



METAVIVOR

**META**vivor:

A volunteer led, non-profit organization that funds research, raises awareness, advocates for and provides support to people with Stage IV metastatic breast cancer.

METAIVIVOR EXISTS TO SUSTAIN HOPE FOR THOSE LIVING WITH STAGE IV METASTATIC BREAST CANCER (MBC). WE FUND VITAL RESEARCH TO HELP IMPROVE THE LONGEVITY AND QUALITY OF LIFE FOR MBC PATIENTS. WE RAISE AWARENESS OF MBC, AND RALLY PUBLIC ATTENTION TO THE URGENT NEEDS OF THE MBC COMMUNITY. WE ALSO PROVIDE SUPPORT TO MBC PATIENTS AND CAREGIVERS.

## Research

METAivivor is the only organization in the US that exclusively funds MBC research through a scientific peer-review process.

Each year, metastasis researchers are invited to submit MBC research proposals. Leaders in the field, joined by MBC oncologists and patient advocates, evaluate the merit of each proposal and advise the METAivivor Board of Directors, which makes the final selection. Since 2009, we have awarded 26 MBC research grants totaling over \$1,800,000, including the following:

- > **DANNY WELCH, PHD (2010)**  
*University of Kansas Medical Center*  
Determining whether the KISS1 metastasis suppressor can prevent seeded cancer cells from growing into full-grown metastases.
- > **ALANA WELM PHD (2011)**  
*Oklahoma Medical Research Foundation*  
Testing the value of tumor grafts in predicting response to therapy. Now in clinical trials.
- > **RAHUL JANDIAL, MD, PHD (2012)**  
*City of Hope National Medical Center*  
Disrupting metabolic adaptations in breast-to-brain metastases.
- > **DR. SOFIA MERAJVER, MD, PHD (2013)**  
*University of Michigan*  
*Comprehensive Cancer Center*  
Engineering metastasis platforms to optimize treatment decisions.
- > **SWARNALI ACHARYYA, PHD (2014)**  
*Columbia University*  
*Institute for Cancer Genetics*  
Reactivating anti-tumor granuloytic cells to provoke immune attacks against breast.
- > **DR. SENDURAI A. MANI, PHD (2015)**  
*University of Texas MD*  
*Anderson Cancer Center*  
Targeting cancer stem cells to treat metastasis.

### DANNY WELCH, PHD

“[Metastasis research] is woefully underfunded. METAivivor raises support for laboratory research directly targeting metastasis ... [and] solicits advice from experts to assure their grants go to the best possible science. This is the place I send my contribution!”

In 2015, METAivivor joined forces with the international Metastasis Research Society to create the Strategic Alliance for Metastatic Cancer Research. The Alliance aligns patient advocates and researchers in promoting, funding and pursuing metastasis research that will improve and extend the lives of metastatic cancer patients. We look forward to expanding our collaboration with other advocacy groups.

## Awareness

Metastatic breast cancer (MBC) is defined by the spread of breast cancer to non-adjacent organs such as the lung, liver, bones and brain. It is fatal in 97–99% of cases.

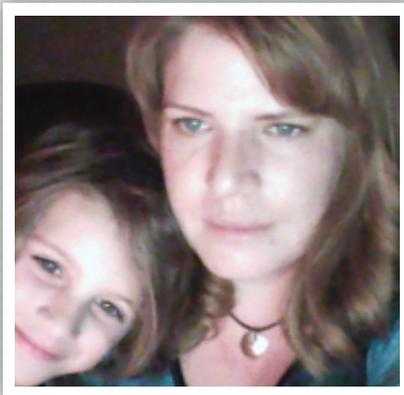
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### Did You Know?

- > Currently, over 230,000 Americans are diagnosed with breast cancer each year
- > 5% of those diagnosed with breast cancer are Stage IV at the time of diagnosis
- > 30% eventually progress from Stages 0, I, II and III to become Stage IV
- > Metastatic breast cancer (MBC) patients live, on average, 18–24 months after diagnosis
- > Stage 0 patients can and do metastasize
- > Patients can and do metastasize 30 years or more after treatment
- > In the US, over 40,000 people die from MBC each year

Remarkably, despite these dire statistics, research focused on the already metastasized state is funded at only 2–3%.

While there is broad awareness of breast cancer, Stage IV, or metastatic breast cancer is a disease that is rarely acknowledged or discussed. METAvivor is seeking to change this. From speaking with legislators to running national campaigns to increasing awareness, METAvivor is at the forefront of advocating for increased public awareness, greater support, and improved treatments for MBC patients.



### ANN BRANAUGH-PHIPPS

*Copperas Cove, Texas*

“I am a 36-year old mother of three very young children; the oldest is six. Shortly after my initial diagnosis, [my doctors] realized that cancer cells had already aggressively traveled throughout my body and had ensconced themselves within my bones. My emotions evolved from resenting the fact that I would lose my breasts and hair, to becoming resentful and jealous of those who did. At least ‘they’ had a war to wage.

Now I fight for time for my children to grow older... for them to collect more memories of me, and perhaps develop stronger coping skills and maturity that will help them navigate their grief. I fight for time, hoping that in my time, a cure will be discovered.”

“[Metavivor] stands out from other cancer related nonprofits. I am amazed at the hard work, quality of work, and dedication each of member of this organization contributes in order to raise awareness and fund research directly related to MBC.”

*Review from Guidestar*

## Patient Support

**METAvivor is a leader in establishing successful peer-to-peer support programs.**

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Based on the success of our extensive program in the mid-Atlantic, we have secured grant funds to assist others in establishing similar programs in their own geographic areas. We are currently taking the names of people who are interested in a comprehensive peer support lead training program that will launch in 2016.

### **DANA MANCIAGLI**

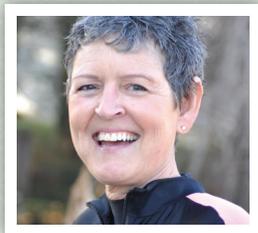
*Bellevue, Washington*

"I was 41 years old, sitting in my office at Microsoft's headquarters; when the call came. I had breast cancer. Since I was BRCA positive, I had a double mastectomy and had my ovaries removed. My identical twin sister Tracy and I were both put on surveillance. Three years later, Tracy was diagnosed. Her cancer was more aggressive than mine, and she too had a double mastectomy and her ovaries removed, followed by chemotherapy. Eventually, she got the "all clear."



But seven years later, Tracey found a lump under her armpit. Once again she had surgery, chemo and radiation, and we celebrated her completion with a trip to Mexico. We had a blast! But six months after our return in July 2013, we learned her cancer had spread to her liver and ribs. Tracy passed away May 18, 2014 peacefully at home, just 53 years old."

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### **DEBBIE GURLEY, Edgewater, Maryland**

In January of 1998, I was diagnosed with breast cancer. I underwent a bilateral mastectomy, and doctors discovered that many of my lymph nodes were also positive for cancer. In March, further testing revealed that my breast cancer had spread to my bones.

My prognosis was grim, so I set out to find the toughest clinical trial available as treatment. The National Cancer Institute at the National Institutes of Health in Bethesda, Maryland, offered the perfect trial for me - ten months of experimental, high-dose chemotherapy with five agents, a stem cell transplant, and gene therapy. My motto became, "What doesn't kill, you makes you stronger." By January of 1999, my disease was stable. Since then, I've had multiple recurrences and some treatment changes.

It's been 17 years since my MBC diagnosis. In the time, I've been a power walker, skier, kayaker, windsurfer, stand-up paddle boarder, biker, hiker, and a volunteer at METAvivor. But I am happiest when I'm in my kitchen, creating tasty treats for my partner, Mike, and our friends.

## Reviews from GuideStar.org

“As a breast cancer surgeon, I am asked to support many breast cancer related non-profit organizations. METAvivor is at the top of my list.”

“As a nurse, I know the stories of MBC women and know the place to send them. METAvivor understands ... like no one else.”

“I am a medical anthropologist, health educator and administrator working with MBC patients for the past 7 years, I know of no other organization for metastatic breast cancer better than METAvivor.”

“... not one penny of donations are used for over-head. I love that.”



“[As] a 20-plus year editor of magazines, including [those] focused on philanthropy and good causes. I never personally joined any organization I covered until METAvivor ... such a clear, unclouded mission ... nothing superfluous or nonessential. They are going to change lives ... and I want to be there to help.”

## Get Involved

We actively seek individual donations, grants, sponsorships, volunteers and other assistance to sustain our operations.

### > **Donate:**

In the US, most of the money raised for breast cancer goes into awareness campaigns, breast cancer prevention, early detection efforts and support services, with very little dedicated toward metastatic breast cancer research.

Your donations will help METAvivor fund the research that will ultimately save the lives of metastatic patients. 100% of every donation goes into our annual research grants, unless otherwise directed by the donor.

### > **Host a Fundraiser:**

100% of fundraiser proceeds go into our research grants. Third party fundraisers are welcome.

### > **Volunteer:**

We are a volunteer led organization and welcome your involvement. As we continue to expand both locally and nationally, we are looking for volunteers who can contribute to the effort.

Please visit our website at **[www.METAvivor.org](http://www.METAvivor.org)** to learn more about volunteer opportunities and how you can contribute your expertise.

## Contact Us

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