CUTC® METASTATIC BREAST CANCER HEROES 2021 ESSAY BOOK 2021 ESSAY BOOK



CUTC[®] READERS HONOR METASTATIC BREAST CANCER HEROES | VOLUME 1

CURE[®] presents our readers with a unique opportunity each year to nominate a colleague, patient, friend and family of outstanding individuals who have made an impact in the lives of those affected by metastatic breast cancer. Together as one community, we can raise awareness and, most importantly, recognize and celebrate our Metastatic Breast Cancer Heroes[®].



CURE[®]'s Healer and Heroes events are designed to inspire, instill hope and celebrate those who truly dedicate their lives to helping the cancer community at large. To learn more about our awards programs, **scan the QR code**.

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CUTC® METASTATIC BREAST CANCER HEROES

$CUT\!\!\!C^{\circ}$ readers honor metastatic breast cancer heroes

VOLUME 1

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VOLUME 1



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This book is dedicated to all of the heroes in this space — patients, doctors, caregivers and advocates — who dedicate their lives and careers to improving care for patients and the metastatic breast cancer community.

If you would like to give this book as a gift to your metastatic breast cancer hero, we've provided this page for your message.

This book honors:

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Passion and Persistence in the Face of Metastatic Breast Cancer

THE INAUGURAL METASTATIC BREAST CANCER HEROES[™] awards program was held in December 2021. Even though it was held virtually, the passion and dedication of our three heroes were palpable through our computer screens.

The metastatic breast cancer community is a unique, strong-willed group of people. Every single person strives to bring awareness to the disease, provide the utmost care to patients, inform those who may not be as familiar with the diagnosis and connect with others who share similar journeys. It's a tightknit group of people who bring a passion and persistence to the area, an exceptional feat to see in action.

The Metastatic Breast Cancer Heroes[™] program, which includes patients, caregivers, advocates and health care professionals, gives people the opportunity to give gratitude and celebrate those who made an impact in the lives of those affected by metastatic breast cancer.

After reading the nominations for our Metastatic Breast Cancer Heroes[™] awards, it's evident that the people recognized for their efforts in the space give their all to every single thing they do. Some will even go the extra length — literally — by way of swimming to raise awareness of metastatic breast cancer.

"(She) has swum in lakes as far away as Ireland, Iceland, Kauai and as close as Lake Monona in Madison, Wisconsin — all in the name of raising money and awareness," a fundraiser at an »

institution wrote in her submission. "Before she enters the water, she says a few words about why she is swimming and always ends her talk with the benediction, 'Research is our best hope.' A lot of people with this swimmer's diagnosis would stay home and rest. Maybe they would do a little virtual fundraising. But taking to the lakes is a unique and personal spin on shedding a light on (her) disease."

Although we honored three Metastatic Breast Cancer Heroes^M — an oncologist, a patient advocate and a nurse-turned-patient with cancer — it's important to note that every person nominated for this recognition is truly a hero in our hearts.

We also presented a special Metastatic Breast Cancer Diversity & Inclusion Hero[™] award to a woman with metastatic breast cancer who took it upon herself to advocate for others with the disease who experience inequities in health care, including Black men and women. She eventually connected with an epidemiologist with metastatic breast cancer and together they created a questionnaire to learn what barriers Black patients faced when enrolling in clinical trials.

"(She) works every day to ensure that the voice of every person with metastatic breast cancer is heard equally," her nominator wrote in his submission. "As a person of color, she understands the disparities faced by many — in the waiting room, the doctor's office, the board room of the pharma conducting the trial and, sadly enough, in the organizations who say they advocate equally for all. And just as she battles her cancer daily, she also fights daily to ensure that everyone with metastatic breast cancer has an equal opportunity."

We look forward to this year's Metastatic Breast Cancer Heroes[™] awards program, which gives us another chance to learn more about the inspiring patients, caregivers, advocates and health care professionals who make an impact in the lives of those affected by metastatic breast cancer despite the troubles they may face along the way.

- Mike Hennessy Jr.

President and CEO of MJH Life Sciences®





Our Metastatic Breast Cancer Heroes[™] Winners



PHOTOS BY TONI OLIVIA PHOTOGRAPHY

NEVER STOP

BRANDI RIBER, RN

FLORIDA CANCER SPECIALISTS, FORT MYERS, FLORIDA

Written by Terry Dalton, Naples, Florida

THE FOLLOWING IS A SHORT unfolding of the story of my daughter Brandi's journey, first with breast cancer, then with metastatic breast cancer.

It was written by Brandi herself, as she was asked to tell her story at Florida Cancer Specialists, where she is an RN, helping patients adjust to the words "you have cancer" every day. She is a hero in their eyes and a living example of what the word "hope" means.

While the words may be lengthy, it shows hope and perseverance at the time when she was faced with the worst news in her life. It is my hope that it will also show hope to others.

It started 11 years ago ...

Written by Brandi: "My breast cancer journey began in July 2009. I had just graduated from nursing school and was beginning the job of my dreams of becoming an oncology nurse. I also had a sweet little girl who was 3 years old. I had noticed a lump on the outside of my left breast and went to my ob-gyn, and was reassured that he didn't feel it was anything, but I was also given a script for an »



ultrasound and a biopsy in case I felt it necessary. I delayed getting the testing done, as I did not feel overly concerned. Until I did ...

I was getting out of the shower one day and noticed a dimpling area on the outside of my breast where the lump was. This is kind of when it all becomes a blur, but I do know that I immediately went for that ultrasound and a biopsy was performed. The next thing I know, I was being told that I would need to meet with the surgeon and oncologist to discuss the next steps. I was diagnosed with infiltrating ductile adenocarcinoma stage 2b on January 4, 2010.

I had my first surgery in January: left side mastectomy with 17 lymph nodes removed, three positive, and a mediport placed for treatments. I had my first chemotherapy on January 22, 2010, a total of six treatments, one every three weeks. I will never forget how tough the treatments were or how much support I had around me at that time to get me through.

I had my last treatment and rang the special bell my own father made on May 7, 2010. Continuing treatment consisted of five years of oral hormonal treatment; however, I was deemed cancer free! I opted to have a double mastectomy with my final reconstruction 11 months from my diagnosis, on December 3, 2010.

I continued the normal monitoring along with the oral treatment and in November 2014, just months shy of the magical five-year mark, I was first diagnosed. This time it was stage 4. The cancer had spread to my liver and some small areas in my sternum. My world had once again been turned upside down.

Although I had a very low chance of recurrence — less than 18% — the next course of action was to have my ovaries removed and a biopsy of the liver to confirm that it was in fact the same type of cancer that had recurred. Fortunately, it was confirmed to be the same type of cancer, and this began my metastatic journey. I was fortunate to be accepted into a clinical trial, and my oncologist was hopeful with this new medication as it showed promising results. I started the new trial therapy in December 2014. This was a double-blinded trial, meaning I had no idea if it was the drug or a placebo I was receiving each month. Soon the scans showed improvement and around the 18-month mark, I was in remission. I continued the study for 64 cycles, which is just over five years, before I »

progressed again in October 2019. The trial drug I had taken has since been approved by the FDA and is now a regimen used as a standard of care for many patients in my situation.

I have since progressed four more times. With each progression a new treatment regimen was started, three of the four being clinical trial studies. During this time, my dental health had deteriorated due to the side effects of long-term use of oral medications. This led to another long journey that currently continues. I have had all my teeth removed and replaced with dental implants. Support was again given to me by family, friends and the generosity of dental professionals to help cover costs along the way.

With my current recurrence just over a month ago, my scans again showed progression in the bones and liver. With the end of another trial study, I have now begun a new clinical trial for IV chemotherapy. I started this new regimen the day before my little girl turned 13 on September 11, 2020. And life goes on ... again, with the support of family and friends, for which I am eternally grateful.

-Written by Brandi Riber, October 2020

Brandi wrote this in October 2020. As of October 2020, she has now progressed well past the many more drug trials that she tried, at least five more recurrences since she wrote this; we have lost track. A recurrence and end of a trial drug occur when the scans show increased activity and involvement instead of shrinking. Never good news, it just means more lesions and new growth, not what anyone wants to hear. Just when she thought that this trial would be the one to help, her hopes were shattered by the news that she would no longer be on the trial. A trial is good and kept in place only if an improvement is seen. She is now out of trials and on chemotherapy once again.

However, Brandi's story is one of hope. Eleven years and counting is a very long time to "do" breast cancer. Having metastatic breast cancer for the last seven years is almost unheard of.

Before Brandi had breast cancer, I did not know that no one dies of breast cancer; one dies from metastatic breast cancer — cancer that has spread to vital organs. Once that occurs, there is no cure, but as you just read, there is hope. We need funding for metastatic breast cancer studies.

She is a vision of hope to the patient who has more questions than they know what to ask and gives firsthand knowledge because she is living it. —Terry Dalton

We need new trial drugs to be invented. We need more hope. Wearing a pink ribbon no longer is enough.

My daughter Brandi just celebrated another year and her reason for living. You read that her daughter Morgan had turned 13 when she began another study, and on September 11, 2021, Morgan and her mom celebrated birthday No. 14. And for that, we are all blessed and grateful beyond words.

Someone will hear the words "metastatic breast cancer" and hopefully, if they read this about my amazingly strong and warrior daughter, they will have hope.

What you don't understand and Brandi doesn't say is that she has missed very little work from the time of her diagnosis. She lives to be at work to educate and show extreme compassion and commitment for her patients. Currently, while she is hooked to her chemo line, she continues to be present at work and doing her job, literally while the drug runs through her veins. She is a vision of hope to the patient who has more questions than they know what to ask and gives firsthand knowledge because she is living it.

Thank you for reading Brandi's story. She is a wonderful nurse who leads a life to help others deal with cancer and a mom who loves her child more than you can imagine.

EDITOR'S NOTE: Brandi Riber, RN, died shortly after the Metastatic Breast Cancer Heroes[™] awards program in December 2021. Our thoughts go out to her family and friends.

WINNER PROFILE

THEY ASK FOR HER BY NAME

AN INTERVIEW WITH Brandi Riber, RN By Katherine Malmo



LIKE MANY NURSES, Brandi Riber, RN, was drawn to the profession because she loves to care for people. Quickly, she found there was something different about working with patients with cancer in the oncology ward.

"You really get to grow a relationship," Riber says. "You see these patients sometimes five, six or seven days a week. They're coming in a lot for treatments and in the thick of the battle and the side effects that come along with it. It's constant care and I absolutely love it."

In January 2010, Riber joined her patients in an unexpected way when she was diagnosed with stage 2b breast cancer and started treatment: chemotherapy, a bilateral mastectomy and hormone-blocking pills. Five years later, her doctors found breast cancer tumors on her liver. Since then, she's been on a variety of treatments and in clinical trials. Her own experience has brought her closer to her patients.

"We're often seeing patients at their worst time. They can be angry, hurt and think we have no idea how they're feeling," Riber says. "But they can look at me and see that I get it. I get it way more than I would like to. I know what it feels like to sit in the chair and get chemo. I know what it feels like to experience all the side effects, the nausea and terrible things that can happen."

WINNER PROFILE

Often patients ask for Riber by name and want to talk to her specifically because they know she's been through a particular regimen or had a particular chemo. Her experience brings a different level of trust and perspective.

"When you're going through treatment yourself, it opens up a whole new conversation," Riber says. "There's more trust, and patients feel like they can come to me and ask me anything because I've been there, done that. And I'm brutally honest about how it's going to be or how it has been for me. And I just think we've created a different world and an unfortunate, but fortunate bond."

When Riber's cancer became metastatic, she learned that she'd have to be on some form of treatment for the rest of her life or the cancer would grow. Lately, she's found she doesn't qualify for many of the clinical trials. But she's still hopeful that more research on metastatic disease will yield a new medication or therapy that will help keep her tumor growth in check.

And even though Riber has been in cancer treatment consistently for eight years, she's still working full time in the oncology ward and raising her 14-year-old daughter.

"She's always been proud of me," Riber says of her daughter. "She's never embarrassed or anything, and just jokes about what a rock star her mom is to be fighting cancer and still working. She's the greatest kid ever and I'm very fortunate."

Since Riber deals with cancer at work and at home, she has a unique perspective and a few things she wants the world to know.

"Metastatic breast cancer is not a death sentence," Riber says. "Terminal doesn't mean your life is over. There's a lot of research being done with advanced science and a lot of hope that new things will come along to keep us alive."

It's not only patients who need to know this; Riber wants physicians to hear this message, too.

"There are no timelines for this diagnosis," she says. "This is just another battle or a different stage in the battle. We have to fight every day for the rest of our lives, but at least we have the rest of our lives."



HOTOS BY DEVON ALBEIT

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SOUL SURVIVOR: HOW ONE BREAST MEDICAL ONCOLOGIST'S PERSONAL EXPERIENCE WITH CANCER INFLUENCED HER PATIENT CARE

DR. BHUVANESWARI RAMASWAMY

STEFANIE SPIELMAN COMPREHENSIVE BREAST CENTER, THE OHIO STATE COLLEGE OF MEDICINE, COLUMBUS, OHIO

Written by **Dr. Claire Verschraegen**, The Ohio State University Comprehensive Cancer Center, Columbus, Ohio

AS A MEDICAL ONCOLOGIST with a 40-year career, I have had the pleasure of interacting with many peers in my field, and in my current position as director of the division of medical oncology at The Ohio State University, I have seen many faculty grow professionally and evolve as very capable researchers and clinicians. From these vantage points, I can attest that Dr. Bhuvaneswari Ramaswamy, a specialist of breast cancer, is a truly gifted, perseverant and compassionate physician whom I have the privilege of closely working with. She is herself a cancer survivor, receiving a diagnosis of a very rare metastatic breast cancer and still undergoing intermittent therapies. Despite these tribulations, she offers tireless dedication to patient welfare through education and compassionate care and demonstrates intellectual prowess and discipline as a successful **»**

laboratory researcher. I can think of no one more deserving of the *CURE*[®] Metastatic Breast Cancer Heroes[™] award.

Since joining The Ohio State University Comprehensive Cancer Center in 2006, Dr. Ramaswamy has been working hard to improve care and quality of life for patients with breast cancer. She is the founder of the Living Well With Advanced Breast Cancer Clinic, specially designed for patients with newly diagnosed metastatic breast cancer, focusing on educating patients about their cancer and empowering them with knowledge, as well as keeping them informed about relevant new tests and clinical trials. She also leads the annual NY Metastatic Breast Cancer Conference, focused on providing patients with metastatic breast cancer with education and resources.

Dr. Ramaswamy routinely goes above and beyond the call of duty to positively impact the lives of patients affected by metastatic breast cancer. When she first received her breast cancer diagnosis in 2016, she was shaken yet she recognized the ways in which her medical knowledge base helped her gain steadier footing in the often-overwhelming landscape of treatment options and outcomes. She instantly understood how her patients — most of whom do not share the same degree of medical knowledge — must feel. Going back to work full-time post-treatment, she used this experience to inform her practice, centering patient education and compassionate care with the goal of supporting informed, independent and fulfilling lives for all her patients.

A formidable researcher, Dr. Ramaswamy is the principal investigator for several investigator-initiated studies, has received continuous National Cancer Institute funding for her research and has authored more than 100 peer-reviewed articles. Her lab focuses on improving »





Our meaning is what drives us, and I can say without a doubt that Dr. Ramaswamy's drive is the wellbeing of her patients.

—Dr. Claire Verschraegen

outcomes in breast cancer by addressing drug resistance and by addressing racial disparity in breast cancer incidence and outcomes. In 2017, she became the section chief of breast medical oncology, where she leads the breast cancer research program, provides mentorship for the junior faculty to become successful investigators and researchers and steers the group toward national prominence in advancing science and the care of patients with breast (cancer). She is a true servant leader who devotes her energy to the success of her colleagues.

As a physician, Dr. Ramaswamy has been consistently recognized for her patient-focused service. She has been named by Forbes as one of the top 27 breast medical oncologists in the nation, and has received the Stellar Practitioner for Compassionate Care Recognition, given to exceptional physicians by patients and caregivers. She was also selected as one of only five women at Ohio State recognized as "Medical Center Marvels." These honors speak to her values as a physician, always placing the patient first and putting her own personal achievements second

after patient care. It is an approach many junior faculty in the division are lucky to learn from, and she leads her section by example. In 2019, she received the Mentor of the Year award, exemplifying her commitment to junior faculty development, and in 2021 she was inducted into the OSU Mazzaferri-Ellison Society of Master Clinicians.

Inspired by her dedicated example, Dr. Ramaswamy's son, Rahul Chakravarthi Ramaswamy, also decided to pursue medicine. In his heartfelt essay "Incoming Call" (*The Oncologist*, June 2021), he offers the following insight gleaned from managing his mother's cancer while training to be a doctor himself: "I now know that we are not fighting against death, but rather we are fighting for more meaningful time. Maximizing the quality of one's life is the most important goal of care for patients with advanced disease. With this approach, the goal posts shift from aggressively staving off death at all costs to focusing back on the patient's goals for life. How do we improve her quality of life? How do we give her the time to accomplish her goals? I now know these are the questions we must ask for our patients. Our own mortality is not the enemy; in fact, it becomes the very idea that gives our life meaning."

Our meaning is what drives us, and I can say without a doubt that Dr. Ramaswamy's drive is the well-being of her patients.

Dr. Ramaswamy is a brilliant and compassionate doctor and scientist who is nothing short of an inspiration to the people around her. She continuously proves her leadership competence and organizational prowess by initiating a team-focused approach to advancing the shared goals of the cancer center and improving outcomes for patients with cancer. Her personal experience with cancer, while unfortunate, has only strengthened her commitment to compassionate care. It is a great honor to nominate Dr. Bhuvaneswari Ramaswamy for the *CURE*[®] Metastatic Breast Cancer Heroes[™] Award.

WINNER PROFILE

LIVING WELL WITH CANCER

AN INTERVIEW WITH Dr. Bhuvaneswari Ramaswamy By Katherine Malmo



DR. BHUVANESWARI RAMASWAMY is a breast medical oncologist and professor at The Ohio State University who sees patients but is also involved in research and clinical trials. It seems she has a part in every aspect of breast cancer research, treatment and education.

In 2016, she stepped even further into the cancer world when she received her own diagnosis of neuroendocrine breast cancer. After treatment, her tumors returned in 2019.

"I have learned to live with cancer, treatment, radiation and therapies," Ramaswamy says. "This has been my life. I thought I understood a lot about what patients went through before. I considered myself compassionate and considerate, but it's difficult to understand what a patient is going through until you are in their shoes."

The most revealing thing she learned during her own treatment was that despite having extraordinary family and medical support, she still felt very isolated. Now, as a doctor, she tries to validate her patients' feelings and their fear of that detachment. She encourages them to acknowledge what they're feeling, but also to enjoy and appreciate what they have. She says patients with metastatic disease shouldn't expect their family and friends to be perfect and have full understanding.

"It gets frustrating when we expect people to answer our concerns in a certain way," Ramaswamy says. "It's rarely going to happen. You'll hear a lot of people say, 'You should look

WINNER PROFILE

on the brighter side.' But if you let those comments, which show they don't understand, get to you, it'll take away your energy. Look at where the person comes from. They come from a good place."

Even though she is well acquainted with her patients' struggles, Ramaswamy says her own diagnosis doesn't even pop into her head when she's meeting with a patient. In those cases, she enjoys being an oncologist and purely professional and empathetic.

"With (metastatic) patients, there's a frustration that we can't cure their disease," she said. "The treatments don't work for everyone, and if they stop working, the patient carries the burden of the fear of death from cancer. This is why I wanted to start the Living Well With Advanced Breast cancer clinic in 2017. There are so many things a stage 4 patient needs to understand. We have to deal with science, new treatments and tests, but also understand nutrition, holistic well-being, role of palliative care physicians, hospice care, symptom management and end-of-life issues. It's scary and we wanted a place that didn't look like a doctor's office where patients could learn and be part of a community."

Living with cancer, seeing patients and starting a clinic is plenty to keep anyone busy, but Ramaswamy still finds time to work in research, where she has two goals. One is to ensure they're doing clinical trials with novel therapeutic agents as well as nontherapeutic agents and looking for new interventions for symptoms. The other is to work with scientists to help them take an idea from the lab to the clinic.

Overall, she finds her work to be extraordinarily rewarding and has deep sympathy and understanding for others who live with metastatic disease.

"It's extremely unfair to have to live with this," Ramaswamy says. "There's no point in questioning, 'Why me?' The good news is that there are newer and newer treatments. Reach out to comprehensive cancer centers and ask the questions to seek the best treatments. You have to learn to live with the cancer, not to be dying with it. You have to appreciate the living, seek the joy. Do you want to spend that time thinking about death or living your life to the fullest? Be engaged and live well with the cancer."

A TIRELESS CHAMPION FOR CHANGE

DIAN 'CJ' CORNELIUSSEN

METAVIVOR RESEARCH AND SUPPORT, INC., ANNAPOLIS, MARYLAND

Written by Bronwyn Belling, METAvivor Research and Support, Inc., Annapolis, Maryland

AFTER HER 2004 STAGE 2 breast cancer metastasized to her lung in late 2006, Dian "CJ" Corneliussen-James, a newly retired Air Force and civil service intelligence officer, was shocked to learn that there was not only a dearth of support for patients with stage 4 disease, but, more critically, virtually no research being done for stage 4 cancer.

Within weeks of her diagnosis, she launched a support program that six months later had 24 members. Soon she was training others to build similar programs in their own areas. Today, her peer-to-peer support program has over 100 groups nationwide. But this was just the beginning.

In 2007, CJ learned that less than 0.5% of the National Cancer Institute's \$5 billion budget was going into stage 4 cancer research. She further learned that breast cancer nonprofits were, at best, devoting a paltry 2% to metastatic breast cancer research. Shocked, she designed the metastatic breast cancer ribbon pin to raise awareness and began raising funds for research. She learned about and contacted the president of the Metastasis Research Society, Danny Welch. And together they began making plans. **»**

From left: DIAN 'CJ' CORNELIUSSEN and BRONWYN BELLING

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Attending her first Metastasis Research Society biennial conference in 2008, CJ learned about the challenges researchers face and the lack of funding for metastatic cancer research. Returning to Annapolis full of ideas, in January 2009, CJ asked three other support group members, math teacher Avis Halberstadt, award-winning CVS pharmacist Karen Presswood and Silopanna CEO Rhonda Rhodes to join her in founding the nonprofit METAvivor Research and Support to fund metastatic breast cancer research. The team quickly set the policy that 100% of every donation would go into the research fund. This policy continues today.

CJ's reputation as a patient advocate for her disease was rapidly spreading. In 2008, she began working with pharmaceutical companies who valued her input on their written products and website development. Starting with Novartis, where she was contributing editor and reviewer for its patient advocate guide, her inputs were soon requested by Eisai, Genentech, Pfizer, AstraZeneca, Eli Lilly and others where she served on advisory boards, wrote and/or edited articles for publication, participated in satellite media tours, gave numerous presentations and was profiled in a widely used motivational film by AstraZeneca. She also began working with organizations such as We Work for Health.

Meanwhile, with the help of Welch and others, CJ put together a research program that in January 2010, one year after METAvivor's founding, awarded its first research grant of \$50,000. Tragically, by then two of the co-founders, Presswood and Rhodes, had died of metastatic breast cancer. More joined the team and more died. Halberstadt passed away in 2014. For some it was too much death, but CJ would not give up.

In 2011, CJ's poster on metastatic breast cancer patient lifestyles and needs won first place for patient contribution at the first international Consensus Conference for Advanced Breast Cancer (ABC1) in Lisbon, Portugal. CJ served on faculty for the ABC conferences from 2012 through 2017. In 2015, CJ gave the widely praised keynote address "Prejudice and MBC" and presented on "Sexual Intimacy and MBC" at ABC4. She was also invited to Madrid, where she discussed her patient program with directors and oncologists at the Clara Campal Cancer Center and addressed medical students at the medical school. **»**


WINNING ESSAY

After serving five years as president of METAvivor, CJ passed the hat to a successor in 2015, but twice stepped back in for one year when a need arose.

CJ continues to do presentations, answer calls and emails, research related subjects and respond to patient queries on a host of issues. She has put out the word that she will do her best to assist anyone wishing to start a research funding program for their own metastatic cancer type and was recently asked to help build a program in the Middle East.

The METAvivor grant program has exceeded expectations. As of 2020, METAvivor had awarded 135 research grants totaling over \$18 million. This year, it will award over \$4 million more. While many have taken up the cry for increased stage 4 research, METAvivor remains the sole U.S. (perhaps world) organization dedicated to awarding annual metastatic breast cancer research grants through a peer review process.

CJ was awarded the Service Above Self award and made a Paul Harris Fellow by Rotary International in 2013, was awarded the Fire and Soul Award by Anne Arundel Medical Center in 2010 for being "the one to take a spark of energy and with determination turn that vision into reality" and in 2019 was a finalist for the National Catalyst for Change Award. CJ graduated from Project LEAD in 2009 and served as a consumer reviewer for the Department of Defense Breast Cancer Research Program in 2010 and 2011.

Beginning with CJ's proactive stance over 13 years ago, immense strides have been accomplished. CJ is certainly one of the most influential and fierce champions of finding a cure for metastatic breast cancer and is imminently qualified for and deserving of recognition through this important new national Metastatic Breast Cancer HeroesTM award.

THE TEAL IS FOR HEALING

AN INTERVIEW WITH Dian "CJ" Corneliussen By Katherine Malmo



DIAN "CJ" CORNELIUSSEN received her diagnosis of stage 2 breast cancer in 2004 and then of metastatic breast cancer in 2006. Her advocacy work started almost immediately after her second diagnosis.

"A volunteer was there to greet me at the hospital as I awaited my first surgery," Corneliussen says. "She brought gifts and said she would be happy to be my mentor and walk me through my first year. She told me it was followed by a second-year support program and then came the party group. I was impressed by all the support. Then when I was diagnosed with (metastatic breast cancer) to the lung, I went back to the hospital for a lobectomy but found no friendly volunteer and learned there were no stage 4 programs. When you metastasize, you become persona non grata."

In January 2007 Corneliussen learned that less than half of 1% of the National Cancer Institute's study proposals focused on metastatic disease for all forms of cancer, not just breast. "It seemed hopeless," Corneliussen says. "I called every cancer organization I could find and told them I wanted to donate to metastatic research specifically, and they said I couldn't. I realized that (metastatic breast cancer) patients needed to do it themselves and to do that, we needed our own identity."

In 2007 Corneliussen got permission from administrators at Anne Arundel Medical Center in Annapolis to establish a metastatic breast cancer support group. She made flyers »

for the first gathering and spread them around town. Eight people showed up to the first event, and the numbers grew quickly. Within six months, there were 24 people in the group, and they'd begun to raise funds for research.

"I wasn't sure how we'd survive," Corneliussen says.

Corneliussen got to work creating a ribbon that could bring awareness to metastatic disease. It was initially only two colors: teal, which stood for healing and spirituality, and green, which stood for immortality. At the last minute, she added a line of pink to indicate the metastasis began with breast cancer. She hoped other metastatic cancers would use the base ribbon of teal and green, replacing the pink with their own cancer's color. She took the first batch of ribbon pins with her to the 2008 biennial meeting of the international Metastasis Research Society. There she found interest, comradery and hope.

"We were a fantastic combination," she said. "Researchers had the ideas but couldn't get their work funded and were thus leaving the field. People couldn't connect with them. They weren't pulling on any heartstrings, but the patient stories did that. We realized we could work together to get the word out and encourage people to support funding for stage 4 research."

In 2009, she formed a nonprofit, METAvivor, with three other women: Rhonda Rhodes, Karen Presswood and Avis Halberstadt. It was decided that 100% of donations would go permanently into metastatic breast cancer research. Even though two of the founders died that first year, they made their mark on the world. By the end of 2021, they have awarded over 200 research grants totaling close to \$22 million.

"Giving realistic hope to patients is the best part of advocacy," Corneliussen says. "When you feel hopeless, that's the worst of this disease. I felt so hopeless when I knew there was little money going into this. We still have a long way to go, but research has noticeably increased."

Today, Corneliussen is 70 and still in treatment, but because her cancer has not spread since her lobectomy and no cancer can be detected, her status is "metastatic with no evidence of disease."

The one message she wants the world to hear is that research on stage 4 disease is still "horrifically" underfunded and many patients die within a few years of diagnosis. Any amount will help.

Beyond that, she recommends supporting patients with metastatic disease by being there for them. "One of the biggest problems I ran into was a loss of connection with the outside world," she says. "People didn't know what to say or do with a metastatic patient. Further, when people get together, they talk about what happens in their daily life. For the metastatic patient, their world often revolves around their treatments, side effects, pain, loneliness, concerns about what will happen to their young children and their elderly parents when they pass away. Friends need to understand this is now their life. This is the topic they know, understand, are current on and thus tend to talk about."

Her message to those out there living with metastatic cancer is one of optimism. There's more money being put into this field than ever before, and there's more interest in moving forward than ever before, Corneliussen said. She adds that it's slow, but change is happening.



Metastatic Breast Cancer Diversity & Inclusion Hero Award Winner



WINNING ESSAY

BUILDING BRIDGES OF INCLUSION

STEPHANIE L. WALKER, B.S.N. TARBORO, NORTH CAROLINA

Written by John Walker, Tarboro, North Carolina

THINGS CHANGE BECAUSE PEOPLE become tired of the same old, same old.

Stephanie L. Walker, B.S.N., spent her working career helping people as a nurse in the pediatric intensive care unit, emergency department and intensive care unit, as an instructor and as a hospice nurse. At every step of the way, she charged herself with ensuring the patients under her care were treated with care and compassion and in line with the Golden Rule. She worked to ensure that the students in her nursing classes understood the importance of following those tenets. When her health forced an early retirement, she struggled to find purpose in her life, for she had always been a giver.

A few years ago, the late Katherine O'Brien reached out to her about advocacy and told Stephanie that she "was going to put her out there." As Stephanie's involvement as a metastatic breast cancer advocate continued to grow, it became obvious to her that there was an absence of color in a number of areas. She began to ask questions of organizations: "How can you advocate »

WINNING ESSAY

for a person of color when you have no one in your leadership who reflects people of color?" She pushed for inclusion on committees and boards and volunteered to participate in programs presented by organizations such as Susan G. Komen.

In medically underserved eastern North Carolina, Stephanie became the face and voice of the metastatic breast cancer community and she worked with civic groups, church groups and businesses to ensure that everyone understood that inclusion helps everyone when the battle with metastatic breast cancer is underway.

To that end, she chaired the MBC Alliance's BECOME project in 2021 to ensure Black people are better represented in cancer research. Building on a 2019 project conducted by Marina Kaplan, an epidemiologist who lived with metastatic breast cancer, BECOME was a research initiative designed to find solutions within the Black community.

The data collected tells a disturbing story. In the United States, the mortality rate for non-Hispanic Black women with breast cancer is 40% higher than for non-Hispanic White women. And while clinical trials help improve outcomes and survival, Black people represent only 3% to 6% of patients in all cancer clinical trials.

The survey responses will help patients make more knowledgeable decisions, educate doctors on how to support patients in joining trials and help researchers understand and design clinical trials in a way that encourages Black participation.

Stephanie works every day to ensure that the voice of every person with metastatic breast cancer is heard equally. As a person of color, she understands the disparities faced by many — in the waiting room, the doctor's office, the board room of the pharma conducting the trial and, sadly enough, in the organizations that say they advocate equally for all. And just as she battles her cancer daily, she also fights daily to ensure that everyone with metastatic breast cancer has an equal opportunity.

Stephanie Walker never set out to become an advocate, but it is a role she has embraced and one in which she has grown as she works to ensure an inclusive and diverse treatment arena.



THIS ONE IS FOR THE UNDERDOG

AN INTERVIEW WITH Stephanie L. Walker, B.S.N. By Katherine Malmo



IT WAS JULY 2015. Stephanie L. Walker, B.S.N., was living outside New Orleans and working as an on-call nurse when she received a diagnosis of de novo metastatic breast cancer. For a while, she was able to manage her treatment around her work schedule, which was one week on and one week off.

In February 2018, the tumors spread to Walker's lungs, and she had to quit her job and move home to Tarboro, North Carolina. But her nursing career provided the primary income for her family and was the source of her medical insurance. Without it, Walker didn't have the money to pay for treatment. She explained the problem to her doctors at Duke Cancer Center and was soon signed up for a charity care program that paid her medical expenses for a year. After that, she got a policy at healthcare.gov and then Medicare.

Walker found that it felt good to advocate for herself and she wanted to help others do the same.

"I'd never known anybody else who was Black and had metastatic breast cancer," Walker says. "But I'm fortunate because I know how to manage my own care and a lot of people living around eastern North Carolina don't. They don't know they have choices and can say no."

In 2019, Walker attended her first Living Beyond Breast Cancer (LBBC) conference for patients with metastatic disease, where she discovered how rewarding advocacy work could be. Walker

called this her "coming-out party" and went on to attend and speak at local Susan G. Komen conferences and the San Antonio Breast Cancer Symposium (SABCS) as a LBBC representative.

"There's a lot of inequities in health care when it comes to Black men and women with metastatic breast cancer," Walker says. "And so I began fighting for the underdogs, whether that person is Black, White or indifferent."

After that, Walker attended coffee chats with researchers through the Komen foundation and became part of its Advocates in Science program.

"I used to tell researchers at these events that I want them to remember my name is Stephanie," Walker says. "So when you go back to your lab and you look at that little mouse, I want you to imagine my face on it. That is Stephanie. I want you to remember you're doing this for me, for a human."

At the SABCS conference, she met Mariana Kaplan, an epidemiologist with metastatic breast cancer, who had noticed how few Black patients enrolled in clinical trials. Together, Walker and Kaplan created the BECOME (Black Experience of Clinical Trials and Opportunities for Meaningful Engagement) questionnaire aimed at Black respondents and designed to learn what barriers Black patients faced when they considered joining trials.

The survey found that the biggest obstacles were not knowing about the trial, transportation and logistical problems and not trusting the organization that ran the trial.

Walker, whose health has been stable since March 2016, continues to find her advocacy work tremendously satisfying.

"My favorite part is helping a person that didn't know how to navigate this journey, empowering them to have some knowledge and to be more successful," Walker says. "Even if it's only helping one or two people by letting them come to my house and use a computer."

Beyond helping other patients, Walker wants to get the word out to people of color about the importance of enrolling in trials.

"Please investigate and join clinical trials," Walker says. "Talk to your doctor, educate your doctor if you have to. It's essential to empower yourself and join what you can. It's going to help us, maybe you or maybe somebody else further down the road."



Nominations

From left: DR. FATIMA CARDOSO and DR. MARIA JOÃO CARDOSO

(1)

PHOTOS BY GONÇALO BARRIG.

THE FIGHT FOR A VOICE

DR. FATIMA CARDOSO

CHAMPALIMAUD CLINICAL CENTER, ABC GLOBAL ALLIANCE, LISBON, PORTUGAL

Written by Dr. Maria João Cardoso, Champalimaud Foundation, Lisbon, Portugal

DR. FATIMA CARDOSO HAS DEDICATED her life to patients with breast cancer. Since her first years as a medical oncologist, she understood that patients with metastatic breast cancer needed someone to fight for their voice to be heard among the usual quotes like "race for the cure" or "let's kill cancer" so common and natural among patients with early breast cancer.

Patients with metastatic breast cancer were, in many countries, put aside and considered not worthy of attention because at the end of the day, they would die. Fatima was impressed by the different realities of patients with metastatic breast cancer around the world in her many travels, especially in low-income countries where even the most basic measures like morphine for pain were inaccessible. She was devastated to see women and men with metastatic breast cancer dying alone, suffering in silence. She started to imagine in how she could help in a meaningful way all those who needed someone to fight for her voice.



She started to imagine in how she could help in a meaningful way all those who needed someone to fight for her voice.

—Dr. Maria João Cardoso

Using her scientific knowledge and her heart, Fatima, through the European School of Oncology, organized the first international breast cancer conference dedicated to metastatic breast cancer, the Advanced Breast Cancer (ABC) Conference.

It was a success, and from 2011 to 2021, the ABC Conference, now in its sixth edition, is the most well-known scientific event dedicated to advanced breast cancer around the world. The ABC guidelines are used by thousands of doctors and patients everywhere. The ABC Conference brings together the most well-known specialists in the world side by side with patients with metastatic breast cancer. It is unique in its conception and wonderful in its execution.

But Fatima felt that ABC was not enough. In 2016, the ABC Global Alliance was established. The alliance is a nonprofit organization dedicated to ABC. It brings together several organizations that seek to improve not only survival but also quality of life for patients with breast cancer. It has been an incredible journey that I had the privilege of seeing happen every day for the last 10 years.

Seeing the progress of the ABC Global Alliance and how Fatima continues to dedicate part of her life to the cause, always available to those who come for her, day or night, from Africa or Asia, makes us understand how the fight for the voice of these patients to be heard was worthy.

From left: MARTA VALLEE COBHAM, B.S.N. RN, and DR. ANNE MOORE

PHOTOS BY BEN HIDER

A GIFTED VOICE AND PASSIONATE ADVOCATE FOR METASTATIC BREAST CANCER RESEARCH

MARTA VALLEE COBHAM, B.S.N., RN

WEILL CORNELL BREAST CENTER, NEW YORK, NEW YORK

Written by **Dr. Anne Moore**, Weill Cornell Medicine/NewYork-Presbyterian Hospital, New York, New York

IT IS A PRIVILEGE TO nominate oncology nurse Marta Vallee Cobham, B.S.N., RN, for a *CURE*[®] Metastatic Breast Cancer Heroes[™] award. She has worked at NewYork-Presbyterian Hospital and Weill Cornell Medicine for over three decades. Starting in the field when the term "research nurse" was still very new, Marta recognized early on the importance and need for clinical research in order to eventually cure metastatic breast cancer.

Marta's passion for clinical research manifests itself in the way she explains the value of research participation. Marta has a unique ability to convey information in a way that breaks down complex protocols and makes people feel reassured. Personally counseling and consenting thousands of patients with breast cancer to participate in clinical trials, Marta is a true partner in their care. Patients know that despite any ups and downs of their disease trajectory, Marta is steadfast in her commitment to remaining by their side. **»**



Marta learned firsthand the impact of metastatic breast cancer when she guided her own sister, Ilka, who received a diagnosis at age 35, through a five-year journey with the disease. Ilka repeatedly told Marta that there was "not enough research to help people with metastatic breast cancer and not enough research on people who 'look like me.'" Marta channels this experience each and every day to improve the lives of others who are navigating the path of metastatic breast cancer.

Marta's commitment to health education and increasing awareness about the importance of clinical trials, evidence-based research, disparities and advances in breast cancer care extend beyond the exam room and across borders. Marta is a highly sought-after speaker, actively involved with volunteer activities throughout New York City as well as in her native Panama. As recently as May 2021, Marta was selected to present at a New York City Council town hall meeting on disparities in health care access and breast cancer care in Brooklyn. Marta also speaks annually at the National Panamanian Friendship Reunion on breast cancer and advances in cancer research. A trusted leader, Marta's gift is her ability to make information accessible to people of all backgrounds and from all walks of life.

Marta personifies the very best of the metastatic breast cancer research profession. She takes care of individual patients as if they were her own family, while simultaneously promoting the importance of clinical trials. Marta is truly a gifted voice and passionate advocate for metastatic breast cancer research.



FIERCE BREAST CANCER ADVOCATE

DALE EASTMAN

ALAMO BREAST CANCER FOUNDATION, SAN ANTONIO, TEXAS

Written by Jonathan Colemere, Alamo Breast Cancer Foundation, San Antonio, Texas

"YOU HAVE BREAST CANCER." Four simple words, then silence. Time itself freezes, as if some cosmic power switch abruptly turned off. Somehow, the cold fluorescent ceiling light continues to softly flicker and hum, an unnerving defiance in the icy suspended tableau of this formerly innocuous examination room. The doctor's mouth slowly moves as the hum crescendos in your head. This can't be happening. Why? Why me!? Oh God, what about my kids? Am I going to die? Slowly, the four words sink in and your new life begins. Ready or not, you are now a warrior.

For thousands of women and men every year, this kind of waking nightmare serves as the cruel orientation to the most important battle of their life. In October 1990, Dale Eastman experienced this horror firsthand. Diagnosed with stage 3 breast cancer at age 49, the San Antonio mother of three was faced with two choices: fight or FIGHT! Dale chose the latter. »

She channeled the anger from her diagnosis into action and crafted a war strategy fit for a general. Dale bravely fought through painful surgeries and sickening chemotherapy to the victory of remission in 1992. She knew that while this battle may have ended, the war was far from over.

Dale knew she had to continue the fight and help others affected by this disease. Her passion and determination eventually led to a meeting in 1992 with three fellow survivors around Dale's kitchen table. This makeshift war room is where the seeds of the Alamo Breast Cancer Foundation were sown.

These brave women spent the next three years carefully crafting, from scratch, a nonprofit organization dedicated to breast cancer advocacy. During their respective breast cancer journeys, Dale and her friends discovered that treatment options available in the 1990s had not changed since the 1970s. Many women, after receiving a diagnosis, had only two or three days to make major decisions regarding surgery and treatment. They deemed this totally unacceptable and vowed to change the status quo. »





Dale and the other Alamo Breast Cancer Foundation founders focused their efforts on identifying the causes of breast cancer with an aim to discover preventives and, hopefully, a cure. The Alamo Breast Cancer Foundation's direct support of evidence-based scientific

Dale Eastman serves as an inspiring leader for the breast cancer community. –Jonathan Colemere

research remains a core function of the foundation. For 24 years, the Patient Advocate Program at the San Antonio Breast Cancer Symposium has provided a remarkable educational platform for the world's breast cancer community. The Patient Advocate Program is world renowned and has served as a model for numerous international scientific conferences.

Dale also designed the Alamo Breast Cancer Foundation as a community resource to help ensure quality care for all women and men affected by breast cancer. Outreach events such as the Alamo Breast Cancer

Foundation's Healthy Women Make Healthy Communities provide valuable resources, educational material and free screening mammograms for San Antonio's uninsured and underinsured populations. Strong partnerships with San Antonio's medical community afford the Alamo Breast Cancer Foundation a broad range of resources to help assist and guide thousands of individuals.

In the nearly 30 years since Dale helped create the Alamo Breast Cancer Foundation, she has continued her fight as a fierce breast cancer advocate. In 1994 she partnered with the National Breast Cancer Coalition to fight for breast cancer funding and research at the federal level. Dale is a proud 1995 graduate of the National Breast Cancer Coalition's Project

LEAD science training course and a participant in numerous advocacy training conferences and advocate leadership summits. She has embraced her leadership in every way possible. Dale became the National Breast Cancer Coalition Texas field coordinator in 1997, managing the Texas Action Network. When the National Breast Cancer Coalition developed a network of team leaders in 2003, Dale was one of the first invited to take on that role. Dale served on the National Breast Cancer Coalition board of directors from 1995 until 2015. She credits her National Breast Cancer Coalition training for her consistent, successful advocacy work.

Dale has led the advocacy charge on the state and national levels, developing relationships with Texas lawmakers. Dale was proud to represent Texas and the National Breast Cancer Coalition at the White House, delivering tens of thousands of signatures in support of research funding. She continues to serve as the chair of advocacy and government relations for the Alamo Breast Cancer Foundation and as a National Breast Cancer Coalition field leader. Her leadership resulted in Texas enacting laws expanding access to care for underserved women with breast and cervical cancer, mandating coverage of routine health care costs associated with clinical trials and mandating advocate involvement in research programs, among many others.

Dale has been appointed to several councils and committees in breast cancer and elsewhere, including the advisory board of the National Institute of Environmental Health Sciences, the Breast Cancer and the Environmental Working Group and the NIH Collaborative Summit on Breast Cancer Research. She has received many awards and recognitions, locally and nationally, for her breast cancer work.

Above all, Dale Eastman serves as an inspiring leader for the breast cancer community. Despite a metastatic recurrence in 2018, Dale exudes unstoppable strength and her passionate dedication to advocacy inspires us every day. She is the mother of our Alamo Breast Cancer Foundation family and we unequivocally consider Dale our hero.

Stay FIERCE, Dale! We thank you, we honor you and we love you.

From left: VICTORIA GOLDBERG and CHRISTINE BENJAMIN, LMSW

RELENTLESS PURSUIT OF PATIENT SUPPORT

VICTORIA GOLDBERG

SHARE CANCER SUPPORT, NEW YORK, NEW YORK

Written by Christine Benjamin, LMSW, SHARE Cancer Support, New York, New York

SHARE CANCER SUPPORT'S breast cancer helpline has been around for decades. It started with a phone and answering machine in the closet of an early SHARE volunteer's New York City apartment. The helpline was primarily for those who had received a diagnosis of early-stage breast cancer, but those with metastatic breast cancer were welcome to call. Volunteers were trained to make peer matches and connect callers with metastatic breast cancer to other volunteers living with metastatic breast cancer. The system seemed to work.

Victoria Goldberg received a diagnosis of early-stage breast cancer at age 43. Ten years later, she received a diagnosis of metastatic breast cancer, which derailed her corporate IT career — one she exceled at. Victoria joined SHARE a year or so after her metastatic breast cancer diagnosis and immediately took several helpline shifts per week. She loved to come into the office, work her shift and socialize with staff and other volunteers. Victoria would often remain on the phone while others left to catch trains, meet friends or catch a show. **»**

Victoria began speaking with most of the callers with metastatic breast cancer. She attended conferences and Project Lead and kept up with the latest research about the treatment of metastatic breast cancer. Victoria would spend hours with each woman discussing her diagnosis, treatment plan, questions to ask her doctor, the emotional impact of living with an incurable disease, family issues and more. Victoria became a lifeline to so many women.

After a year or so of working this way, Victoria began talking to me about the need for a helpline dedicated to those living with metastatic breast cancer. The helpline, she said, would be staffed by volunteers who are living with metastatic breast cancer. I told her I would think about it. A few days later, Victoria asked if I had thought about it. I hadn't. She asked again during her next shift, and again after that. Victoria was relentless in her desire to help, and felt she would be able to make a bigger impact by helping more people if she could bring others on board to share the workload.

TalkMets was born about three years ago. It's a dedicated helpline by and for those living with metastatic breast cancer.

Running a helpline as a volunteer would be enough for most people, but Victoria decided she could help even more women if she became a support group facilitator, which she did, and a host of "Our MBC Life" — a podcast created, produced and hosted by a group of people living with metastatic breast cancer.

Victoria's drive is unimaginable. She has this much energy and passion even while in continued treatment for her own disease. She has helped so many women deal with the devastating impact of a fatal disease diagnosis. Victoria has talked many women off the ledge and onto the path back to living life.





ONE WOMAN, MANY LAKES

MARY GOOZE

OREGON, WISCONSIN

Written by Janie Winston, B.S., University of Wisconsin Foundation, Madison, Wisconsin

WHAT DOES IT MEAN TO live one's life to the fullest with stage 4 cancer when there is no cure in sight? In late summer of 2015, I was introduced to Mary Gooze. I knew Mary had terminal breast cancer and was swimming in every lake she possibly could to raise awareness for this disease. The diagnosis was grim, and Mary and her husband, Rob, felt the best chance of hope was to raise money to go directly to late-stage breast cancer research on a local level.

Mary, a retired teacher, had received a breast cancer diagnosis and was treated in 2012. Twenty months after Mary's initial diagnosis, she was training for one of her now-routine swims when she was told her cancer was back — and it had metastasized. As she entered the water, Mary felt stronger and stronger, giving her the idea to start an initiative called One Woman, Many Lakes. The goal: to raise awareness, to educate and to raise much-needed funds for research.

After several meetings with researchers and clinicians at the University of Wisconsin (UW) Carbone Cancer Center, the Goozes put all their philanthropic and fundraising »


efforts toward the More for Stage IV Fund, which they created at UW-Madison to open more opportunities for survival for women like Mary.

Six years after we met at the UW Carbone Cancer Center, the Goozes have raised \$2 million for stage 4 breast cancer research, funding new projects on immunotherapy, liquid biopsies and improved treatment options for patients with stage 4 disease. They have provided funding for over 75 researchers and engaged the community to rally around this often-overlooked cause.

Through her swims, Mary has met politicians, journalists and other patients thriving with stage 4 breast cancer who are inspired by her. She has encountered community members who ended up holding private fundraisers in their homes. Mary also now holds onto the spirits of young women she's connected with who have sadly passed away — women like Heather McManamy, whose obituary went viral and who wrote, "Cards for Brianna: A Lifetime of Lessons and Love from a Dying Mother to Her Daughter."

Mary has swum in lakes as far away as Ireland, Iceland, Kauai and as close as Lake Monona in Madison, Wisconsin — all in the name of raising money and awareness. Before she enters the water, she says a few words about why she is swimming and always ends her talk with the benediction: "Research is our best hope." A lot of people with this swimmer's diagnosis would stay home and rest. Maybe they would do a little virtual fundraising. But taking to the lakes is a unique and personal spin on shedding a light on Mary's disease.

Through these adventures, Mary has influenced and inspired so many other women with stage 4 cancer who have taken on fundraisers of their own — all for the More for Stage IV fund at the cancer center. Numerous women have been inspired to raise money for their birthdays, with one setting a goal to raise \$40,000 for her 40th, and another woman attempting \$50,000 for her 50th. Both surpassed their goals. Meanwhile, Rob and Mary have always been open to matching a certain amount during these fundraisers. They decided to raise \$70,000 for Mary's 70th this past summer.

On top of that, Rob surprised Mary on her 70th birthday by establishing a \$2 million endowment in their names to a breast cancer oncologist who will now focus on metastatic breast cancer research in his lab.

Anyone who encounters the Goozes leaves inspired and with hope. Mary has mentored so many others who have a similar diagnosis. They go to the nation's capital, peer-review breast cancer research and are active in so many ways. After one meeting with a gym owner, the gym held a night of awareness for their fund, several of their attorneys hosted a fundraiser at home, a group of volleyball players organized a tournament and a group of artists did an art show with proceeds going to More for Stage IV. This is just a small sample of people in our community who have been touched by Rob and Mary's story.

While Mary is living with this, it does not define her. She and Rob continue to travel all over the world, hiking and swimming, kayaking and fishing. They are also involved in many other organizations, Rob having been the president of the Madison Rotary, on the board for Special Olympics and treasurer for Three Gaits, a therapeutic horseback riding nonprofit. The couple also support the Madison libraries, the Madison housing nonprofit Porchlight and the American Red Cross.

Metastatic breast cancer research is underfunded because a lot of research dollars go to prevention and early-stage cancer. Through the More for Stage IV fund, we have been able to advance our knowledge and research of this devastating disease and bring that same hope to patients across Wisconsin and the world.

MY BREAST FRIEND

CHRISTINE GUARINO, RDH, CMF, CFM

A WORLD OF PINK FOUNDATION, SMITHTOWN, NEW YORK

Written by Michele Ortiz, Hauppauge, New York

SEVERAL YEARS AGO, my friend went back to school to be a prosthetic fitter. While interning at a plastic surgeon's office, she saw a need for women with breast cancer in their after-surgery stage. From that experience was born her vision of A World of Pink.

I will never forget the day she walked into the dance studio and announced that she was starting a business to help women with breast surgery aftercare. I had to chuckle thinking only Christine would take on more than she was already doing — a mother of three, a dental hygienist and now starting a company! »







With her company and foundation, Christine has changed the lives of countless women in New York and across the country. She designed the first breast prosthetics for women of color, fashionable but comfortable bras for post-mastectomy surgery and so much more. Her foundation's fundraisers (galas, golf outings and more) raise money to give to patients who can't afford the aftercare they need and deserve. Christine makes sure they know they can get their bras for free through their insurance.

The annual gala is a big production. Christine involves the whole community. From local college dance teams and aspiring musicians to retired football players and other professional athletes, everyone is involved in the evening's events. Patients are invited to model, wear a pretty gown, get their hair and makeup done. They are escorted down the runway by either their surgeon or by one of the athletes in attendance. At the end of the night, all survivors are invited onto the runway.

Christine Guarino is always on the go, finding ways to help women feel beautiful and good about themselves after surgery. She is an inspiration and beyond generous with her time and contributions. She cannot help people enough. I am honored to be her friend.



COMPASSIONATE GUIDANCE THROUGH A CLINICAL TRIAL

GIL R. GUERRA, B.A., CCRP

THE UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTER, HOUSTON, TEXAS

Written by Gail Barr, Pearland, Texas

I AM HONORED TO NOMINATE Gil R. Guerra for the Metastatic Breast Cancer Heroes[™] award. Gil is a senior clinical studies coordinator and research trial nurse at The University of Texas MD Anderson Cancer Center in Houston. He trains and supervises a cadre of research trial nurses and teaches them how to compassionately care for patients. He is amazing at what he does! He is skilled in palliative care, oncology and cancer research. He does everything possible to help his patients understand clinical trials and how they might benefit from them, answering most questions before they are even asked. He has a gentle way of guiding his patients through the sometimes arduous hoops required by clinical trials and putting »

Treatment never ends. Patients with metastatic breast cancer need someone as dedicated and caring as Gil.

them at ease. Gil is always available to smooth out any bumps or problems that arise for his patients. He shares his vast knowledge and educates patients and their caregivers about the ins and outs of the trials in which they participate.

—Gail Barr

Because of his supportive rapport with his patients, his name often has come up in our local support group, resulting in everyone wishing they had "a Gil." He is an inspiration and is one of the reasons a group of patients began a grassroots effort to establish the Advanced Breast Cancer Program and Clinic at MD Anderson, so everyone would have a Gil to guide them through their metastatic breast cancer journey. The needs of a patient with metastatic breast cancer are far different from those of an early-stage patient, and those needs continue for the rest of their lives. Treatment never ends. Patients with metastatic breast cancer need someone as dedicated and caring as Gil.

Gil has been my clinical trial nurse and my metastatic breast cancer hero for eight years, and I can't think of anyone more deserving of the Metastatic Breast Cancer Heroes[™] award. My husband and I both consider him a friend and extended member of our family. ■



BRINGING HOPE AT A DARK HOUR

DR. NANCY U. LIN

DANA-FARBER CANCER INSTITUTE, BOSTON, MASSACHUSETTS

Written by Dr. Harold Burstein, Dana-Farber Cancer Institute, Boston, Massachusetts

I AM DELIGHTED TO NOMINATE my colleague and friend Dr. Nancy U. Lin for the *CURE*[®] Metastatic Breast Cancer Heroes[™] award for those having impact on the lives of women with advanced breast cancer.

Dr. Lin has devoted her professional life to the treatment of women with breast cancer, and her academic focus has been on the treatment of patients with metastatic breast cancer to the brain. It is difficult to describe the devastating consequences of brain metastases on the emotional and physical well-being of our patients. Of all the awfulness of the relentless toll of breast cancer, the diagnosis of brain metastases stands alone and strikes at the core of human identity and feeling. It is most common in the most resistant, refractory of breast cancers, and there are few treatment options.

Dr. Lin has been a beacon of hope for countless women with metastatic breast cancer. Her clinical knowledge in this area is unsurpassed. However, it is her compassion, her warmth »



and her caring that so distinguish her remarkable work as a physician. She brings empathy and understanding of an unparalleled degree.

But her contribution has not simply been in the finest of compassionate care. She has resolved to improve outcomes for such patients, with clinical trials dedicated to the unique



DR. HAROLD BURSTEIN PHOTO PROVIDED BY **DANA-FARBER CANCER INSTITUTE**

circumstances of such patients and by building a multidisciplinary team of experts from neurosurgery, neuroimaging and radiation oncology to help provide the optimal care of women with brain metastases. The group collected under her leadership has revolutionized the way in which our patients with brain metastases are seen, evaluated and cared for, and achieved incredible progress in the quality of life for such women. They know that there are dedicated, caring physicians completely focused on achieving the best for them.

For women afflicted by this particular syndrome, the hope that Dr. Lin has created has proven to be a shelter, a source of comfort and a place of hope despite a very challenging diagnosis.

For her skill and wisdom as a clinician, for her insights as an investigator and for redefining

how we can care for women with advanced breast cancer, Dr. Lin is most deserving of your recognition with a Metastatic Breast Cancer Heroes[™] award. **G**

A MOST ADMIRED COLLEAGUE

DR. NANCY U. LIN

DANA-FARBER CANCER INSTITUTE, BOSTON, MASSACHUSETTS

Written by Elizabeth Frank, Dana-Farber Cancer Institute, Boston, Massachusetts

IT IS A PRIVILEGE TO nominate my colleague at Dana-Farber Cancer Institute, Dr. Nancy U. Lin, for the Metastatic Heroes[™] award. Nancy is an outstandingly talented medical oncologist and an amazing advocate for people living with metastatic breast cancer.

Nancy is not only a caring and compassionate care provider who goes the extra mile on behalf of her patients, but also a leading clinician scientist. Her research focuses on improving treatment for patients with advanced disease, especially those living with breast cancer brain metastasis. Nancy has been the principal investigator on clinical trials leading to new treatments for breast cancer brain metastasis, has co-led a commission to advocate for the inclusion of patients with active breast cancer brain metastasis on clinical trials and is heavily involved in preclinical research projects to help us better understand why breast cancer travels to the brain.

She is an outstanding mentor to junior colleagues, demonstrating by example that tackling hard questions is critically important. Nancy has also built a program at Dana-Farber that »



supports patients living with metastatic disease by helping them access the types of psychosocial, integrative and educational resources that can improve the quality of their lives. Related to this study is a large cohort study of patients living with metastatic breast cancer that is providing clinically annotated data along with a rich biospecimen collection to investigators studying metastatic breast cancer.

Those of us who are fortunate to work with Nancy know that when she is approached about a project or program that can help patients, she is all about figuring out to how to make it work. Nancy's efforts thus far have already led to meaningful improvements in treatment for patients.

As a patient with breast cancer, patient advocate and colleague of Nancy's, I feel certain that her work, and the work of those she mentors and inspires, will continue to extend and improve life for patients living with metastatic breast cancer.

TRAILBLAZER, ADVOCATE, INNOVATOR AND CLINICIAN FOR PATIENTS WITH METASTATIC BREAST CANCER

DR. NANCY U. LIN

DANA-FARBER CANCER INSTITUTE, BOSTON, MASSACHUSETTS

Written by Dr. Rachel Freedman, Dana-Farber Cancer Institute, Boston, Massachusetts

DR. NANCY U. LIN IS most deserving of this award. It is hard to find the words to describe how much she has done for the metastatic breast cancer community, including patients, caregivers, researchers and clinicians. She also does everything with grace, humility, generosity and kindness, and is a true mensch and friend in every aspect of what she has done and continues to do.

To give you a sense of what she has accomplished to date: Dr. Lin is an international expert in the care of patients with metastatic breast cancer. She has led many high-impact, practicechanging clinical trials, runs the metastatic disease program at Dana-Farber Cancer Institute and is a staunch supporter and advocate for developing and nurturing optimal ways of caring for patients. She leads our central nervous system metastatic program at Dana-Farber and »



is a mentor to many on how to build programs, run trials, think about research and deliver the highest-quality care to patients with this disease.

She built the EMBRACE program (Ending Metastatic Breast Cancer for Everyone) at our center from the ground up. EMBRACE is both a clinical and research program for patients with metastatic breast cancer. Patients enrolled to EMBRACE are offered a unique package of services, support groups, research opportunities and educational forums and are a part of a large registry that allows us to track patients for prescreening of studies, possible opportunities for clinical trials and understanding patterns of care and tumor genomics.

Nancy continues to push the limits of what is available to our patients, is constantly evolving and innovating around caring for patients with metastatic breast cancer and is the most collegial, kind, supportive colleague you could hope for. Her work really deserves this special recognition. I truly believe there is no one on the planet doing more for patients with metastatic breast cancer than Dr. Nancy Lin. Thank you for considering her for this award.

THE VISION OF EMBRACE

DR. NANCY U. LIN

DANA-FARBER CANCER INSTITUTE, BOSTON, MASSACHUSETTS

Written by Melissa Hughes, M.S.c., Dana-Farber Cancer Institute, Boston, Massachusetts

AS WE APPROACH OUR 10th annual Metastatic Breast Cancer Forum this October 2021, it is an important moment to honor Dr. Nancy U. Lin, the director of Dana-Farber Cancer Institute's (DFCI) EMBRACE (Ending Metastatic Breast Cancer for Everyone) program. Dr. Lin had the vision of this program in her mind when writing the original protocol to initiate the research cohort study focused on patients with metastatic breast cancer in 2009. At the center of her vision is the primary goal to provide consistent support and care to patients with metastatic breast cancer diagnoses through enhancements in their longitudinal care, education and supportive care resources. While her research interests focus upon improving the outcomes of people living with metastatic breast cancer through clinical trials, in particular, those with breast cancer brain metastases, Dr. Lin felt strongly that there needed to be a clinical program to make sure every one of the patients with metastatic breast cancer being cared for at DFCI felt fully supported.

To date, her vision is now a reality with over 3,200 patients with metastatic breast cancer having participated in the EMBRACE program since its inception in 2015. As our leader, Dr. Lin works tirelessly to develop and organize the annual forum, newsletters and webcasts that have been provided to the patients throughout the year for six years. She is meticulous in her direction

She inspires us all with her tenacity, clarity, kindness and grace in how she moves the research agenda ahead.

-Melissa Hughes, M.S.c.

of our EMBRACE program and its integration into clinic, where our team of clinical research coordinators track every patient with metastatic breast cancer to ensure that each one is being considered for the appropriate clinical trial based on their subtype, treatment history and any genomic and/or molecular alterations.

She is devoted each week in leading the multidisciplinary brain metastases tumor board with her colleagues where they discuss specific cases with breast cancer brain metastases and potential treatment and clinical trial options for these patients. After these tumor boards, I feel that Dr. Lin is at her best in these moments, as she is doing exactly what she trained and hoped

to do for her patients with metastatic breast cancer. Her thoughtful scientific leadership continues to bring rise to innovative studies based on the patients' contributions of their clinical data and biospecimens collected under the EMBRACE research study and other protocols focused on advanced breast cancer.

In more recent years, the success of her program spawned a request for proposals sponsored by the National Comprehensive Cancer Network/Pfizer to extend the vision and goals of the DFCI's EMBRACE program to other cancer centers across the United States. While she has touched thousands of patients through the DFCI program and other cancer centers' programs, it

never ceases to amaze me during patient panels and support groups sponsored by EMBRACE that we will hear from at least one patient with metastatic breast cancer who is so grateful and proud to be one of Dr. Lin's patients. She inspires us all with her tenacity, clarity, kindness and grace in how she moves the research agenda ahead for patients with metastatic breast cancer, while ensuring that each patient in our clinic is treated with the best quality of cancer care.

With her motivating leadership and generous mentorship to our team and myself over the last seven years, it is very evident that I am so proud to nominate Dr. Nancy U. Lin for a Metastatic Breast Cancer Heroes[™] award for all she has accomplished to address the needs of patients with metastatic breast cancer. **©**



ADVANCING OUTCOMES AND QUALITY OF LIFE FOR PATIENTS WITH METASTATIC DISEASE

DR. NANCY U. LIN

DANA-FARBER CANCER INSTITUTE, BOSTON, MASSACHUSETTS

Written by Dr. Sara Tolaney, Dana-Farber Cancer Institute, Boston, Massachusetts

DR. NANCY U. LIN HAS dedicated her career to advancing quality of life and outcomes for patients with metastatic breast cancer. She is the director of the metastatic breast cancer program at Dana-Farber Cancer Institute and is the founder and director of the EMBRACE (Ending Metastatic Breast Cancer for Everyone) program for patients with metastatic breast cancer. She also directs a program for patients with breast cancer-related brain metastases. She has wanted to help patients navigate living with metastatic disease better; she created a regular forum for patients with metastatic disease that provides information on art therapy options, advice on coping with the disease, sharing information with children and more. She has also created a system to share tumor genomic information back to the patient and with

any local oncology providers, letting them know about possible treatment options. She has a group of EMBRACE coordinators who meet with our patients with metastatic breast cancer in clinic and help connect them to any services they may need and to any clinical trials they may be eligible for by coordinating any necessary prescreening or referrals. Additionally, she built a database to track all patients with metastatic breast cancer over time, with the goal of being able to ask important questions about treatment outcomes in the metastatic setting.

Beyond this, Nancy is a compassionate provider who is loved by her patients. She goes out of her way to make sure each patient receives the best cancer care possible. She gets numerous referrals from our local community oncologists but also from oncologists across the country. She helped create a tumor board specifically for patients with breast cancer-related brain metastases that she oversees, and oversees a robust portfolio of brain metastases trials. Patients often travel from all over the country to see her for evaluation and consideration for these studies.

Her dedication and passion toward improving the lives of patients with metastatic breast cancer is unparalleled and I can think of no one more deserving of this award.



DR. SARA TOLANEY
PHOTO PROVIDED BY DANA-FARBER CANCER INSTITUTE

ENDING METASTATIC BREAST CANCER FOR EVERYONE

DR. NANCY U. LIN

DANA-FARBER CANCER INSTITUTE, BOSTON, MASSACHUSETTS

Written by Dr. Ines Vaz-Luis, Gustave Roussy, Villejuif, France

I FEEL EXTREMELY PLEASED to nominate Dr. Nancy U. Lin for the Metastatic Breast Cancer Heroes[™] award 2021. I was privileged to first meet her 10 years ago when I was her mentee as an international fellow in the breast oncology program at Dana-Farber Cancer Institute. She is an associate professor of medicine at Harvard Medical School, director of the metastatic breast cancer program and a senior physician at Dana-Farber.

Nancy is a unique clinician. Her patients adore her and she has tremendous clinical skills and the ability to listen and to help patients in their breast cancer journey. She acts very much as a mentor to the people she cares for, guiding them through the often long and difficult cancer road they need to navigate.

In this context, she founded the Ending Metastatic Breast Cancer for Everyone (EMBRACE) program, which combines a strong research program with wraparound clinical services dedicated to women who receive a metastatic breast cancer diagnosis. At this point, over 3,000 patients have participated in the EMBRACE clinical and research program since its inception in 2015.

The clinical program provides a structured pathway of care combining extensive patient educational support with coordination within a network of health care providers. EMBRACE also provides access to clinical trials, with almost 2,000 patients who have consented to tumor prescreening for a specific clinical trial so far. In addition, it created a unique research infrastructure including an annotated dataset, over 5,000 research blood samples collected, and 2,434 patients consenting for OncoPanel next-generation tumor sequencing. This resource allowed for a multitude of research projects with unique ability in improving the scientific understanding, which then translates to improvement of care of patients living with metastatic breast cancer.

In addition, Nancy is a champion of research and management of patients with



DR. INES VAZ-LUIS

metastatic breast cancer to the brain. She has led several significant clinical trials that led to Food and Drug Administration approval of new drugs for patients with HER2-positive breast cancer that has spread to the brain. Nancy is now focused on assessing the genomic alterations that occur with the development of breast cancer-related brain and central nervous system metastases.

Nancy's influence reaches deeply throughout Dana-Farber Cancer Institute and extends to throughout the nation and across the world. As a medical oncologist — and a daughter of someone who died from metastatic breast cancer — I am inspired and thankful for having found Nancy on my path and having her lead my way into my profession.

In summary, I can think of no more deserving individual to receive this award.



THE MOST HOPEFUL PERSON I FOLLOW

LARA MACGREGOR

HOPE SCARVES, LOUISVILLE, KENTUCKY

Written by Susan Vanderver, Potomac, Maryland

LARA MACGREGOR IS AN amazing young woman and patient with metastatic breast cancer who has inspired me and many others through her bright and hopeful outlook. Not only has she used her energy to support her teenage sons, but she has also poured her efforts into establishing a thriving nonprofit organization and spends time sharing her metastatic breast cancer story through blogs, Instagram and Facebook. She's even writing a book.

Hope Scarves is Lara's organization, dedicated to providing scarves to patients with cancer who lose their hair. I lost my hair before Hope Scarves was founded, but I support the need to help those experiencing the effects of chemotherapy treatments. When I donated to Hope Scarves a few years ago, I received a thank you note from Lara. She promoted her organization's motto: "To live life over cancer."

I've never actually met Lara, but she is my social media friend, posting often. I feel as though I know her and I share her hope and her pain. Although we both received our **»**

diagnoses in 2007, our paths have diverged. Mine was metastatic inflammatory breast cancer, and I have thrived for over 14 years because I respond well to a treatment called Herceptin (trastuzumab). I fully recognize the gravity of the metastatic breast cancer diagnosis.

Lara's was a different kind of breast cancer that was treated but returned as metastatic in 2014. Since then, she has been on many treatments that worked for a while, until they didn't.

She has brought so much light and attention to the cause of metastatic breast cancer.

—Susan Vanderver

At this point, Lara is running out of options. She is madly trying to be a good mother and wife, transition her nonprofit to a new leader, keep her social media community informed and supportive and finish her book.

Lara has been inspirational to so many in this new world of sharing on social media. In spite of the terrible trials she has experienced, she remains positive and hopeful, and shares this perspective with others. She has brought much light and attention to the cause of metastatic breast cancer.

Lara's situation scares me because it is likely a future that I, and many other patients

with metastatic breast cancer, will face at some point. Yet Lara has handled this situation with grace and energy, positivity and hope, which has created a special relationship that is truly unique. Lara has many fans and friends who hope, right along with her, that the next treatment she receives will be the one to save her.

EDITOR'S NOTE: Lara MacGregor died in January 2022 before this book went to print. Our thoughts go out to her family and friends.



IT ALL BEGINS WITH A REASSURING SMILE

DR. MARIA RAQUEL NUNES

JOHNS HOPKINS SIDNEY KIMMEL COMPREHENSIVE CANCER CENTER AT SIBLEY MEMORIAL HOSPITAL, WASHINGTON, D.C.

Written by Linda McCarthy, Front Royal, Virginia

FOR CURE''S INAUGURAL Metastatic Breast Cancer Heroes[™] awards, I would like to respectfully nominate Dr. Maria Raquel Nunes, a breast medical oncologist at the Johns Hopkins Sidney Kimmel Comprehensive Cancer Center at Sibley Memorial Hospital, as well as assistant professor of oncology for The Johns Hopkins University School of Medicine.

Beyond her impressive and well-deserved medical and academic credentials, Dr. Nunes is widely revered by patients and colleagues alike for her boundless warmth, empathy and kindness. And that smile. We all love that reassuring smile.

It was her smile that first greeted me during my initial appointment in 2017. Having recently received a diagnosis of metastatic breast cancer, I had traveled 75 miles to Sibley from my mountainside home to be seen by Dr. Nunes. With her smile, I was immediately swept up in a calming and liberating wave of optimism. **»**

NS HOPKINS EDICINE ENEY NUMBEL PROTY CANCER CATE (19)

Raquel Nunes MD

DR. MARIA RAQUEL NUNES PHOTOS BY WILL REINTZELL





As I soon learned, that wonderful smile is an outward manifestation of Dr. Nunes' innate sense of purpose. And Dr. Nunes' purpose is to always do the best by her patients.

Deeply embodied in Dr. Nunes' sense of purpose is a desire to actively involve those patients in discussions and decisions representing a broad range of treatment possibilities. No false hopes. No magical cures. Just the latest and greatest in available options, grounded in solid science and research, both of which Dr. Nunes enjoys and fosters.

During these conversations, Dr. Nunes invites questions as well as candid, even differing viewpoints. The resulting free-flowing dialogue between patient and practitioner is as enlightening as it is encouraging.

Who knew that metastatic breast cancer could be effectively stabilized without the horror show that often accompanies raw chemo? I didn't until Dr. Nunes originally proposed an oral drug regimen. When the effectiveness of one of the drugs ultimately waned, she recommended that I enroll in a Hopkins-affiliated clinical trial. Here, I have remained for over two years.

Thankfully, the retooling is working; during my last visit, heady medical terms like "awesome" and "beautiful" were used to describe results of the obligatory CT scan and labs. As if this alone weren't cause for celebration, the scan also revealed the offending tumor was "smaller." »

Needless to say, there were smiles all around in exam room 4 that day, with Dr. Nunes leading the pack.

Dr. Nunes' sincere desire to engage her patients in every aspect of their care isn't limited to purely clinical queries.

At the start of this past January's visit, she sensed an undercurrent of despair, reminiscent of my first Sibley visit. Even with my face shielded in a mandatory COVID-19 mask, Dr. Nunes realized something was very wrong. Putting the results of the morning's labs on momentary hold, she paused from the routine portion of the visit to find out just what was troubling me so.

"My sister died from cancer yesterday," I blurted out. "She fought hard for seven years, but it wasn't enough."

Then I proceeded to soak that annoying mask in a torrent of tears.

Dr. Nunes, who must see her share of distraught and despairing patients with cancer, pulled as close to me as polite social distancing would allow and began to listen intently as I recounted memories of my sister and her endless zest for life.

Kate had an extraordinary singing voice, was an accomplished fiddler and was studying opera, even as cancer was consuming her lungs. She was a true believer in music's power to lift lives and souls, and her beloved fiddle will be raffled to raise funds for educational music programs.

All this I unloaded on the gracious and giving Dr. Nunes, who had never met Kate.

When I finally finished, Dr. Nunes peered over her mask and reflected on the loss of my talented sister and her courageous struggle. How she must have touched so many people. How her music must have been so special.

Then Dr. Nunes looked directly into my teary eyes, reaching past the grief to remind me that my sister wouldn't want me to abandon my own cancer battle — an admonition Kate had quietly proffered, the last time I saw her, two months before she died.

Throughout these past four years, there has been any number of instances when I came away from an appointment believing Dr. Nunes was the most compassionate and dedicated

I am truly grateful for everything Dr. Nunes has done for me since beginning my cancer journey.

—Linda McCarthy

doctor ever to don a white coat. True to her innate sense of purpose, Dr. Nunes' genuine concern for my medical and personal well-being was never more on display than it was that dreary January afternoon.

All the while, a merciless global pandemic continued to subject health care heroes like Dr. Nunes to unrelenting mental, emotional and physical challenges.

I am truly grateful for everything Dr. Nunes has done for me since beginning my cancer journey. "Awesome" and "beautiful" test results. The incredible, shrinking tumor. A sympathetic ear when it was needed the most. Heartfelt words of support and consolation to go along with that sympathetic ear.

Oh, and her smile. I'll always be grateful for her reassuring smile.



MAKING LEMONADE FROM LEMONS

JENNIFER REYNOLDS

PINK WARRIOR ADVOCATES, NEW BRAUNFELS, TEXAS

Written by Charlene Doll, Seguin, Texas

IN 2013, JENNIFER REYNOLDS received a breast cancer diagnosis. She found herself pretty much going through the treatments and the anxiety that comes with that diagnosis without knowing anyone else who had been on this journey. Once Jen was done with her treatments, she felt a passion to help others. It started with a simple blog, making drain bags and pillows for those locally who had mastectomies, and grew into a program where warriors could reach out to other warriors and survivors for support and information so they never felt alone.

Unfortunately, Jen received another diagnosis September 2018. The ugly beast had raised its head again and was now metastatic. The cancer was now in her liver and spine and Jen could barely stand or walk before an operation. Some would have lain in that bed and felt sorry for themselves, but Jen found her strength in continuing to help others even more.

Out of Jen's little idea in 2014 and dedication has grown a nonprofit organization, Pink Warrior Advocates, that offers support to breast cancer warriors and survivors through several programs, including the following: **»**

- Chemo and mastectomy kits.
- Mastectomy bra program in concert with AnaOno.
- MetaWish, which grants wishes to stage 4 warriors.
- TV Thursdays.
- Financial aid: Before COVID-19, our community blessed Pink Warrior Advocates with donations that gave us the ability to award up to \$10,000 per month to help local warriors with medical bills, rent, food, etc.
- With Jen's innovative fundraiser ideas, Pink Warrior Advocates continues to be able to give up to \$5,000 per month locally during these COVID-19 times.

All of this would be an amazing feat for a healthy person, but Jen has metastatic breast cancer. She has had to change treatments several times in the past three years. With each one, she has had to learn to deal with new side effects. Through it all, she keeps a positive attitude and works hard to make this organization better and help more people.

Jen has truly learned to take the lemons life threw at her and make some very sweet lemonade for others.

I hope you will be able to see what a special person she is. Being her mom, I have always known that, but what she has accomplished truly amazes me every day and so many others in our community.

EDITOR'S NOTE: Jennifer Reynolds died in January 2022 before this book went to print. Our thoughts go out to her family and friends.




A SUPPORT SYSTEM FOR OTHERS

BRANDI RIBER, RN

FLORIDA CANCER SPECIALISTS, FT. MYERS, FLORIDA

Written by Karen Poland, Fairborn, Ohio

I WOULD LIKE TO NOMINATE Brandi Riber to be considered for the designation of Metastatic Breast Cancer Hero.

Having known Brandi as a child and seeing her mature into a beautiful, strong, determined woman has been a privilege. Her story is unique in that she has not only been battling the disease herself for 11 years, but she also cares for patients with cancer in her job as an oncology nurse. Brandi has been known to perform her duties at work while connected to an IV that is pumping in her own chemo treatment. She has been on nine clinical trials and throughout the ups and downs has done her best to maintain a positive attitude. Brandi faces her challenges with fierce determination while balancing life as a single mom of a teenage daughter, Morgan. Brandi and her ex-husband, Adam, try to maintain a loving family life for their child.

Brandi's parents are my dearest friends. They have been a source of strength and support for their daughter as she goes through all the highs and lows of a cancer diagnosis, trials »



and treatment. My heart goes out to them as they assist her in trying to make her life as "normal" as it can be. My husband was diagnosed with pancreatic cancer in 2012, and he and Brandi became very close as a support system for each other. He always told Brandi that he admired her attitude and her willingness to try any type of treatment so that others may benefit from a cure.

I believe Brandi is a Metastatic Breast Cancer Hero. I hope you will consider my nomination.

EDITOR'S NOTE: Brandi Riber, RN, died shortly after the Metastatic Breast Cancer Heroes[™] awards program in December 2021. Our thoughts go out to her faåamily and friends.

BEACONS OF LIGHT, HOPE AND COMMUNITY

ROOTS & WINGS INAUGURAL BOARD MEMBERS (VOLUNTEERS)

ROOTS & WINGS CHARITABLE FOUNDATION, WILMETTE, ILLINOIS

Written by **Diana Keen**, Roots & Wings Charitable Foundation, Wilmette, Illinois

ON AUGUST 4, 2014, at age 36, I was diagnosed with metastatic inflammatory breast cancer, a rare and aggressive form of breast cancer that isn't detectable until stage 3 or 4 and comes with a poor prognosis. Inflammatory breast cancer proved its aggressiveness over the years, and consistent treatment brought about challenging side effects that continually threatened my quality of life. I needed to learn more than just how to fight. I needed to learn to thrive.

Integrative oncology taught me how to thrive and support my mind, body and spirit while facing incurable cancer. It also taught me the importance of paying witness and gratitude to the community that supports you. Cancer doesn't just change your life, but it also significantly impacts your nearest and dearest. I wouldn't be able to walk this journey alone and am forever grateful for those who walk with me, from my excellent medical professionals and integrative practitioners to, most of all, my family and dearest friends. They are my beacons of light, hope and ultimate community support. They are my metastatic breast cancer heroes. »



In 2019, thriving five years post-diagnosis (a milestone not granted to many with metastatic inflammatory breast cancer), I felt a strong calling to give back to the metastatic breast cancer community. I wished more patients with metastatic breast cancer had easy and affordable access to integrative support to increase their quality of life. Patients with metastatic breast cancer endure so much for a long time. Having resources to improve those days is a game-changer. I started sharing the idea of supporting the metastatic breast cancer community with some of my closest friends and they all responded immediately with ideas on how they could help.

These beacons — Claire Holland, Anne Marques, Liz Moore, Erin Wanke, Heidi Pfetcher, Meghan DeRoma and Beth Szostek — are outstanding women who, without hesitation, volunteered to be on the inaugural 2020 board of what is now the Roots & Wings Charitable Foundation. They not only are my heroes but also now are true heroes to the metastatic breast cancer community. They give their time and talents generously when their busy schedules are filled with careers, families, community involvement, personal projects and so much more. Together, with incredible team members, we created the mission for Roots & Wings: to offer support to integrative and wellness programs that increase emotional, physical and spiritual well-being during the continuous oncology treatment for metastatic breast cancer.

In our first year, we have provided affordable and accessible integrative support at some leading metastatic breast cancer institutions in the United States, including Dana-Farber Cancer's Zakim Center for Integrative Therapies, Duke Cancer Institute's Supportive Care and Survivorship Center, and Rush University Cancer Center. We are supporting more metastatic breast cancer fighters than I could have ever hoped or dreamed. Their commitment, along with a dedicated volunteer team, are the reason Roots & Wings is flourishing. Without these beacons of light, hope and support, without these metastatic breast cancer heroes, Roots & Wings and its mission would still be a whisper of a wish.

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ROOTS WINGS

ROOTS & WINGS BOARD MEMBERS with DIANA KEEN (BOTTOM ROW, CENTER)
PHOTO BY **BK ROSE STUDIO**

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UCLA Health

Joshua Rosenberg MD Hematology-Oncology

DR. JOSHUA D. ROSENBERG PHOTO BY JULIE CAMPBELL

CHANGE IS NEVER EASY

DR. JOSHUA D. ROSENBERG

UCLA HEALTH, VENTURA, CALIFORNIA

Written by Marissa Holzer, Ventura, California

SWITCHING TO A NEW oncologist is never easy. When my prior oncologist, whom I loved and trusted and had built a relationship with, told me he would be retiring, I was thrown into panic mode. His announcement came in a goodbye letter along with a list of his recommendations to replace him. As I read through the list of potential new oncologists, I recognized a few names, some from past encounters and some I had only heard of. Not one name on the list stood out to me as someone I could entrust my care to. After I talked over my concerns with my retiring oncologist, he insisted I see one particular oncologist from his list.

I was reluctant. I was afraid. I was worried it would be awkward. This oncologist, who was so highly recommended by my retiring oncologist, had graduated from high school a few years after me, making us close in age. We had mutual friends as we had grown up in the same town. I had to make a decision. I chose to trust my retiring oncologist one last time. »

He cares for me from head to toe, inside and out, from side effects to the emotional aspects of living with metastatic breast cancer.

He told me I would not find a smarter or more caring doctor, and I know now he was right. I should have known immediately, as he had never led me wrong before. It took a couple of visits for me to become more comfortable and to realize it was absolutely the right decision.

Over the last couple of years, my new oncologist has always made time for me, whether in person, via message or by virtual visit. I never feel rushed. He listens and is present. He has more compassion than anyone I know. At my appointments, we chat as if we are longtime friends. As the years go by, my trust and confidence in him continue to grow. He cares for me from head to toe, inside and out, from side effects to the emotional aspects of living with metastatic breast cancer. He supports me in all ways and is on my team and in my corner.

It is with my deepest gratitude that I would like to nominate Dr. Joshua D. Rosenberg as my Metastatic Breast Cancer Hero, with a nod to now-retired Dr. Evan Slater. Without them, I know I would not be here to write this today.

A HERO WHO NEVER GIVES UP ON PATIENTS

DR. ATILLA SORAN

UNIVERSITY OF PITTSBURGH MEDICAL CENTER, PITTSBURGH, PENNSYLVANIA

Written by Dr. Eli Avisar, University of Miami Health System, Miami, Florida

AS SURGEONS, WE TEND TO concentrate on patients with curable breast cancer and when faced with metastatic breast cancer, we typically step back and refer the patients to the medical oncologist. Dr. Soran is one of the pioneers who decided to explore further the role of surgery in the treatment of patients with metastatic breast cancer. Maybe surgically removing the primary site of breast cancer could slow the disease and progression of the disease. For that reason, he embarked on a series of studies aiming to analyze this working theory.

In collaboration with a group of cancer specialists in Turkey and in the U.S., Dr. Soran enrolled 274 patients with metastatic breast cancer at presentation in a randomized trial, in which roughly half the patients underwent surgery to remove the site of primary disease followed by systemic therapy, and half were treated by standard systemic therapy with no surgery. The study demonstrates that in a subgroup of patients with bone-only metastatic disease, which is associated with a longer life expectancy than visceral metastatic disease, the five-year median follow up was better after the primary site was removed surgically, confirming the working **»**

UPMC

Atilla Soran, MD Surgical Oncology

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DR. ATILLA SORAN PHOTO BY JOE APPEL



hypothesis. This is now one of the seminal studies quoted when surgery for metastatic disease is being considered.

As a result of this first study, the group led by Dr. Soran has now completed a second study, enrolling 505 patients with bone-only metastases and randomizing them to surgical removal of the local and regional disease (breast and lymph nodes) and systemic therapy before or after the surgery or systemic therapy with no surgery. The results confirmed again a better survival within the surgery group as early as after three years.

Finally, Dr. Soran has pioneered genomic analysis of metastatic breast cancer in order to potentially identify treatable mutations.

For his dedication to metastatic breast cancer from a surgical aspect, I believe that Dr. Soran is a hero well suited for this award.

MORE THAN A HERO: MY MOM'S DOCTOR WITH HOPE AND FAITH

DR. VICENTE VALERO

THE UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTER, HOUSTON, TEXAS

Written by Angelina Kim, Del Mar, California

WHEN MY MOTHER WAS told she has cancer, I didn't understand. I was a toddler. The only things I saw were the pipes coming out of Mommy, the white clip-thingy on her finger and an oxygen tube sticking into her nose. I saw people in crisp, white coats with that weird head-plug-necklace-thingy around their necks who spoke in very serious voices, clear orange pill jars, blue scratchy gowns and so many papers with boxes and lines and unintelligible words I couldn't read yet. I didn't understand what was happening, but everyone else did.

As the days went on, my mom seemed to get better. My family moved to sunny Del Mar, California, where there were these things called beaches and oceans and sunburns! Some people would take pointy-boards and ride the waves. I would kick the ripples and yelp with joy and fear as the salty water rode down my throat. I winced as the bright sunbeams »

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DR. VICENTE VALERO

PHOTO PROVIDED BY MD ANDERSON CANCER CENTER



pummeled my eyes. But Mommy's cancer came back, and she had to go to Houston again. This is what happened to my family and me eight years ago.

No one in my family was a medical professional, and this mysterious, growing and deathbringing disease didn't have a cure yet. We could only look to the doctors, pray and hope that things would soon be all right. Most doctors said she might have two years, but Dr. Valero was different. He had faith and hope in my mom that she could get better. And his new perspective gave a purpose in our lives. It gave us a reason to breathe, a reason to keep on living the next few hours without being overwhelmed by fear. Then the next few hours turned into the next days, weeks, months and years. It is a miracle that my mom is still with us. But sometimes I wonder, what if she were given two years to live and everyone in my family saw no light at the end of the tunnel? What if there were no amazing doctors who believed my mother could survive her battle against cancer? What if there were no Dr. Valero, who gave my mother lifesaving medicine and encouraged her through the fight?

Our world today is like an unfinished puzzle. There are people suffering in this world, those who are dying from diseases like cancer or losing faith that there is a purpose to their lives. Will you give up on finishing the puzzle or will you keep on having faith, like Dr. Valero, and continue to search for the missing puzzle pieces that will save lives? I ask you to consider Dr. Valero for a Metastatic Breast Cancer Heroes[™] award because with his wonderful support, my mother is still with us today, happy and healthy and the best mother ever! And I hope this award can inspire many people to keep on searching for missing pieces of the puzzle with faith and hope. ■



TURNING SORROW INTO JOY: THE ONCOLOGIST WHO GAVE MY LIFE BACK

DR. VICENTE VALERO

THE UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTER, HOUSTON, TEXAS

Written by Minchi Kim, Del Mar, California

WHEN YOU FIRST RECEIVE a diagnosis of cancer, you pray it is localized. If it is, you are still in shock but gradually learn to fight, eagerly share survivors' stories and gratefully go back to your life. However, when your cancer comes back as metastatic cancer, you are in a completely different game in which you feel you are facing the deepest valley of death, afraid of asking how many years or months.

I am a 43-year-old patient who received a diagnosis of stage 3 breast cancer at age 31. After completing 14 rounds of chemo, seven different types of operations and about 40 rounds of radiation treatment, I was so thankful that I could go back to our home and normal life with my then 3-year-old daughter. Three years later, when I was in Korea visiting my parents and getting a comprehensive checkup with CT scans, I found out I had multiple tumors in the »

liver — stage 4 metastatic breast cancer. The sorrow, despair and fear that came with the new diagnosis were beyond what I could ever have imagined. My family, friends and colleagues were incredibly gracious and supportive, but I knew it was only God who could extend my life through the hands of my oncologist and his team.

I reached out to Dr. Valero for help and he immediately responded to my email by offering help with scheduling a biopsy and suggesting a phase 2 clinical trial. I was on the next available flight to Houston and signed up for the study medicine, according to his recommendation. I am so thankful that he took lots of extra time studying my case and investigating new treatment options. As a result, I am doing great and enjoying each and every day with much joy and gratitude.

Dr. Valero walks into his consult room with a big smile and unbelievably accurate details of my medical history. When I ask a question, he answers with clear evidence and in-depth analysis from new research findings and is always ready to recommend the best possible treatment options for each case. Most of all, he has the most compassionate heart. He listens with much care and empathy and finds the best way to encourage his patients going through the darkest time of their lives. When my cancer came back, all I prayed for was one healthy and happy summer with my 5-year-old daughter without being or feeling sick. But we have been celebrating many more summers and her birthdays for almost 10 years now. Without his kind care and support, I would not have survived as a mom, wife, daughter, sister and friend. Dr. Valero is a godsend, a hero who turned my sorrow into joy and countless other patients.





List of All 2021 Nominees

Marta Vallee Cobham, B.S.N., RN New York, New York

Dr. Fatima Cardoso Lisbon, Portugal

Dian 'CJ' M. Corneliussen Annapolis, Maryland

Jill Drury, PharmD BCOP, MBA Lake County, Illinois

Dale Eastman San Antonio, Texas

Victoria Goldberg New York, New York

Mary Gooze Oregon, Wisconsin

Christine Guarino, RDH, CMF, CFm, Founder Smithtown, New York

Gil R. Guerra, B.A., CCRP Houston, Texas

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Brandi Riber, RN Fort Myers, Florida

Dr. Joshua D. Rosenberg Ventura, California

Dr. Ahmad Nashat Abed Alfattah Shamout Amman, Jordan

Dr. Ruby Sharma Lake Success, New York

Dr. Atilla Soran Pittsburgh, Pennsylvania

Dr. Vicente Valero Houston, Texas

Stephanie L. Walker Tarboro, North Carolina

Dr. Yuan Yuan Duarte, California



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CURE[®] **Metastatic Breast Cancer Heroes[™] Volume 1** is a collection of inspiring essays written by patients, survivors, advocates, caregivers and colleagues about the people who touch lives while caring for those affected by metastatic breast cancer. These essays offer lessons about healing in the face of adversity, persevering against the odds and discovering kindness and compassion that can occur during one's cancer journey.

"(Her) drive is unimaginable. She has this much energy and passion even while in continued treatment for her own disease. She has helped so many women deal with the devastating impact of a fatal disease diagnosis. (She) has talked many women off the ledge and onto the path back to living life."

- ABOUT A METASTATIC BREAST CANCER HERO NOMINEE FROM NEW YORK, NEW YORK

"We have been celebrating many more summers and birthdays for almost 10 years now. Without his kind care and support, I would not have survived as a mom, wife, daughter, sister and friend. (He) is a godsend, a hero who turned my sorrow into joy and countless other patients."

- ABOUT A METASTATIC BREAST CANCER HERO NOMINEE FROM HOUSTON, TEXAS

"Their commitment, along with a dedicated volunteer team, are the reasons (this organization) is flourishing. Without these beacons of light, hope and support, without these metastatic breast cancer heroes, (this organization) and its mission would still be a whisper of a wish."

- ABOUT A METASTATIC BREAST CANCER HERO NOMINEE FROM WILMETTE, ILLINOIS



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