would be better for treating us.

4. **Who should participate in a clinical trial?**

   For each clinical trial, the accompanying study protocol describes who can and cannot join the study. These enrollment characteristics may include age, gender, medical history, previous treatment, current health status, and the particular type or stage of cancer. After you have signed an informed consent form, which indicates that you agree to participate in the clinical trial, a doctor or nurse will assess your medical history, perform a physical exam and perform laboratory tests to determine whether you meet the eligibility criteria. Do not feel discouraged if you cannot join a specific clinical trial. The research team’s top priority is to ensure that the study is right and safe for all of the patients. So if you are not selected, you can try to join another clinical trial.

5. **Where can I find a clinical trial?**

   - [Clinicaltrials.gov](https://clinicaltrials.gov) has almost 8,000 breast cancer clinical trials.
   - [Breastcancertrials.org](https://breastcancertrials.org) has over 600 breast cancer clinical trials. There are almost 90 trials for early stage breast cancer and over 200 trials for advanced breast cancer.
   - [CenterWatch](https://www.centerwatch.com) has more than 1,000 breast cancer clinical trials. They are all currently recruiting study subjects.
   - [AbbVie’s](https://www.abbvie.com) Clinical Trial Database lets you search for trials near you.

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**Today, people are living longer in part because of the results of clinical trials. Clinical trials also help us learn more about diseases and other health conditions.**

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Partner Updates

MBC Alliance

Clinical Trials Webinar: Dr. Erin Corbain partnered with MBC Alliance to lead a 1-hour “Clinical Trials 101” webinar. This overview of clinical trials included a discussion of the types of clinical trials, how to find clinical trials and other important information regarding patient participation in clinical trials. The webinar can be found at here.

Expanded Analysis of Atypical Responders: In “Atypical Responders Analysis,” an article that was co-authored by MBC Alliance, the authors emphasized the need to restructure how we develop treatments. They presented a call-to-action to researchers to strategically focus studies on individuals with MBC who respond better than expected to a medication, rather than the norm of focusing on those with the average response. The idea is that if we explored the reasons underlying an unusual response to a medication (such as the response that are much better than the average response), we could increase our understanding of how cancer progresses and how treatment resistances develops. In addition, what we learn about this group of individuals could help identify biomarkers and develop personalized medicine. You can read more about the study here.

Differential Outcomes in De Novo and Recurrent Metastatic Breast Cancer: Musa Mayer of MBC Alliance co-authored an article that was published in the journal Breast Cancer Research and Treatment. The study examined tumor characteristics and survival among women with two types of MBC - de novo MBC and recurrent MBC - over a 20-year period. The researchers reported that women with de novo stage IV MBC had a five-year survival rate of 44% compared to 20% for women whose metastasis was the result of recurrent stage I-III disease. In addition, over the 20-year period, the incidence of de novo MBC remained stable and the five-year survival increased over time. On the other hand, the incidence of recurrent MBC declined and the five-year survival decreased over time. In other words, improved survival exists for patients with de novo MBC who are on the appropriate treatment, and treating recurrent MBC remains a challenge for clinicians. This study highlighted that de novo MBC and recurrent MBC respond differently to treatment, and it suggested the need for further studies that look at the differences between de novo MBC and recurrent MBC. Additional details of this study can be found here.
Partner Updates

MBC Project

The Metastatic Breast Cancer Project is a patient-driven movement that directly engages metastatic breast cancer patients via social media and advocacy organizations, including Tigerlily Foundation. Patients participate by sharing their tumor samples, their medical information, and their voices. They may also participate by partnering with the project team to help increase the development of future therapies. Women and men with metastatic breast cancer can sign up for the project by visiting MBCproject.org and clicking "Count Me In." There is no cost to participate and only minimal effort is required to have a major impact.

Since the October 2015 launch, more than 4,300 patients have said “Count Me In” and joined. On the project’s two-year anniversary, the first de-identified genomic, clinical, and patient-reported data generated from the project was released in an open, publically accessible platform. This data is freely available, enabling anyone to view and use it for research to accelerate understanding of this disease. Additional data will be released every six months as it is generated. This milestone clearly demonstrates the power of working together with patients to speed progress in metastatic breast cancer research. You can find out more and access the data by visiting MBCproject.org/data-release.

One of the major goals of the MBC Project is to help improve outcomes for African-American women with breast cancer. Black women are 40% more likely to die from breast cancer.

One of the major goals of the MBC Project is to help improve outcomes for African-American women with breast cancer. Black women are 40% more likely to die from breast cancer – and this disparity has been increasing even as treatments for breast cancers have improved. Black women are also more likely than white women to get breast cancer before age 40, and they also have the highest rates of triple negative breast cancer (TNBC), an aggressive subtype for which treatment options are more limited. These statistics speak to the urgency in understanding these differences to improve outcomes for black women with breast cancer.

While there has been a lot of progress in understanding the biology of breast cancer, we still know very little about the influence of tumor biology on these racial disparities, mainly because the genomics of tumors from black patients with breast cancer remain understudied. We believe that by studying tumors of African-American patients with metastatic breast cancer, we will be able to better understand the biological reasons for these disparities. In order to do so, we and other researchers need to think deeply about recruitment strategies and patient access to research. There is a long history of medical mistrust in the African-American community because of years of abuse endured by black patients. The research community, our project team included, must focus on listening to and learning from minority populations in order to understand how we can work together to rebuild trust. We have been working closely with African-American patients and advocates to better understand the disparities that exist in this population – and want to continue to work with many underrepresented communities in order to address the disparities in research participation.

We are currently piloting new strategies for outreach and engagement for the MBC Project. We are proud to have had Tigerlily Foundation as an advocacy partner since March 2016, and are thrilled to be partnering with them closely this year. One of our new collaborative initiatives involves working with students from Howard University to use grassroots, on-the-ground networking in order to disseminate information about advanced breast cancer and encourage people to share information about the MBC Project in their communities.

The MBC Project is constantly evolving based on feedback from patients, advocacy partners, and community members – and we’d love to hear from you at info@mbcproject.org with ideas for outreach or engagement so that we can continue to drive this research forward.

- MBC Project team
Partner Updates

HUMBLE Program

This partnership between Tigerlily Foundation and the students of HUMBLE (Howard University Metastatic Breast Cancer Learning Experience) is led by Shawn Johnson. Through the HUMBLE Program, students aim to use grassroots, on the ground networking in order to disseminate information about advanced breast cancer and encourage people to share information about the Metastatic Breast Cancer Project (MBCproject) in their communities. The HUMBLE group aims to help address the lack of representation from African American women and men with metastatic breast cancer in the MBCproject.

Silent Unity

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.

A Journey of Courage and Hope for Couples

Join our partners at the Johns Hopkins Breast Center for a Couples Retreat Designed for Women Living with Metastatic Breast Cancer.

September 21 - 23, 2018

A Journey of Courage and Hope for Couples is a breast cancer retreat designed for women living with breast cancer metastases and their spouse/partner.

Confronting breast cancer as a couple can be a challenging undertaking for even the strongest relationships. Dealing with the chronic nature of Stage IV breast cancer requires endurance, hope, support and sharing.

This weekend event is an opportunity for couples to retreat from the routines of treatment and daily life to experience a program of individual and mutual healing and renewal. Couples will share their journey with others on a similar path. Ideas will be exchanged about the challenges and struggles as well as ways of coping and finding hope in the present.

The retreat is a time for respite, reflection and sharing.

PROGRAM
The retreat is a facilitated program that offers time for discussion and planned activities (i.e. yoga, labyrinth walk, massage, and more) in a comfortable setting. The focus of the retreat is on the personal journey of women and their spouse/partner.

LOCATION
A Journey of Courage and Hope for Couples will be held at: Bon Secours Spiritual Center
For additional overnight accommodations, contact Bon Secours Spiritual Center: (410) 442-1320

REGISTRATION
This free retreat includes meals and 2 nights lodging, use of facility and program. Attendance is limited to 10 couples and excludes those who have attended a prior Hopkins metastatic breast cancer retreat. For more information, contact:

Mary Capano, MSN, RN, 443-287-0592
e-mail: mcapano1@jhmi.edu
We thank all of our sponsors for their generous support.

If you would like to sponsor a Tigerlily Foundation program or event, please contact us at info@tigerlilyfoundation.org.