FOR PATIENTS, SURVIVORS & THEIR CAREGIVERS

BREAST CANCER

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Cancer Updates, Research & Education®

# From SECRECY to *Support*

*The Advocacy Movement Has Brought Breast Cancer Out of the Shadows*


ALSO INSIDE



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BREAST CANCER SPECIAL ISSUE · 10.20

# IMPORTANT SAFETY INFORMATION

**TRODELVY can cause serious side effects, including:**

- **Low white blood cell count (neutropenia).** Low white blood cell counts are common with TRODELVY and can sometimes be severe and lead to infections that can be life-threatening. Your healthcare provider should check your blood cell counts during treatment with TRODELVY. If your white blood cell count is too low, your healthcare provider may need to lower your dose of TRODELVY, give you a medicine to help prevent low blood cell count with future doses of TRODELVY, or in some cases may stop TRODELVY. Your healthcare provider may need to give you antibiotic medicines if you develop fever while your white blood cell count is low. **Call your healthcare provider right away if you develop any of the following signs of infection during treatment with TRODELVY:** fever, chills, cough, shortness of breath, or burning or pain when you urinate.
- **Severe diarrhea.** Diarrhea is common with TRODELVY and can also be severe. Your healthcare provider should monitor you for diarrhea and give you medicine as needed to help control your diarrhea. If you lose too much body fluids (dehydration), your healthcare provider may need to give you fluids and electrolytes to replace body salts. If diarrhea happens later in your treatment, your healthcare provider may check you to see if the diarrhea may be caused by an infection. Your healthcare provider may decrease your dose or stop TRODELVY if your diarrhea is severe and cannot be controlled with anti-diarrheal medicines.
  - **Call your healthcare provider right away** the first time that you get diarrhea during treatment with TRODELVY; if you have black or bloody stools; if you have symptoms of losing too much body fluid (dehydration) and body salts, such as lightheadedness, dizziness, or faintness; if you are unable to take fluids by mouth due to nausea or vomiting; or if you are not able to get your diarrhea under control within 24 hours.

**Do not receive TRODELVY if you have had a severe allergic reaction to TRODELVY.** Ask your healthcare provider if you are not sure. TRODELVY can cause severe and life-threatening allergic reactions during infusion (infusion-related reactions). Tell your healthcare provider or nurse right away if you get any of the following symptoms of an allergic reaction during an infusion of TRODELVY or within 24 hours after you receive a dose of TRODELVY: swelling of your face, lips, tongue, or throat; hives; skin rash or flushing of your skin; difficulty breathing or wheezing; lightheadedness, dizziness, feeling faint, or pass out; chills or shaking chills (rigors); or fever.

**Nausea and vomiting.** Nausea and vomiting are common with TRODELVY and can sometimes be severe. Before each dose of TRODELVY, you will receive medicines to help prevent nausea and vomiting. You should be given medicines to take home with you, along with instructions about how to take them to help prevent and treat any nausea and vomiting after you receive TRODELVY. Call your healthcare provider right away if you have nausea or vomiting that is not controlled with the medicines prescribed for you. Your healthcare provider may decide to decrease your dose or stop TRODELVY if your nausea and vomiting is severe and cannot be controlled with anti-nausea medicines.

**Before receiving TRODELVY, tell your healthcare provider about all of your medical conditions, including if you:**

- have been told that you carry a gene for uridine diphosphate-glucuronosyl transferase A1 (UGT1A1)*28. People who carry this gene have an increased risk of getting side effects with TRODELVY, especially low white blood cell counts.
- have liver problems.
- are pregnant or plan to become pregnant. TRODELVY can harm your unborn baby. Your healthcare provider should check to see if you are pregnant before you start receiving TRODELVY. TRODELVY may cause fertility problems in females, which could affect your ability to have a baby. Talk to your healthcare provider if fertility is a concern for you.
  - Females who can become pregnant should use effective birth control during treatment and for 6 months after your last dose of TRODELVY. Talk to your healthcare provider about birth control choices that may be right for you during this time.
  - Males with a female partner who can become pregnant should use effective birth control during treatment and for 3 months after your last dose of TRODELVY.
  - Tell your healthcare provider right away if you or your partner become pregnant during treatment with TRODELVY.
- are breastfeeding or plan to breastfeed. It is not known if TRODELVY passes into your breastmilk and can harm your baby. Do not breastfeed during treatment and for 1 month after your last dose of TRODELVY.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Certain medicines may affect the way TRODELVY works.

The most common side effects of TRODELVY include nausea, low white blood cells (neutropenia), diarrhea, tiredness, decreased red blood cell count, vomiting, hair loss, constipation, rash, decreased appetite, stomach-area (abdomen) pain and respiratory infections.

These are not all of the possible side effects of TRODELVY. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

HER2=human epithelial growth factor receptor 2; HR=hormone receptor.

For patients with **metastatic triple-negative breast cancer (mTNBC)** who have received at least two therapies for metastatic disease

# I'M TAKING ON mTNBC


Not an actual patient.

*Ask your doctor about **TRODELVY***

TRODELVY™
sacituzumab govitecan-hziy
180 mg for injection

## What is TRODELVY?

TRODELVY™ (sacituzumab govitecan-hziy) is a prescription medicine used to treat adults with a certain type of breast cancer known as triple-negative (HR and HER2 negative) that has spread to other parts of the body (metastatic) and who received at least two therapies for metastatic disease.

TRODELVY is approved based on medical studies that measured how many patients responded and how long they responded. Continued approval may depend on benefit demonstrated in additional medical studies.

It is not known if TRODELVY is safe and effective in people with moderate to severe liver problems or in children.

**Please see Brief Summary of full Prescribing Information on following pages.**

**VISIT TRODELVY.COM TODAY TO LEARN MORE**

**Patient Information**
TRODELVY™ (troh-DELL-vee)
(sacituzumab govitecan-hziy)
injection

**What is the most important information I should know about TRODELVY?**

**TRODELVY can cause serious side effects, including:**

- **Low white blood cell count (neutropenia).** Low white blood cell counts are common with TRODELVY and can sometimes be severe and lead to infections that can be life-threatening. Your healthcare provider should check your blood cell counts during treatment with TRODELVY. If your white blood cell count is too low, your healthcare provider may need to lower your dose of TRODELVY, give you a medicine to help prevent low blood cell count with future doses of TRODELVY, or in some cases may stop TRODELVY. Your healthcare provider may need to give you antibiotic medicines if you develop fever while your white blood cell count is low. **Call your healthcare provider right away if you develop any of the following signs of infection during treatment with TRODELVY:**
  - fever
  - chills
  - cough
  - shortness of breath
  - burning or pain when you urinate
- **Severe diarrhea.** Diarrhea is common with TRODELVY and can also be severe. Your healthcare provider should monitor you for diarrhea and give you medicine as needed to help control your diarrhea. If you lose too much body fluids (dehydration) your healthcare provider may need to give you fluids and electrolytes to replace body salts. If diarrhea happens later in your treatment, your healthcare provider may check you to see if the diarrhea may be caused by an infection. Your healthcare provider may decrease your dose or stop TRODELVY if your diarrhea is severe and cannot be controlled with anti-diarrheal medicines.

  **Call your healthcare provider right away:**
  - the first time that you get diarrhea during treatment with TRODELVY
  - if you have black or bloody stools
  - if you have symptoms of losing too much body fluid (dehydration) and body salts, such as lightheadedness, dizziness or faintness
  - if you are unable to take fluids by mouth due to nausea or vomiting
  - if you are not able to get your diarrhea under control within 24 hours

**What is TRODELVY?**

TRODELVY is a prescription medicine used to treat adults with breast cancer that is:

- estrogen and progesterone hormone receptor (HR) negative, and human epidermal growth factor receptor 2 (HER2)-negative (also called triple-negative breast cancer), **and**
- that has spread to other parts of the body metastatic, **and**
- who previously received at least two therapies for metastatic disease

It is not known if TRODELVY is safe and effective in people with moderate or severe liver problems.

It is not known if TRODELVY is safe and effective in children.

**Do not receive TRODELVY if you have had a severe allergic reaction to TRODELVY.** Ask your healthcare provider if you are not sure.

**Before receiving TRODELVY, tell your healthcare provider about all of your medical conditions, including if you:**

- have been told that you carry a gene for uridine diphosphate-glucuronosyl transferase A1 (UGT1A1)*28. People who carry this gene have an increased risk of getting side effects with TRODELVY, especially low white blood cell counts. **See "What is the most important information I should know about TRODELVY?"**
- have liver problems.
- are pregnant or plan to become pregnant. TRODELVY can harm your unborn baby. Your healthcare provider should check to see if you are pregnant before you start receiving TRODELVY.
  - Females who can become pregnant should use effective birth control during treatment and for 6 months after your last dose of TRODELVY. Talk to your healthcare provider about birth control choices that may be right for you during this time.
  - Males with a female partner who can become pregnant should use effective birth control during treatment and for 3 months after your last dose of TRODELVY.
  - Tell your healthcare provider right away if you or your partner become pregnant during treatment with TRODELVY.
- are breastfeeding or plan to breastfeed. It is not known if TRODELVY passes into your breastmilk and can harm your baby. Do not breastfeed during treatment and for 1 month after your last dose of TRODELVY.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Certain medicines may affect the way TRODELVY works.

**How will I receive TRODELVY?**

- Your healthcare provider will give you TRODELVY into your vein through an intravenous (IV) line.
- TRODELVY is given 1 time each week, on Day 1 and on Day 8 of a 21-day treatment cycle.
- You will receive the first dose of TRODELVY over 3 hours. If you tolerate the first dose well, future doses may be given over 1 to 2 hours.
- Before each dose of TRODELVY, you will receive medicines to help prevent infusion reactions, and nausea and vomiting.
- You will be monitored for side effects during and for at least 30 minutes after you receive each infusion of TRODELVY.
- Your healthcare provider may slow down or temporarily stop your infusion of TRODELVY if you have an infusion-related reaction, or permanently stop TRODELVY if you have a life-threatening infusion-related reaction.
- Your healthcare provider will decide how long you will continue to receive TRODELVY.

**What are the possible side effects of TRODELVY?**

TRODELVY can cause serious side effects, including:

- **See "What is the most important information I should know about TRODELVY?"**
- **Severe and life-threatening allergic reactions.** TRODELVY can cause severe and life-threatening allergic reactions during infusion (infusion-related reactions). Tell your healthcare provider or nurse right away if you get any of the following symptoms of an allergic reaction during an infusion of TRODELVY or within 24 hours after you receive a dose of TRODELVY:
  - swelling of your face, lips, tongue, or throat
  - hives
  - skin rash or flushing of your skin
  - difficulty breathing or wheezing
  - lightheadedness, dizziness, feeling faint or pass out
  - chills or shaking chills (rigors)
  - fever
- **Nausea and vomiting.** Nausea and vomiting are common with TRODELVY and can sometimes be severe. Before each dose of TRODELVY, you will receive medicines to help prevent nausea and vomiting. You should be given medicines to take home with you, along with instructions about how to take them to help prevent and treat any nausea and vomiting after you receive TRODELVY. Call your healthcare provider right away if you have nausea or vomiting that is not controlled with the medicines prescribed for you. Your healthcare provider may decide to decrease your dose or stop TRODELVY if your nausea and vomiting is severe and cannot be controlled with anti-nausea medicines.

The most common side effects of TRODELVY include:

- tiredness
- decreased red blood cell count
- hair loss
- constipation
- rash. **See "Severe and life-threatening allergic reactions" above.**
- decreased appetite
- stomach-area (abdomen) pain

TRODELVY may cause fertility problems in females, which could affect your ability to have a baby. Talk to your healthcare provider if fertility is a concern for you.

These are not all of the possible side effects of TRODELVY.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**General information about the safe and effective use of TRODELVY.**

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. You can ask your pharmacist or healthcare provider for information about TRODELVY that is written for health professionals.

**What are the ingredients in TRODELVY?**

**Active ingredient:** sacituzumab govitecan-hziy
**Inactive ingredients:** 2-(N-morpholino) ethane sulfonic acid (MES), polysorbate 80 and trehalose dihydrate

Manufactured by: Immunomedics, Inc., 300 The American Road, Morris Plains, NJ 07950, USA
U.S. License No. 1737
For more information about TRODELVY, go to www.TRODELVY.com or call 1-888-983-4668.

The Patient Information has been approved by the U.S. Food and Drug Administration. Issued: April 2020

Immunomedics


2020-US-TROT-00088

TRODELVY™
sacituzumab govitecan-hziy
180 mg for injection

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# A Look Back at the Movement That Changed the Breast Cancer Journey

**DURING EACH OCTOBER'S** Breast Cancer Awareness Month, the color pink makes its mark on everything from T-shirts to ribbons to merchandise, raising awareness about the disease and generating funds for research. Love the association with pink or hate it, the color is a reminder of the decades of patient advocacy that have brought breast cancer out of the shadows and into the public conversation and scientists' labs.

In this special issue of *CURE*®, we look back at that patient advocacy movement and tell the story of how it began and where it has taken us. Our cover article begins in the 1950s, when the word "breast" couldn't be uttered in public and women were not consulted before being given mastectomies. We follow the movement through the rich culture of advocacy that has raised billions of dollars for research and led to not only a much deeper understanding of the disease but also choice for patients about how to treat it. Today's community welcomes a wider swath of those affected by breast cancer, including previvors who face an inherited predisposition to the disease. We hope you enjoy this feature brimming with the stories of advocacy pioneers, including Terese Lasser and Susan G. Komen founder Nancy Brinker.

In this issue, we also delve into the question of when patients with early-stage breast cancer can safely be spared surgery. In cases of ductal carcinoma in situ, stage 0 cancer, there is debate about whether surgery is always needed and if it should be lumpectomy or mastectomy. This type of breast cancer is considered preinvasive, and the difficulty in choosing a treatment revolves around a lack of methods for predicting which cases are aggressive and more likely to recur. In our feature article, we present the latest thoughts on this topic.

A third feature explores new developments in treating breast cancer that has spread to the brain.

Elsewhere in this issue, we consider the safety and potential benefits of a shorter course of hypofractionated radiation therapy for certain women with breast cancer. We also discuss blood-based biomarkers as a way to predict the recurrence of triple-negative disease.

Five people who have metastatic breast cancer, all ambassadors for a website that provides emotional support, let us glimpse life with the disease through their eyes. In the same vein, a group known as The Breasties aims to inform and encourage younger people affected by women's cancers, and two of their founders discuss their experiences.

We hope that this array of material is both inspiring and educational, offering insights that help you ask key questions and make solid decisions about your care. As always, thank you for reading.

**MIKE HENNESSY SR.**
*Chairman and Founder*

# cure®

is proud to be partners with a number of leading advocacy groups across the country, giving them national reach and visibility for their cutting edge initiatives, programs, content, research and thought leadership.


## What Is IBRANCE® (palbociclib)?

IBRANCE is a prescription medicine used in adults to treat hormone receptor-positive (HR+), human epidermal growth factor receptor 2-negative (HER2-) breast cancer that has spread to other parts of the body (metastatic) in combination with an aromatase inhibitor as the first hormonal based therapy in postmenopausal women or in men.

## Important Safety Information for Patients

**IBRANCE may cause serious side effects, including:**

**Low white blood cell counts (neutropenia).** Low white blood cell counts are very common when taking IBRANCE and may cause serious infections that can lead to death. Your doctor should check your white blood cell counts before and during treatment.

If you develop low white blood cell counts during treatment with IBRANCE, your doctor may stop your treatment, decrease your dose, or may tell you to wait to begin your treatment cycle. Tell your doctor right away if you have signs and symptoms of low white blood cell counts or infections such as fever and chills.

**Lung problems (pneumonitis).** IBRANCE may cause severe inflammation of the lungs during treatment that can lead to death. Tell your doctor right away if you have any new or worsening symptoms, including chest pain, cough with or without mucus, and trouble breathing or shortness of breath.

**Your doctor may interrupt or stop treatment with IBRANCE completely if your symptoms are severe.**

**Before you take IBRANCE, tell your doctor about all of your medical conditions, including if you:**

- have fever, chills, or any other signs or symptoms of infection.
- have liver or kidney problems.
- are pregnant or plan to become pregnant; IBRANCE can harm your unborn baby.
  - Females who are able to become pregnant should use effective birth control during treatment and for at least 3 weeks after the last dose of IBRANCE. Your doctor may ask you to take a pregnancy test before you start treatment with IBRANCE.
  - Males with female partners who can become pregnant should use effective birth control during treatment with IBRANCE for at least 3 months after the last dose of IBRANCE.
- are breastfeeding or plan to breastfeed. It is not known if IBRANCE passes into your breast milk. Do not breastfeed during treatment with IBRANCE and for 3 weeks after the last dose.

**The most common side effects of IBRANCE include:**

- Low red blood cell counts and low platelet counts. Call your doctor right away if you develop any of these symptoms during treatment:
  - dizziness
  - shortness of breath
  - weakness
  - bleeding or bruising more easily
  - nosebleeds

**Other most common side effects include:** infections, tiredness, nausea, sore mouth, abnormalities in liver blood tests, diarrhea, hair thinning or hair loss, vomiting, rash, and loss of appetite.

IBRANCE may cause fertility problems in males. This may affect your ability to father a child. Talk to your healthcare provider about family planning options before starting IBRANCE if this is a concern for you.

These are not all of the possible side effects of IBRANCE. For more information, ask your doctor.

**Tell your doctor about all of the medicines you take, including** prescription and over-the-counter medicines, vitamins, and herbal supplements. IBRANCE and other medicines may affect each other, causing side effects.

Do not drink grapefruit juice or eat grapefruit products while taking IBRANCE as they may increase the amount of IBRANCE in your blood.

Tell your doctor if you start a new medicine. Take IBRANCE exactly as your doctor tells you.

If you take too much IBRANCE, call your doctor right away or go to the nearest hospital emergency room.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

**Please see Important Facts About IBRANCE on the following page.**

**To learn more, talk to your doctor.**

**Can't afford your medication? Pfizer may be able to help.**
**Visit IBRANCE.com.**

IBRANCE®
palbociclib | 125 mg tablets

*Hormone receptor-positive includes estrogen receptor-positive (ER+) and/or progesterone receptor-positive (PR+)

 March 2020 PP-IBR-USA-3244-01

IBRANCE®
palbociclib | 125 mg tablets

# IMPORTANT FACTS

IBRANCE® (EYE-brans)
(palbociclib)

The risk information provided here is not comprehensive. This information does not take the place of talking to your healthcare provider about your condition or treatment. To learn more about IBRANCE talk to your healthcare provider or pharmacist. To obtain the FDA-approved product labeling call 1-800-438-1985 or visit www.IBRANCE.com.

## What is IBRANCE?

IBRANCE is a prescription medicine used in adults to treat hormone receptor (HR)-positive, human epidermal growth factor receptor 2 (HER2)-negative breast cancer that has spread to other parts of the body (metastatic) in combination with:

- an aromatase inhibitor as the first hormonal based therapy in postmenopausal women or in men, or
- fulvestrant in people with disease progression following hormonal therapy.

It is not known if IBRANCE is safe and effective in children.

## What is the most important safety information I should know about IBRANCE?

**IBRANCE may cause serious side effects, including:**

**Low white blood cell counts (neutropenia).** Low white blood cell counts are very common when taking IBRANCE and may cause serious infections that can lead to death. Your healthcare provider should check your white blood cell counts before and during treatment.

If you develop low white blood cell counts during treatment with IBRANCE, your healthcare provider may stop your treatment, decrease your dose, or may tell you to wait to begin your treatment cycle. Tell your healthcare provider right away if you have signs and symptoms of low white blood cell counts or infections such as fever and chills.

**Lung problems (pneumonitis).** IBRANCE may cause severe or life-threatening inflammation of the lungs during treatment that can lead to death. Tell your healthcare provider right away if you have any new or worsening symptoms, including:

- chest pain
- cough with or without mucus
- trouble breathing or shortness of breath

Your healthcare provider may interrupt or stop treatment with IBRANCE completely if your symptoms are severe. **See "What are the possible side effects of IBRANCE?" for more information about side effects.**

## What should I tell my healthcare provider before taking IBRANCE?

**Before taking IBRANCE, tell your healthcare provider about all of your medical conditions, including if you:**

- have fever, chills, or any other signs or symptoms of infection.
- have liver or kidney problems.
- are pregnant, or plan to become pregnant. IBRANCE can harm your unborn baby.
  - Females who are able to become pregnant should use effective birth control during treatment and for at least 3 weeks after the last dose of IBRANCE. Your healthcare provider may ask you to take a pregnancy test before you start treatment with IBRANCE.
  - Males with female partners who can become pregnant should use effective birth control during treatment with IBRANCE for at least 3 months after the last dose of IBRANCE.
  - Talk to your healthcare provider about birth control methods that may be right for you during this time.
  - If you become pregnant or think you are pregnant, tell your healthcare provider right away.
- are breastfeeding or plan to breastfeed. It is not known if IBRANCE passes into your breast milk. Do not breastfeed during treatment with IBRANCE and for 3 weeks after the last dose.

**Tell your healthcare provider about all of the medicines you take, including** prescription and over-the-counter medicines, vitamins, and herbal supplements. IBRANCE and other medicines may affect each other causing side effects.

## How should I take IBRANCE tablets?

- Take IBRANCE exactly as your healthcare provider tells you.
- IBRANCE tablets may be taken with or without food.
- IBRANCE should be taken at about the same time each day.
- Swallow IBRANCE tablets whole. Do not chew, crush or split IBRANCE tablets before swallowing them.
- Do not take any IBRANCE tablets that are broken, cracked, or that look damaged.
- Avoid grapefruit and grapefruit products during treatment with IBRANCE. Grapefruit may increase the amount of IBRANCE in your blood.
- Do not change your dose or stop taking IBRANCE unless your healthcare provider tells you.
- If you miss a dose of IBRANCE or vomit after taking a dose of IBRANCE, do not take another dose on that day. Take your next dose at your regular time.
- If you take too much IBRANCE, call your healthcare provider right away or go to the nearest hospital emergency room.

## What are the possible side effects of IBRANCE?

**IBRANCE may cause serious side effects. See "What is the most important safety information I should know about IBRANCE?"**

The most common side effects of IBRANCE when used with either letrozole or fulvestrant include:

- low red blood cell counts and low platelet counts. Call your healthcare provider right away if you develop any of these symptoms during treatment:
  - dizziness
  - shortness of breath
  - weakness
  - bleeding or bruising more easily
  - nosebleeds
- infections (see "What is the most important safety information I should know about IBRANCE?")
- tiredness
- nausea
- sore mouth
- abnormalities in liver blood tests
- diarrhea
- hair thinning or hair loss
- vomiting
- rash
- loss of appetite

IBRANCE may cause fertility problems in males. This may affect your ability to father a child. Talk to your healthcare provider about family planning options before starting IBRANCE if this is a concern for you.

These are not all of the possible side effects of IBRANCE.

**Keep IBRANCE and all medications out of the reach of children.**

**Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.**

**To learn more, talk to your doctor.**

These IMPORTANT FACTS are based on IBRANCE® (palbociclib) Patient Information LAB-1372-1.0, Rev. 11/2019.

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# Kinase Inhibitors Hold Promise in Treating Breast Cancer That Has Spread to the Brain

**ANY HEALTH ISSUE THAT** has to do with the brain imparts concern and fear, for good reason: This delicate, mysterious organ defines how we think and act and who we are. In many cases, patients undergo surgery and radiation without many effects on brain function, but sometimes the consequences are more pronounced, particularly in certain areas of the brain. And, of course, medically, cancer in the brain, whether from a primary tumor or disease that spreads from elsewhere, can be very serious.

The brain can be a common site of metastasis of breast cancer, depending on the biology of the disease. For example, higher-grade cancers, such as those that are triple-negative or HER2-positive, are more likely to spread to the brain. In the case of HER2-positive disease, this may be because recent advances led to more targeted treatments. This may sound like a purely positive development because these antibody-based therapies do a better job of targeting cancer cells; however, they are large molecules and thus do not penetrate the blood-brain barrier well. That's why, until recently, the standard of care in HER2-positive breast cancer that spread to the brain has been surgery or radiation.

In February, a combination of the chemotherapy capecitabine and Nerlynx (neratinib), a kinase inhibitor capable of crossing the blood-brain barrier, received Food and Drug Administration (FDA) approval. That was a move in the right direction, because newer drugs that inhibit the activity of proteins known as kinases are quite effective in the brain and, in some cases, may be used in place of local therapies such as surgery or radiation.

Then, in April, the FDA approved the tyrosine kinase inhibitor Tukysa (tucatinib) combined with a standard regimen, capecitabine and the monoclonal antibody Herceptin (trastuzumab), for patients with inoperable or metastatic HER2-positive breast cancer. Tukysa adds an element to the regimen that, in a clinical trial, helped slow the progress of disease that had spread to the brain and prolonged life.

> "Newer drugs that inhibit the activity of proteins known as kinases are quite effective in the brain and, in some cases, may be used in place of local therapies such as surgery or radiation."

Investigators are studying Tukysa plus another drug used to treat HER2-positive breast cancer, Kadcyla (T-DM1), and looking into other novel drugs expected to cross the blood-brain barrier.

Decades ago, no one would have thought that patients could live for years with brain metastases, but that is exactly what is happening. We hope to soon have even more effective drugs that can treat brain metastases from breast cancer, as is the case in melanoma, for which immunotherapy is now replacing radiation as the first option for disease that has spread to the brain. C

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*Editor-in-Chief*
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MIKE KITADA

PARTICIPANTS in a retreat held by The Breasties have a bonding moment.

# Breast Friends

*A group extends a hand to those affected by breast or reproductive cancers, especially younger previvors, patients and caregivers.* By BETH FAND INCOLLINGO

**IN THE DARKEST TIMES,** people who can offer understanding and support provide the best balm for the spirit.

Five young women found that out when they were affected by breast cancer as patients, previvors or caregivers, and it spurred them to create an organization aimed at supporting others facing those situations. The Breasties (thebreasties.org) works to empower those affected by breast and reproductive cancers through connection with others, particularly those who are younger. Its distinctive name combines "breast" and "bestie."

Launched as a nonprofit organization in 2018, the New York City-based group now has more than 46 chapters across the U.S., Canada and the U.K.

*CURE*® sat down with two of the group's founders, Allie Brudner Brumel and Brianna "Bri" Majsiak, to learn more about the nonprofit organization and the support it offers.

Brumel, a speech pathologist and professor at New York University, is a survivor of breast cancer who carries the BRCA1 gene mutation, which causes an inherited predisposition to breast, ovarian and other cancers. Majsiak, a senior health producer at EverydayHealth, is not BRCA positive but has a strong family history of breast cancer and recently underwent a sensation-preserving preventive bilateral mastectomy.

The group's other founders are Paige More and Leslie Almiron, who is the associate finance director at the Ovarian Cancer Research Alliance. More underwent a preventive bilateral mastectomy after discovering she carried the BRCA1 gene mutation. At age 23, Almiron received a diagnosis of breast cancer that later became metastatic. Jessica Bonilla, Brumel's caregiver and best friend, is the group's chief of wellness.

**Q: *CURE*®: Why did you feel The Breasties was needed?**

**A: Brumel:** I received a diagnosis of triple-negative breast cancer in January 2017, and during treatment, I felt like I was the only young person going through this. I was 28 at the time, and I struggled to find anybody in my age group with a similar situation until I turned to social media, and that was where I connected with Paige, who connected me with Bri.

It was the first time where I felt like "Wow, there are other people who get it." It sounds selfish, but we created The Breasties because it was something we so desperately needed. We were looking for a place where we felt like we belonged and felt supported.

We decided to put together small get-togethers, like workout classes and potluck dinners, and then a retreat where we went skiing in the Pocono Mountains, just to do something fun and take our minds off everything we'd been through. We applied for our nonprofit status in February 2018.

**A: Majsiak:** I met Paige at a support group meeting of a nonprofit for women at high risk of breast cancer. Paige was a few weeks out from her preventive mastectomy. We realized that there were only a few of us on the younger side and making preventive decisions, and the environment didn't seem very welcoming to young women. We realized there had to be more for us. Paige started sharing her story on social media and bringing together women in the New York area, and that's how we all came together.

**Q: You state on your website that the group supports survivors, previvors, warriors, thrivers, carevivors and supporters. Can you please discuss this mission?**

PHOTO COURTESY OF THE BREASTIES

**A:** **Brumel:** We all have different stories. I'm a survivor, Bri and Paige are on the preventive side, and Jess is a caregiver. All of us have been affected by cancer in different ways, but there's this connection between us. All of us want the same thing: We want to find a place where we feel supported and seen and motivated and empowered, because it's hard going through any sort of cancer diagnosis or having a loved one affected or losing a loved one or finding out you're at high risk.

On retreat, it's been so magical to see the connections happen from provider to survivor and thriver to caregiver. We're all about inclusivity, so we say that anyone who feels aligned with our mission and feels like a Breastie is a Breastie. We don't want anyone to feel alone.

**Q: Please describe the kinds of events The Breasties holds.**

**A:** **Majsiak:** The retreats, which are free and funded by our annual October gala, are typically two nights and three days, over a weekend. About 350 women have attended so far. They're a mix of bonding and shared storytime so that people can get to know each other, as well as a variety of events, like skiing, snowboarding, whitewater rafting and hiking. We always like to incorporate something fun, because it's so hard after going through chemo or surgery — you feel like you can't get back to your old self, that your body is only capable of harming you. We like to show everyone that your body is capable of so much more than just getting sick. Your bodies are strong; your bodies are resilient.

Our first year, we had five retreats, and we still had hundreds of women reaching out; we could accommodate only about a fourth of them. We thought, "What can we do to bring as many people together as we can?" We realized that would be a camp, kind of like a retreat on steroids. So, we put together a camp last summer and had 500 people come together for the weekend. That was a paid, at-cost event.

This year, due to COVID-19, camp was a virtual event, and we still had over 450 people enroll. We had live events happening throughout the weekend online. It wasn't the same, but it still was a really nice way to bring the community together during these very strange times.

**Q: How can someone become an ambassador and lead a group of Breasties in their own community?**

**A:** **Majsiak:** Our retreat in March was actually our first ambassador training retreat. We had over 60 women come to that weekend to learn how to host a meetup and raise funds at the local level. We have an ambassador handbook that we share with anybody who's interested. Things look a little bit different now with everything being virtual, but typically, the requirement is that they do one meetup a month. We would share the event and try to help them find people in their community to attend. Then, after about four of those events, they would take a swing at being an official ambassador.

**Q: Together, you and the other co-founders have created a large community. What has this community meant to each of you?**

**A:** **Brumel:** We created this organization because we needed it. When we started, it was not even a year out from my diagnosis. When you're going through active treatment, it's like fight mode, and there's not a lot of time or mental capacity to process it. I never fully processed that I had cancer and it was scary, and that was taking a huge hit on my mental health. With The Breasties, I was meeting amazing people, and the retreats, although we were leading them, became a source of healing for me. They let me process everything I had gone through, grieve for my past self and body, and just connect with incredible, strong, beautiful people that I wouldn't have been able to meet otherwise.

It's amazing to do something every day that you really are passionate about. After a cancer diagnosis, going back to my job just didn't feel the same. I felt like I had a bigger purpose and drive in me, and so it's nice to be able to fuel that energy and give it to something that's bigger than me.

**Majsiak:** It's been life-changing. It's been a process of us healing as we're creating community and space for others, and it's been the most beautiful blessing. I healed so much of my grief, like losing my mom (to cancer), through this community. I never thought I'd meet someone who'd say, "Hey, I know that experience." Some of my closest connections have been with mothers who are survivors and have a constant fear of not being there for their children, and that's a connection I never would have expected to make.
Having very recently gone through surgery and navigated preventive decisions, I would not have known what exists if it wasn't for this community. I'm constantly learning and engaging with people. It's been so surreal to go through the experience and feel the support that we're building.

**Q: What kind of feedback have you received from people who have come to The Breasties for support?**

**A:** **Brumel:** So many people have mentioned how life-changing it was, because they got invaluable resources or met their new person, their best friend, through this organization.

I remember walking through the campus at Camp Breasties last year and seeing a girl sitting on the bench by herself, on the phone. I was eavesdropping because I wanted to make sure she was OK, and I heard her say, "Mom, you don't understand — there are 500 (people like me) here," which I thought was just so special.

**Q: What else should people know?**

**A:** **Majsiak:** Right now, we're doing a lot of virtual support. We want everyone to know that even though the world is shut down, support is still out there. We like to say that the community's not canceled. We have dozens of virtual events each month around all different topics, and there is something for everyone. C


# Virtual Running Shoes

*Organized as a virtual event, the DONNA Foundation's 2021 National Marathon to Finish Breast Cancer will allow participants to run in their neighborhoods — or on their treadmills.* By KRISTIE L. KAHL

**THE COVID-19 PANDEMIC** has turned many meetings and events virtual, from medical appointments to family gatherings and celebrations. Now, the DONNA Foundation is throwing its running shoes into the cyberspace ring, with plans to hold its National Marathon to Finish Breast Cancer virtually Feb. 12-14, 2021.

Through its "Everywhere, Together" campaign, the foundation announced that the DONNA Marathon Weekend and the Fearless Series, which together encompass all signature DONNA events, will be conducted in a virtual format through the spring of next year.

"We felt it was really important that we mitigate risk to the organization and to our runners and survivors, in particular, when making that decision," says Michelle McCullough, chief financial officer of the DONNA Foundation, which provides financial assistance and support to those living with breast cancer and funds breast cancer research. "Gathering in large groups is just not a safe thing right now, and we felt that making that decision and planning for a really good unique virtual experience in 2021 would allow us to continue to provide financial support through our programs and to our survivors and really set us up to have a significant event in 2022."

> **"Our hope is that we get participation not just nationwide but worldwide, to celebrate finish lines literally across the world."** — *MICHELLE MCCULLOUGH, CFO*

## PRE-COVID-19 MILESTONE

Although those events will be virtual, the foundation was able to host its February 2020 National Marathon to Finish Breast Cancer, the only U.S. marathon dedicated to breast cancer research and care, without a hitch before the pandemic forced many into quarantine.

"It's interesting now that we are where we are. And looking back, we can consider it a milestone, but at the time, we certainly didn't know," McCullough says. "For us, this is our signature event … If we couldn't have the race this year, it would have been devastating. We feel very fortunate that we were able to pull that off before things changed."

She feels especially lucky that she got to participate in 2020 — her run that day qualified her for the Boston Marathon. "When I thought about what the race meant to me, (I realized it's about) what it supports, as well as being able to (participate) in my community, (in the Beaches Town Center) that I run every single day. It was just kind of a no-brainer," McCullough says. "I was really excited about the event because I ended up reaching my goal and qualifying for Boston, and I was able to do that on a really beautiful day running stride for stride, the whole 26.2 miles, with a dear friend of mine. (We crossed) the finish line together with lots of friends and family there waiting for me. It was probably the most special year ever."

PHOTOS COURTESY OF DONNA FOUNDATION; JOGGER VECTOR ART: MAST3R / ADOBESTOCK


At left, **KATE** and **WINSTON MAYS** enjoy the 2020 DONNA Marathon Weekend. Below, **CATHERINE MARTIN**, center, and fellow runners spend a moment together during the event.


**JULIE STACKHOUSE** runs toward the finish line in 2020.

PHOTOS COURTESY OF DONNA FOUNDATION

## LOOKING TO 2021

Bringing the 2021 run into the virtual space was key to holding a safe event. Another upside of that decision is that the new format will enable more people to participate. "Our hope is that we get participation not just nationwide but worldwide, to celebrate finish lines literally across the world to drive the awareness and support for our foundation that we need to continue our programs," McCullough says.

The virtual setting will also foster flexibility in running the 2021 events, she says: "It's going to be a lot of fun to allow participants to do things their way. They can create their own start and finish line." This means that participants can sign up for the events and then run on their own. For example, someone signed up for the 5K would run 3.1 miles on their own, perhaps in their neighborhood or even on a treadmill.

## CREATING A COMMUNITY

In 2015, Allison Ruona received a diagnosis of ductal carcinoma in situ, right around the time of that year's marathon weekend. A close friend was running in the event, and Ruona decided that she could not miss it the following year. She signed up in 2016 and has participated ever since.

"(Participating in the weekend is) another way to bring awareness to people," Ruona says. "Anything that lets people talk about (breast cancer) in a positive light … helps them to relate. It's a good way to just get the message out there and get people to talk about it and be aware."

McCullough notes that the race serves to recognize those affected by breast cancer. "We think of (the National Marathon to Finish Breast Cancer) as a celebration of survivorship," she says. "Our cancer patients and survivors, they live in this place of fear. And DONNA Marathon Weekend allows them to celebrate the hope and love that they're surrounded with. That's something that's really special and unique. It's not just another race, but there's tremendous meaning behind it." C

**LEARN MORE ONLINE**

To learn more and register for the virtual DONNA Marathon Weekend, visit **BreastCancerMarathon.com**.

# When to *Skip* Surgery

## Can mastectomy or lumpectomy be avoided in women with ductal carcinoma in situ?

*By* DEBORAH ABRAMS KAPLAN

Donna Pinto began getting mammograms at age 40 because her grandmother died of breast cancer at 50. In 2010, a suspicious mammogram led Pinto, then 44, to a needle biopsy in her right breast. The pathology showed ductal carcinoma in situ (DCIS), considered the earliest form of breast cancer. DCIS refers to abnormal cells found only inside a milk duct.

Pinto's surgeon wasn't quite convinced, thinking the results might indicate atypical ductal hyperplasia, a marker for women who might have a risk factor for developing breast cancer. A subsequent surgical biopsy showed intermediate-grade DCIS. Pinto was given two treatment options: full mastectomy or partial mastectomy with seven weeks of daily radiation.

She held off on treatment as she dove into research that revealed varying medical opinions, some saying to avoid treatment unless the diagnosis was high-risk DCIS, and that low- and intermediate-grade DCIS were potentially overtreated and more studies were needed. "That was different from the information I received," says Pinto, who chose active surveillance.

With a rise in breast cancer screening has come a rise in DCIS diagnoses, which make up 20% to 25% of all breast cancers in the United States. More than 60,000 women each year receive a diagnosis of the condition. Labeled a stage 0 cancer, DCIS is considered pre-invasive. »

» For ductal carcinoma in situ, **DONNA PINTO** rejected lumpectomy and mastectomy and opted for active surveillance.

How to treat DCIS continues to be debated and researched by the medical community. That's because preventing an invasive breast cancer diagnosis in women with DCIS does not appear to reduce the chances of dying from breast cancer, which has led to concerns about overtreatment. In 20% to 30% of patients who don't receive treatment, DCIS will progress to invasive breast cancer, according to Dr. Mridula George, a medical oncologist treating breast cancer at Rutgers Cancer Institute of New Jersey.

A month after the surgical biopsy, Pinto had a breast MRI followed by two mammograms over the next 18 months. The second mammogram showed potentially invasive cancer, so Pinto underwent two lumpectomies, the second to clean up the margins, which potentially had cancer cells. The diagnosis was low- or intermediate-grade DCIS; a second pathology opinion downgraded it to low-grade. Because the margins were still potentially positive, her doctor again encouraged her to get a mastectomy or at least undergo three weeks of radiation. "I felt like I was being bullied," she says. "I found a new doctor."

The Oncotype DX Breast DCIS Score test, which was new at the time, showed that Pinto was at low risk of developing invasive cancer. Her DCIS has not progressed in 11 years. She started the website DCIS411.com to support and educate other women with the diagnosis.

## DECIDING ON DCIS TREATMENT

The discussion about de-escalating surgery for low-grade DCIS and early stage invasive breast cancer is not new, but there's a continuing research focus to determine when it's safe for women to avoid surgery.

Doctors tend to recommend lumpectomy for localized DCIS as a first treatment approach. After surgery, the patient often receives breast radiation. Mastectomy is not typically recommended, says Dr. Alastair Thompson, chief of breast surgery and a researcher at Baylor College of Medicine in Houston. The patient may also be given anti-hormonal therapy or an endocrine medication for longer-term protection against progression and future breast changes.

National Comprehensive Cancer Network (NCCN) guidelines call for performing a lumpectomy at a minimum for DCIS at any stage. "One thing to understand about medicine is that changing practice has to be based on evidence that shows it is not going to be detrimental

DONNA PINTO BY EDER ESCAMILLA

to the patient in terms of future risk of invasive cancer," George says. Currently, physicians cannot accurately predict which patients are at increased risk of progression to invasive cancer.

Women who decline breast surgery can consider taking anti-estrogen (hormonal) therapy to decrease the risk of progression if the cancerous cells express the estrogen or progesterone receptor. So far, preliminary studies support this approach for lower-grade DCIS, but larger studies are needed. "Most patients are more receptive to having the surgery versus taking a pill (long term)," George says. Hormonal therapy has potential side effects. For instance, tamoxifen, the treatment of choice for premenopausal women, can cause fatigue, hot flashes, and a small risk of developing blood clots or uterine cancer.

Women who receive a DCIS diagnosis in their 30s and 40s or have a family history of breast cancer may want to get genetic testing, George says. Those with mutations such as BRCA1 or BRCA2 have an increased risk of DCIS turning into invasive breast cancer, and a bilateral mastectomy might be recommended. A patient who takes that route would not need radiation or hormonal therapy if the tumor is estrogen- or progesterone-receptor positive, George says.

## COMPARING STRATEGIES IN CLINICAL TRIALS

"It's ironic that, in the 1990s, the data was saying we can do breast conservation, and surgeons who didn't grow up with that were uncomfortable with it. Women wanted to conserve their breasts," says Dr. Benjamin Anderson, a breast surgeon at the University of Washington and Fred Hutchinson Cancer Research Center in Seattle. "Now, the pendulum has swung. More women want bilateral mastectomies, and surgeons are saying you don't need to do that."

Researchers in clinical trials are investigating whether surgery offers a benefit. For instance, the COMET trial, which began in 2016, is comparing surgery with or without radiation, as well as with or without endocrine therapy, to active surveillance with or without endocrine therapy for five years. Researchers want to determine which groups of women with low-risk DCIS might be spared from surgery. Thompson, one of the trial's co-principal investigators, says they've recruited 568 of the 1,200 participants needed. "It will be awhile before we determine what the answer is," Thompson says. After recruiting ends, it will take at least two years of follow-up to reach the first reporting point to determine results.

Two European trials tried to answer the same question but closed early because not enough patients were recruited. "Most folks know they want one treatment or the other and are not willing to be randomized," Thompson says. A Japanese trial is offering active monitoring and tamoxifen, not surgery.

Thompson is also involved with the Precision collaboration, which builds on multiple studies conducted over the past 20 years in the United States, the United Kingdom and Europe. It aims to distinguish features of those with DCIS who will progress versus those who won't.

## HANDLING INVASIVE BREAST CANCER

The most common form of breast cancer, invasive ductal carcinoma, makes up 80% of all breast cancer diagnoses. It occurs when cancer that began in a milk duct moves into the breast tissue.

There's flexibility in managing DCIS because the mortality rate is relatively low, according to Anderson. "(But) with invasive breast cancer, now you're talking about a different arena," he says.

Treatments include breast surgery, chemotherapy, radiation therapy, targeted therapy and/or hormonal therapy, depending on the cancer subtype. "These treatment options are used to reduce the chance of the cancer coming back and trying to prevent stage 4 cancer, which is not curable," George says. Not all women need all three approaches.

Women with invasive breast cancer typically get neoadjuvant therapy, which is drug treatment before surgery, to shrink the tumor. Multidrug treatments are so effective in 30% to 50% of some subtypes, particularly for breast cancer that is human epidermal growth factor receptor 2 (HER2) positive or triple-negative, that the cancer »

» **PINTO,** seen here in 2010 with her husband, **GLENN,** older son, **SKYLER,** and younger son, **CODY,** says her DCIS has not progressed in 11 years.

« With her oncologist, **VALERIE FRASER** founded the Inflammatory Breast Cancer International Consortium (ibcic.org) to bring researchers together throughout the world to advance science, medicine and treatment options.

will disappear, so there's no tumor left at the operation, Thompson says.

Treatment used to be more difficult for those with HER2-positive invasive cancers. Drugs such as Herceptin (trastuzumab) and Perjeta (pertuzumab) have been game changers, Anderson says. Some patients have evidence of a complete pathological response, meaning the absence of any detectable cancer on samples of affected breasts and lymph nodes. "Those are the patients we say we might not have to operate on," he says, though radiation would still be used. This approach is being verified in ongoing clinical trials but is not the current standard of care.

Women with invasive breast cancer typically get a sentinel lymph node biopsy, a procedure to remove the nodes to determine if cancer cells are present. It's usually done during lumpectomy or mastectomy to look for cancer spread. Experts don't recommend eliminating the procedure, because it helps with cancer staging and assessing the risk of disease recurrence based on the number of positive lymph nodes, George says.

Currently, not all patients get axillary lymph node dissection, which removes anywhere from 10 to 40 lymph nodes. Lymphedema is a possible long-term side effect of lymph node surgery, affecting 20% to 30% of patients. Excess fluid buildup causes swelling, usually in the arms and legs but sometimes affecting other parts of the body. Patients with one or two positive nodes who had breast-conserving surgery will get radiation, so dissection may not be done, George says. If the patient did not respond to neoadjuvant systemic therapy and has positive node involvement, axillary lymph node dissection will be considered.

"The group we now struggle with is those with mastectomies and one or two positive sentinel nodes," says Dr. Lee Wilke, director of the breast center and a breast surgeon at University of Wisconsin Health in Madison, because these women may not all get radiation. "The question is, is it safe to not remove the axillary nodes?"

## ASSESSING THERAPY'S RESPONSE

Without surgery, it is difficult to determine if all cancer cells are eliminated from the tumor bed. Imaging cannot detect everything, and needle biopsies can miss spots. "There is no strong agreement as to what is the best form of imaging and biopsy to give you a very accurate assessment," Thompson says. Leaving behind tumor cells is a missed opportunity to offer treatment that potentially protects against future cancer growth or spread.

Imaging might include mammogram, ultrasound, MRI or PET scans. Biopsies can be done with a small or big needle, with multiple passes necessary. "Bigger needles give a better idea of what's there, but these biopsies are not trivial things to go through," Thompson says, and there can be false negatives. At the moment, there's no gold standard for assessing whether any cancer remains.

VALERIE FRASER BY LINDSAY JAYE PHOTOGRAPHY

During treatment, **FRASER** promised herself that, if she survived, she would find a way to take her son, **COLIN FRASER**, to England and Scotland, the birthlands of her parents and their families.

PHOTO PROVIDED BY VALERIE FRASER

"If we don't operate, we don't have a good way of knowing if everything is gone," he says.

Women with triple-negative breast cancer who experience a complete clinical response, with nothing seen in the breast or lymph nodes on biopsy, may in the future be advised to avoid surgery but still get radiation, Thompson says. At present, physicians still operate to prove nothing is left, he adds.

Liquid biopsy, which evaluates the blood for cancer cells, is approved for patients with stage 4 disease because the cancer has already spread. No liquid biopsy tests are approved for cancer stages 1 to 3 but are under active investigation to see if they can detect microscopic disease or predict who may have a higher chance of recurrence.

"The holy grail will be the ability to detect cancer cells in the blood and know whether there's evident cancer still remaining," Wilke says. Residual disease may or may not be seen in a liquid biopsy: "It's like looking for a needle in a haystack."

## DECIDING ABOUT SURGERY

In 2007, Valerie Fraser learned she had two different cancers in the same breast: invasive ductal carcinoma and inflammatory breast cancer. Inflammatory breast cancer is rare, at 1% to 5% of all breast cancers. The diagnosis came after Fraser developed a quarter-size rash in her left breast, which eventually swelled, doubling in size, resulting in multiple workups. Her cancer was HER2 positive, and she was treated with Herceptin, followed by Herceptin and chemotherapy. After chemotherapy, her breast looked normal again, and imaging showed a complete response with no evidence of tumors. In spite of this, doctors recommended the normal treatment — surgery and radiation — to kill any remaining cancer cells. At that time, biopsies were not done to look for a pathological complete response, she says, though she would have considered that approach.

Like Pinto, Fraser spent a lot of time researching her disease. She says the risk of recurrence for inflammatory breast cancer is greatest in the first two years, and getting radiation and mastectomy after chemotherapy would have eliminated these options if the cancer recurred later. Therefore, she decided to proceed with careful monitoring. She also continued with Herceptin, and 13 years later has had no recurrence. Fraser went on to become a research advocate and, with her oncologist, founded the Inflammatory Breast Cancer International Consortium (ibcic.org) to bring researchers together throughout the world to advance the science, medicine and treatment options.

Avoiding surgery was not a hard decision, Fraser says, though she knows it's a psychologically difficult one for many women because they don't know if they had a pathological complete response to treatment. Clinical guidelines for surgical treatment of invasive breast cancer have not changed in recent years, and surgery is still recommended, Thompson says.

However, neither DCIS nor invasive breast cancer is one condition, Thompson says: "What we as a community tend to do is group people together and assume they're all the same." Treatment decisions must be individual, with patients and their doctors being mindful that evidence for subgroups in both cancer types can benefit from a specific approach rather than an across-the-board decision.

George has patients in their 80s and 90s who opted to forgo invasive breast cancer surgery. They may take hormonal therapy if appropriate and follow up more frequently. These older patients with early stage cancers are more likely to die from other causes, she says.

With shared decision-making, doctors review the risks and benefits of each approach, and the patient decides what to do. "As physicians, we work with patients to make sure they are comfortable with whatever approach they take. We don't have a crystal ball to know whether it's right or wrong," Wilke says.

Today, treatment is more personalized based on cancer type, stage, genetics, age and comorbidities. Twenty years ago, a conversation about breast cancer treatment would have taken her 30 minutes; now it can take an hour and a quarter or longer, Wilke says. "It's a lot to factor in," she says. "It's important for people to understand they have a lot of options."

# *Beyond* the Breast

## Two women living with metastatic breast cancer that has spread to the brain describe the tools that are helping to keep them alive.

*By* MEERI KIM, PH.D.

FLORI HENDRON BY GINA SHELDON

Flori Hendron was taking a shower when she felt a tiny lump near her armpit. She was 38 with no family history of breast cancer, so she figured the growth would be benign. To be safe, she scheduled a doctor's appointment.

"I followed up on it, and that launched my adventure with breast cancer back in 1996," says Hendron, now 62, a resident of Los Angeles. The mother of two endured a lymph node dissection, a lumpectomy, radiation and chemotherapy to treat her early-stage disease. "I went into that year of treatment like a warrior, even though it beat me up so badly. My kids were 6 and 8, so there was no way I was going to die."

Afterward, she assumed she had won her hard-fought battle with cancer. Instead, it turned out that first small lump marked the beginning of an agonizing, decades-long war. In 2002, a large spongy lump appeared in the same breast, leading to a double mastectomy with reconstruction. In hindsight, Hendron wishes she had skipped the reconstruction. The surgery left her extremely sick with multiple infections, and at the same time, the cancer continued to spread. »

« **FLORI HENDRON,** a survivor of brain metastases from breast cancer, started painting while recovering from her bilateral mastectomy in 2002 and never stopped.

Later that year, after a horrible bout with several chemotherapies that didn't work and spread of the cancer through lymphatic vessels in the skin, Hendron finally started taking Herceptin (trastuzumab), a targeted therapy for patients with HER2-positive breast cancer. She'd known from the start that her cancer was HER2-positive, she says, but was considered ineligible for the drug until 2002 because her tumor was too small and her disease wasn't advanced enough. The drug kept her cancer-free, and after 20 months of treatment, she stopped taking it in April 2004.

"I used to race forward and get things done quickly in my career, and in breast cancer, I did the same thing but with blindfolds," says Hendron, who spent most of her professional life in product design, brand development and marketing. "I should have never stopped the Herceptin, but I just didn't know enough yet."


In 2007, she received a stage 4 breast cancer diagnosis. The disease had spread to her lungs and sternum, and although Hendron also asked for brain imaging to check for metastases, her oncologist at the time dismissed her request as it was not the standard of care in the absence of symptoms. After she switched to a new oncologist, an MRI scan revealed a single brain metastasis in her frontal lobe.

"Over the years, I've learned that if a doctor belittles you or is unsupportive, it's time for a new doctor," she says. "Be a fully active participant in your own survival and insist on what you need."

Nunny Reece, who also is living with stage 4 breast cancer, agrees that patients must advocate for themselves and pay attention to their bodies. She first found a lump in her breast in 2015 at age 37, but her doctor told her that she simply had dense breasts and shouldn't worry.

Two years later, in June 2017, Reece discovered a new lump under her arm. She also noticed blotches on her skin and experienced pain throughout her body. Even though her doctor gave her a diagnosis of lupus, she decided to schedule a mammogram because the pain wasn't going away.

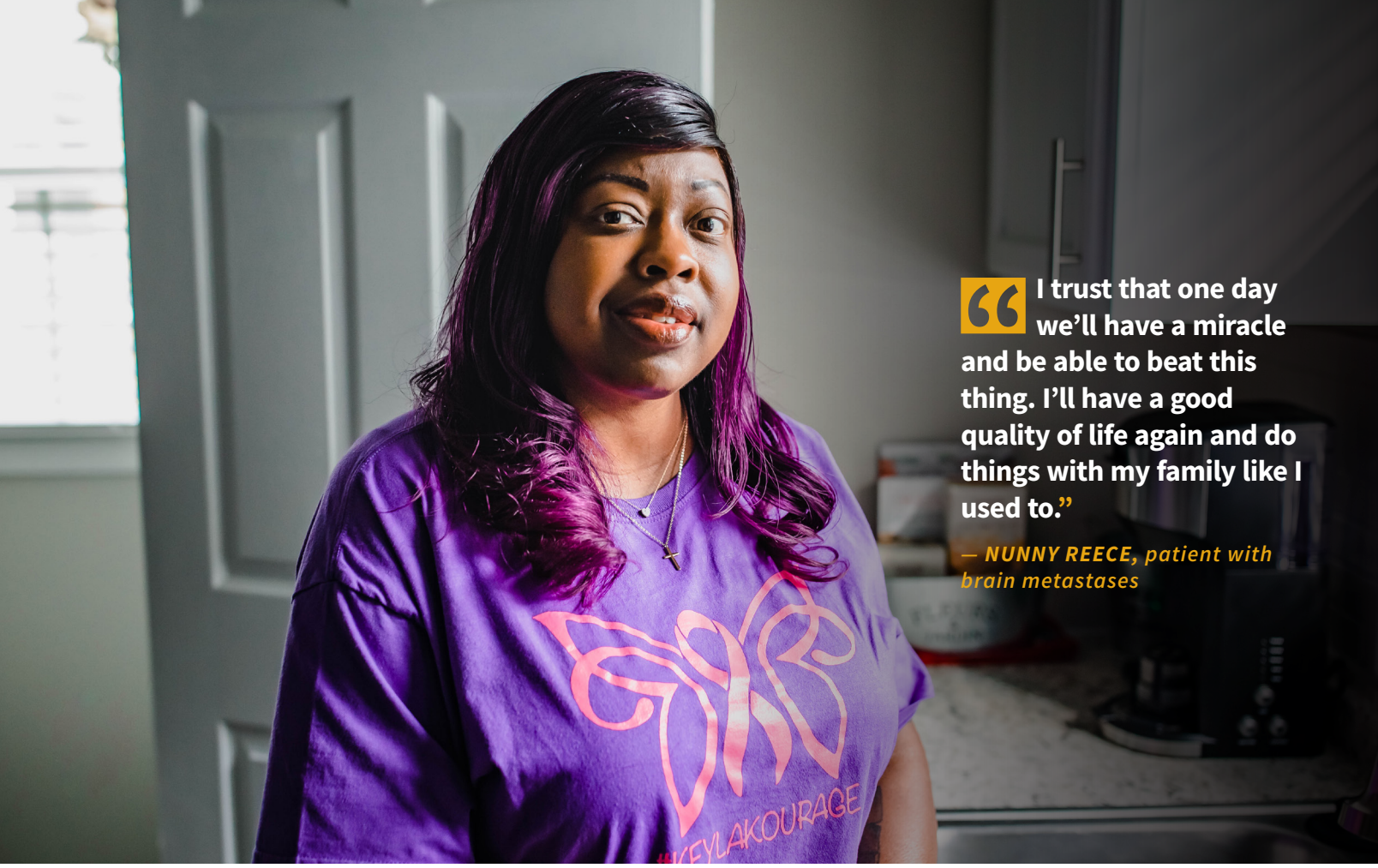
"First they told me I needed to see a surgeon because I have breast cancer. At that time, I had no information other than that it was breast cancer, so I assumed it was early stage," says Reece, now 42, a resident of Hope Mills, North Carolina. "I was so shocked when the doctor told me, with tears in her eyes, that they (couldn't) do surgery because I (was) already at stage 4."

Having lost her father to stage 4 colon cancer just a year earlier, the mother of three felt devastation and heartbreak. The disease — which was hormone receptor (HR)-positive but HER2-negative — had spread to her lungs, lymph nodes and bones. Her doctors first tried hormone therapy, a treatment for breast cancers that are fueled by hormones, but it didn't work. They moved on to oral, then IV chemotherapy drugs, which helped for a while.

In December 2019, Reece experienced frequent headaches and dizziness, common symptoms of brain metastases. An MRI confirmed that the cancer had spread to her brain.

"Brain metastasis is quite common in the metastatic breast cancer setting (in which cancer has spread beyond the breast and nearby lymph nodes), and it is becoming more problematic as we're getting more novel drugs to the market that are doing a better job of controlling systemic disease," meaning cancer throughout the body, says

FLORI HENDRON BY GINA SHELDON




NUNNY KEYLA REECE BY JENNIFER COCHRAN

Dr. Rashmi K. Murthy, assistant professor of breast medical oncology at The University of Texas MD Anderson Cancer Center in Houston. “For patients with HER2-positive, metastatic breast cancer, for example, up to 50% of individuals can develop brain metastases during the course of their disease.”

## SPOTTING SYMPTOMS OF SPREAD

More women like Hendron and Reece are living longer with metastatic breast cancer and will at some point require treatment for brain metastasis. Current options, such as radiation and surgery, aren’t a possibility for all patients, depending on the number of tumors, and can have lingering side effects. For many patients, the development of brain metastases greatly limits life quality and expectancy.

Fortunately, new targeted therapies and immunotherapies show promise for brain metastases. These innovations have the potential to treat secondary tumors while minimizing harm to healthy brain tissue and reducing the possibility of negative long-term side effects.

“We’re all taught in medical school that the brain doesn’t regenerate, so it’s very difficult once you have a neurologic symptom to have full recovery, unless it’s very short-lived,” says Dr. Carey K. Anders, medical director of the Brain and Spine Metastases Program at the Duke Cancer Center in Durham, North Carolina. “We don’t want our patients to have to live with a neurologic symptom that could alter their daily life, whether it affects driving, caring for themselves and their family, (or) doing their work or the hobby that they love.”

Despite all the new therapies that have emerged, breast cancer remains the second most common cause of death in women. Most of those deaths are caused by metastatic breast cancer. Although just 6% of patients have metastatic breast cancer at initial diagnosis, nearly 30% with early-stage breast cancer will eventually develop metastatic disease.

The brain, bones, lungs and liver are common sites of breast cancer metastases. Breast cancer is the second leading source of brain metastases after lung cancer, and 10% to 15% of all patients with the disease will develop at least one secondary brain tumor.

Among patients with metastatic breast cancer, the risk of spread to the brain can be higher depending on the disease’s subtype. Those with HER2-positive disease are the most susceptible, with about half of all patients developing brain metastases. About 25% to 45% of women with triple-negative metastatic breast cancer will develop brain metastases, which also represents an elevated risk of brain metastases compared with non-triple-negative breast cancer. Breast cancers with estrogen receptors, called ER-positive cancers, that are also HER2-negative tend to have a lower risk.

Brain metastases are associated with a poor prognosis. After diagnosis, overall survival ranges from three months »


**REECE** considers her husband, **SCOTT REECE**, and three sons her inspiration for trying treatment after treatment to fight breast cancer that has spread to her brain.

to just over two years. Metastases are most often discovered using MRI with a contrast solution delivered intravenously to improve image clarity. Physicians watch for common symptoms of brain metastases in patients when deciding whether to order a scan.

"Symptoms that we look out for are headaches, especially if they happen with nausea and vomiting that can't be really well explained by a patient's chemotherapy, for example," says Dr. Nancy Lin, director of the Metastatic Breast Cancer Program at Dana-Farber Cancer Institute in Boston. "We also worry about seizures, or if someone has weakness on one side of their body."

## RANGE OF THERAPY SIDE EFFECTS

Treatment may involve local therapies directed at the brain metastases, such as surgery and radiation therapy, as well as systemic therapies that treat cancer throughout the body. Surgery could be a viable option for a single, large brain tumor, depending on its location. But for most patients, initial treatment involves either focused radiation or whole brain radiation, depending on the number of metastases and how early diagnosis occurs.

Because she had a single tumor, Hendron had a noninvasive procedure in February 2008 called Gamma Knife stereotactic radiosurgery, which uses 3D imaging to deliver a powerful, precise dose of radiation to a targeted area. It took just a single outpatient session without any incisions or anesthesia to successfully treat her lesion. Side effects of stereotactic radiosurgery can include fatigue, swelling, headache, nausea and vomiting and usually last for a few weeks after treatment.

"Gamma Knife was the easiest treatment I ever had and the most effective," Hendron says. "I was in the hospital at 7 a.m. and home by 11 a.m. I wore my own clothes and didn't need any pre-meds or post-meds."

Reece had a very different and much more harrowing experience. She had 12 metastases throughout her brain and was treated with 10 rounds of whole brain radiation. Because it delivers radiation to the entire brain, including healthy tissue, this type of treatment can lead to serious problems later in life, such as memory loss, strokelike symptoms and poor brain function. Patients also suffer from painful short-term side effects such as headache, nausea, vomiting, fatigue and hair loss.

"Treatment has not been good to me. It has been a struggle; really, really tough," Reece says. "The side effects from the whole brain radiation were bad. I was nauseous, throwing up, dizzy. The MRI showed that it did help, though, and some of the metastases in my brain decreased in size."

Fortunately, advances in local therapies aim to help more patients like Reece reap the benefits of radiation therapy without the harsh side effects. For example, a modification to whole brain radiation that avoids damage to the hippocampus, a region of the brain associated with memory, is now the standard of care at many institutions. Study findings have also shown that Namenda (memantine), a drug originally used to treat Alzheimer's disease, can help protect the brain and may improve cognitive outcomes in patients undergoing whole brain radiotherapy.

In addition, the number of metastases that can be treated with stereotactic radiosurgery instead of whole brain radiation continues to increase as the technology improves. "When the original radiosurgery studies came out, the number of lesions was three to four that could be treated safely with radiosurgery at one time, and anything more than that required whole brain. We're now up into the teens," Anders says. "There is data to support irradiating 10-plus lesions, and I know we've been doing

NUNNY KEYLA REECE BY JENNIFER COCHRAN

that routinely at our cancer institute to try to avoid whole brain radiation therapy."

Perhaps the most exciting advance lies in the results of the phase 3 HER2CLIMB clinical trial of Tukysa (tucatinib), a new HER2 kinase inhibitor used to treat HER2-positive breast cancer, in patients with brain metastases. Tukysa crosses the blood-brain barrier, a membrane that separates circulating blood from the brain, which most cancer therapies can't do. Patients who received Tukysa along with chemotherapy and Herceptin experienced a higher rate of tumor shrinkage, including metastases in the brain, and also had a longer period of time where they lived without worsening disease, and lived longer overall, compared with patients who received only standard chemotherapy and Herceptin.

In April 2020, the Food and Drug Administration (FDA) approved Tukysa in combination with Herceptin and Xeloda (capecitabine) based on these findings for previously treated patients with advanced inoperable or metastatic HER2-positive breast cancer.

Several clinical trials focusing on new treatments or combinations for brain metastases are recruiting or plan to recruit patients with breast cancer. For instance, an upcoming phase 2 study will involve genetic testing of the brain lesion to check for alterations that could be matched to a therapeutic target. A phase 3 trial in the recruiting stage will see if combining Tukysa with Kadcyla (T-DM1; ado-trastuzumab emtansine), a targeted therapy for HER2-positive breast cancer, improves survival.

As similar treatments gain FDA approval, improved guidelines around screening will likely emerge to catch and treat brain metastases earlier. Right now, the standard is to screen only patients who have symptoms.

"We are definitely evaluating patients who have any kind of neurological symptoms for brain metastases, but it's not necessarily an immediate part of their diagnostic work-up," Murthy says. "As we get more and more therapeutics that show efficacy across the blood-brain barrier, I certainly think that is going to change. The approval of tucatinib has certainly changed my practice to evaluate patients for brain metastases."

## SCREENING: PROS AND CONS

The topic of screening for brain lesions has become controversial in the field of breast cancer, mostly because of a lack of evidence. However, multiple studies in the works will attempt to disentangle the effects of regular brain MRIs on patients with breast cancer.

"We don't have definitive data to say that screening is useful, and screening has the potential to be harmful if it's done in a way that leads to treatment changes that may or may not be necessary," says Lin, who does not routinely screen patients but has a very low threshold for ordering a brain scan. "People could end up getting (potentially harmful) treatments that they don't necessarily need or getting switched off the treatments that would otherwise have worked. That's the argument against universal screening for brain metastases."

Hendron and Reece get regular brain MRIs to check for the appearance of new secondary tumors. In 2019, Hendron's doctors uncovered three more brain metastases, which were treated with stereotactic brain radiation therapy. Since then, her scans have been stable.

> **"We don't want our patients to have to live with a neurologic symptom that could alter their daily life, whether it affects driving, caring for themselves and their family, (or) doing their work or the hobby that they love."** — *CAREY K. ANDERS, Duke Cancer Center*

"I often say cancer is a mind game. The body game is what the doctors and medicine do, but the mind game is the work we have to do," she says. "The biggest piece of advice is: You just have to learn to be present. All we have is this moment, and each person has to find what works for them to be in the moment."

For her, the best self-care activities are art and writing. Hendron started painting while recovering from her bilateral mastectomy in 2002 and never stopped. She even developed and facilitated an art program at Cedars-Sinai Medical Center, where she taught other cancer survivors how to connect with the healing process through art expression.

Reece, whose cancer remains active in her liver and lungs, started her eighth line of treatment with Halaven (eribulin), a type of chemotherapy used to treat metastatic breast cancer, in September. If that doesn't work, she plans to consider any clinical trials that she might be eligible for. The driving force behind trying treatment after treatment, despite the excruciating side effects and risk of disappointment, is her family: her husband of 20 years and three sons.

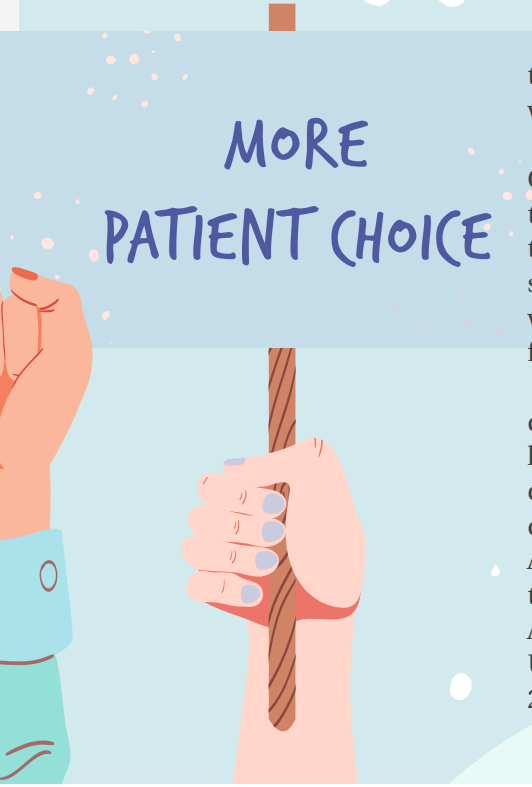
"Day-to-day life is a struggle. Some days I'm OK, but my OK is different from everyone else's OK. I'm able to get out of bed today, wash my face, brush my teeth," says Reece. "But through my relationship with God, I trust that one day we'll have a miracle and be able to beat this thing. I'll have a good quality of life again and do things with my family like I used to."


FUNDING FOR RESEARCH
EARLY DETECTION
BETTER TREATMENTS

# From Secrecy to Support

**The breast cancer patient advocacy movement that started in the 1950s pulled the disease out of the shadows, bringing patients' options to light.**

*By* STACY WILLINGHAM




When Jane Perlmutter learned in 1985 that she had mucinous carcinoma in her right breast, what struck her most was the veil of secrecy surrounding the disease.

"I was diagnosed in my early 30s, and at that time, cancer was still the C-word that people whispered about," Perlmutter says. "And the word 'breast' was rarely even published."

While Perlmutter received treatment at Memorial Sloan Kettering Cancer Center (MSK) in New York City, she recalls, a volunteer from the American Cancer Society's peer-to-peer support program, Reach to Recovery, came into her room. "She told me that she was a 17-year survivor, and that was so powerful to me," Perlmutter says. "That was the first time I really believed that I could survive this, so after I finished my treatment, I felt as though I was chosen to get involved."

In the 35 years since, Perlmutter has been heavily involved in cancer advocacy and said she owes her activity, in part, to those who laid the groundwork. The breast cancer patient advocacy movement officially got its start in the early 1950s, and in the past 70 years, the disease has morphed from a shameful secret to a prominent issue. Awareness has grown about the importance of early detection and treatment and the need for dedicated research and care programs. And breast is the cancer that garners the most funding through U.S. nonprofit organizations, reaping $460 million in donations in 2015 alone. »

KATSYARINA / ADOBESTOCK ADAPTED BY GWEN SALAS

**» JANE PERLMUTTER** received a breast cancer diagnosis in 1985 and was inspired to help end the secrecy shrouding the disease.

Over the decades, the money brought in through rising awareness has helped researchers identify a variety of types of breast cancer; move from a standard treatment of radical mastectomy to the possibility of lumpectomy; and add chemotherapy, hormonal medications, targeted drugs and immunotherapy to the list of available options.

## GOING PUBLIC

At its core, the breast cancer patient advocacy movement can be credited to a handful of brave women who first came forward with their stories, founding support groups and, eventually, political activism groups. Their goal: Raise awareness and money, and bring the patient experience into the conversation among scientists and clinicians to affect cancer culture, drug development, treatment options, Food and Drug Administration (FDA) regulations and more.

Terese Lasser was one of the first women to kick-start the movement when, in 1952, she went to MSK to have a malignant breast lump biopsied under general anesthesia. She awoke to find herself, in her words, "bound like a mummy in surgical gauze," and learned that a radical mastectomy had been performed without her knowledge or verbal consent.

Emotionally devastated by the mastectomy, Lasser also became infuriated with the cavalier attitude of her male surgeon, who shrugged off her questions about prosthesis options and rehabilitation exercises. Turning her anguish into action, Lasser founded Reach to Recovery in 1953 to bring women with breast cancer together to address the needs that their surgeons did not view as important. In 1969, the program that would inspire Perlmutter to join the fight was incorporated into the American Cancer Society.

In the early days of breast cancer advocacy, the biggest obstacle was the lack of open discussion. Patients like Lasser cleared that hurdle, and public figures took the cause a step further. Child movie star Shirley Temple Black became the first woman to openly write about her experience with breast cancer in 1972 in a monthly women's magazine, famously stating: "The doctor can make the incision; I'll make the decision."

In 1974, first lady Betty Ford shared news of her breast cancer diagnosis and radical mastectomy with the American public through a televised press conference; just three weeks later, Happy Rockefeller, the wife of Vice President Nelson Rockefeller, disclosed the discovery of a malignant lump in her own breast.

Patient and advocate Rose Kushner boosted the movement in 1975 by publishing "Breast Cancer: A Personal History and an Investigative Report." In her book, Kushner took issue with radical mastectomies and with performing biopsy and mastectomy together instead of delaying treatment until a patient had time to consider her options.

JANE PERLMUTTER BY LINDSAY JAYE PHOTOGRAPHY

> **"When women were growing up, you were a good girl if you didn't say anything, if you didn't challenge authority. You basically went along to get along — until the early '80s, with the rise of the feminist movement and as women watched the AIDS activists."** — *DR. JANET OSUCH*

That public discussion led to women learning more about self-examination and medical options, but real change in the doctor's office came with the rise of female surgeons, including Dr. Susan Love and Dr. Janet Osuch.

"When I went into surgery, and even when I went to medical school, there were quotas for how many women they would take," Love says. "When I finished, nobody would offer me a job because nobody wanted a woman, so I started my own practice. And the only patients they would send me were women with breast problems."

In 1985, Dr. Bernie Fisher, a surgeon and pioneer in the breast cancer patient advocacy movement, published an article comparing total mastectomies with lumpectomies, a form of breast preservation. Through a randomized study of stage 1 and 2 breast tumors, Fisher found that lumpectomy was at least as effective as mastectomy in treating breast cancer in these patients. Although his findings were instrumental in giving women a choice, it was primarily female surgeons like Love and Osuch, whose practices were soon flooded with patients who had breast cancer looking for options, who made change possible.

"I started doing breast preservation as soon as Fisher published that article, and that was not what most male surgeons were doing," Osuch says. "But that was part of what attracted women to my practice. They came from all over Michigan. Women brought something really special to the field of surgery because they tended to listen to their patients more."

In 1986, the state of Michigan amended its Public Health Code to state that "a physician who is administering the primary treatment for breast cancer … shall inform the patient, orally and in writing, about alternative methods of treatment," serving as just one example of how advocacy turned into action.

## POWER IN NUMBERS

Good timing also helped drive breast cancer patient advocacy. In the early 1980s, two movements seemed to collide, setting the stage for women to organize around breast cancer like never before.

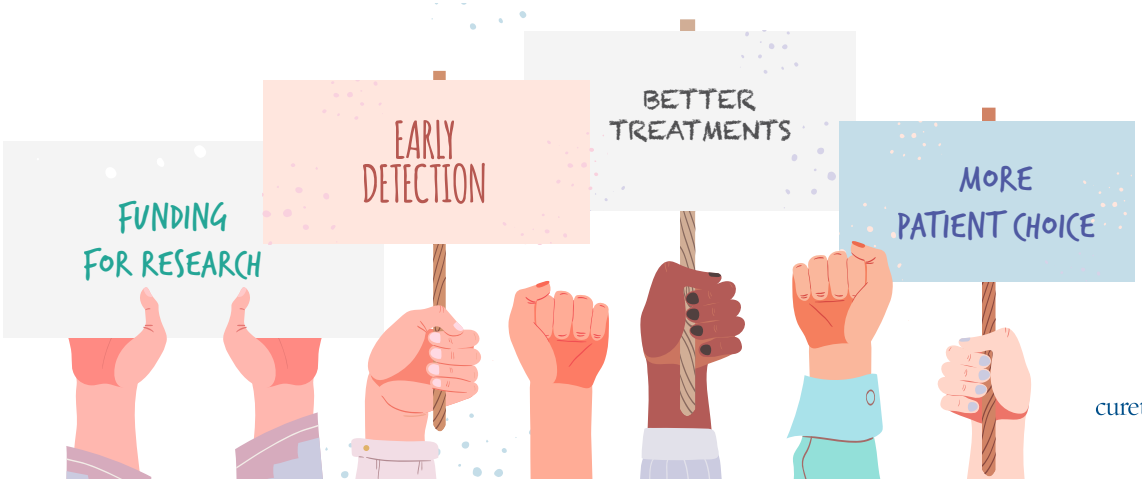
"When women were growing up, you were a good girl if you didn't say anything, if you didn't challenge authority," Osuch says. "You basically went along to get along — until the early '80s, with the rise of the feminist movement and as women watched the AIDS activists."

The AIDS movement was one of the first disease-specific efforts to increase research and funding, sometimes using aggressive and "in-your-face" tactics, and women took note. In 1980, Nancy Brinker was watching as her sister Suzy died from breast cancer at the age of 36. "I can't tell you what that did to me," Brinker says. "It changed my world, my entire life."

At the end of her life, Brinker's sister made her promise to do everything in her power to end breast cancer, which led Brinker to launch the Susan G. Komen Breast Cancer Foundation — now simply known as Susan G. Komen, named after her sister — in 1982.

The creation of the organization, just two years before Brinker's own breast cancer diagnosis, marked the first public effort to raise money specifically for breast cancer, tearing a page out of the AIDS playbook. Susan G. Komen's Race for the Cure, which began in 1983, quickly became one of the world's largest 5Ks dedicated to breast cancer awareness. Susan G. Komen itself has become the largest and most-funded nongovernmental breast cancer organization in the United States.

Besides playing a role in equating the color pink with breast cancer awareness and support, Susan G. Komen has raised and given away about $3 billion for research, as well as launched a community approach to detection »




KATSYARINA / ADOBESTOCK

and care. In addition to allocating $1 billion to fund the careers of young scientists, many of whom are now the leaders of some of the best labs in the country, the organization funneled the other $2 billion directly into over 104 communities around the world, where Susan G. Komen teaches women about the disease, funds, detection, care and support programs, and helps people with any stage of breast cancer find and participate in clinical trials.

## ADVOCATE INVOLVEMENT

The AIDS movement not only revealed the effectiveness of disease-specific efforts, it also helped women realize they could have educated and informed conversations with scientists and surgeons, with the ultimate goal of influencing breast cancer policymaking.

In 1991, several advocacy groups formed the National Breast Cancer Coalition (NBCC), "a collaboration of activists, survivors, researchers, policymakers, grassroots groups and national organizations that have come together as disruptive innovators for social change." The group's mission is to link organizations across the country to give them a voice in government, laboratory and community decisions, and initiatives related to breast cancer.

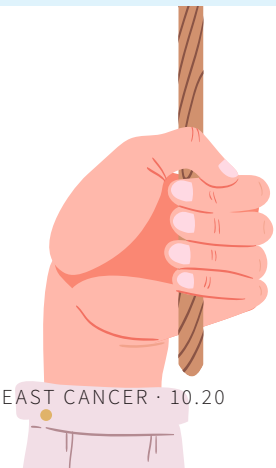
"The NBCC was really instrumental in getting research funding, and they were the main movers in saying: 'We played a key role in getting this funding, and we want a seat at the table to have an influence in how the research is done,' " Perlmutter says. "NBCC trained advocates so they understood enough of the science to be good contributors, and then researchers began to realize that we were smart, good people who had a different perspective to share, and they began to engage us in peer review and research."

The involvement of advocates in research, she says, was a groundbreaking advance; for example, clinical trials designed purely from a scientist's perspective can fail due to conditions or requirements that aren't comfortable for patients, leading to low enrollment or nonadherence.

"Getting advocates involved early to tell scientists how patients are likely to react to a trial design will make a difference in how well the trial does," Perlmutter says.

Efforts like these resulted in greater understanding of the value of patient engagement and encouraged its widespread use. Organizations that now operate with patients top-of-mind include the Patient-Centered Outcomes Research Institute (PCORI), which funds studies that offer patients and caregivers the information they need to make important health care decisions, and the FDA's Patient-Focused Drug Development program, defined on the FDA website as a "systematic approach to help ensure that patients' experiences, perspectives, needs and priorities are captured and meaningfully incorporated into drug development and evaluation."

> **"When I metastasized … I was told by my oncologist to expect death in two to three years and then told by the breast center staff … to avoid the center and hide my diagnosis from other patients. It was all too depressing and would frighten other patients to learn that actually happened."**
>
> *— DIAN "DJ" CORNELIUSSEN*



## MOVING FORWARD

Over the course of 70 years, the coordinated breast cancer patient advocacy movement pulled the disease out of the shadows and into the spotlight, turning breast cancer into the most funded cancer in the country. So, what's next?

"Breast cancer advocacy took breast cancer out of the closet, and it made people recognize that many cancer patients are basically cured when they are detected early," Perlmutter says. "But metastatic breast cancer survivors feel as though they have not been represented. Most of the funding goes to early stage breast cancer, but if you can prevent metastasis, you can make a bigger impact."

When she learned in 2005 that she had stage 2a ductal carcinoma in situ, Dian "CJ" Corneliussen was initially impressed with the support she received. However, when her cancer metastasized to her lung a year later, her experience was radically different.

"When I was diagnosed with primary breast cancer, I was inundated with offers of support and friendship," Corneliussen says. "When I metastasized a year later, I was told by my oncologist to expect death in two to three years and then told by the breast center staff — (the place where) I was diagnosed and frequently sought emotional support — to avoid the center and hide my diagnosis from other patients. It was all too depressing and would frighten

**JANE PERLMUTTER,** left, enjoys a moment with her twin sister, **MARION,** her "cheerleader" in cancer, advocacy and life.

other patients to learn that actually happened. There was no support, no one to talk to, and then I learned there was virtually no research about metastatic breast cancer."

Corneliussen felt that the breast cancer movement pushed the concept that patients only experienced metastasis if they "did something wrong," she says. Feeling isolated and alone, as well as shocked at the contrast between her two experiences, she decided to found METAvivor, a metastatic breast cancer research, support and awareness organization, in 2009.

According to METAvivor, although 30% of people who receive a diagnosis of early stage breast cancer will eventually experience metastasis, a minority of funds raised for breast cancer research are directed at disease that has spread.

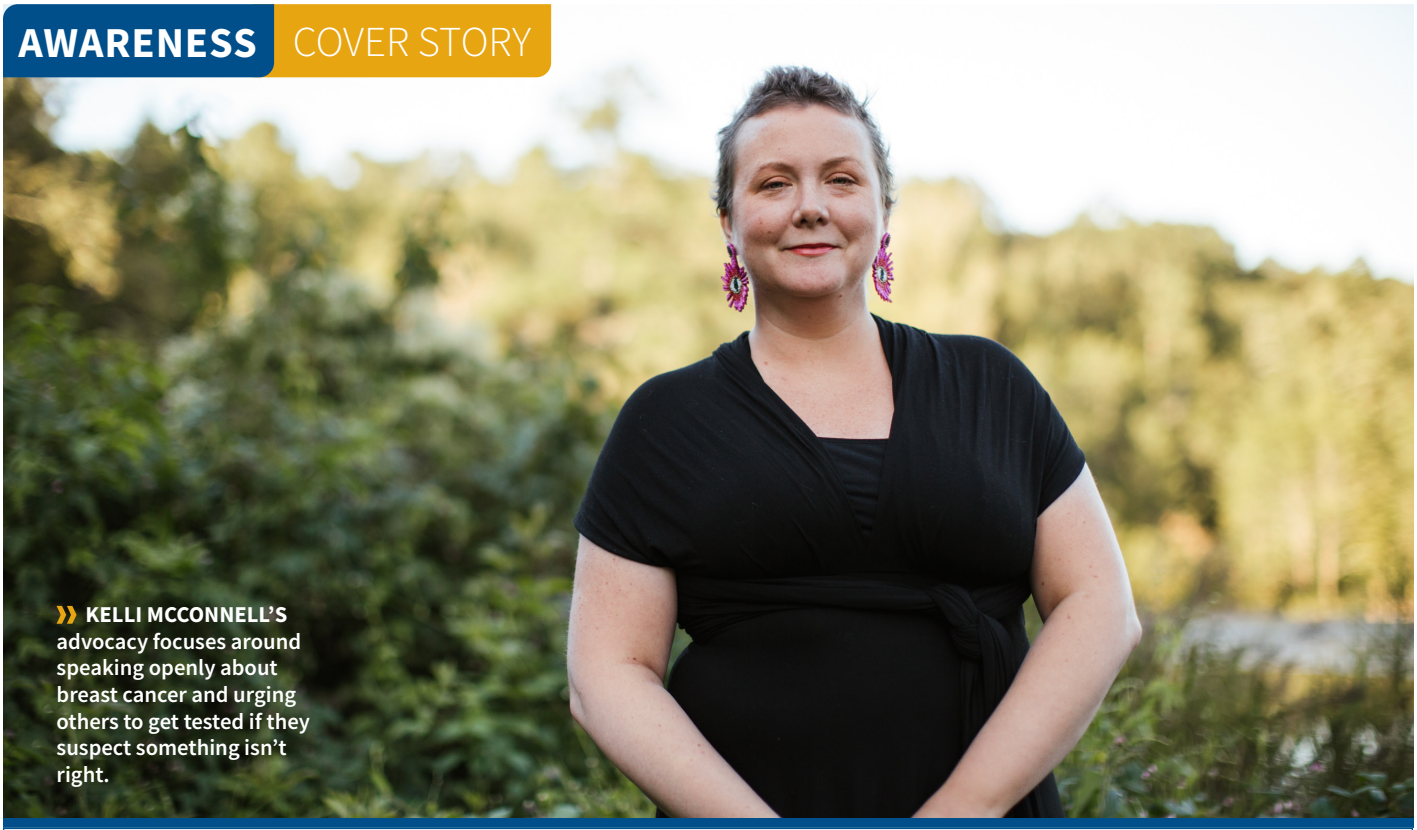
"We're trying to expand the culture of breast cancer," Corneliussen says. "It isn't just about your breast and whether you get to keep it or lose it. It's about your life."

The movement also has begun focusing more on young survivors and their issues related to fertility and sexuality that are unique to their age. And, there is also a growing understanding and awareness of previvorship, or living with an inherited predisposition to breast cancer. Previvors who test positive for breast cancer-associated gene mutations are closely observed through regular screening so that any cancers will be detected early; they are also asked to consider preventive surgeries, such as the removal of their breasts, ovaries and fallopian tubes. For more than 15 years, patients and previvors with these gene mutations have been able to turn to Facing Our Risk of Cancer Empowered (FORCE), the only national nonprofit organization dedicated to supporting them. The group includes resources for men, who can be affected by or pass down these inherited genes.

Finally, the issue of health equity and disparity in care is a major focus across the entire breast cancer patient advocacy network. More sisters networks focused specifically on Black and Hispanic patients with breast cancer have formed, and there is a push toward ensuring that advocates are compensated for their time, which would help make advocacy involvement, which has traditionally been volunteer based, more representative of the entire population.

For Brinker, addressing health equity is the next necessary step toward fulfilling the promise she made to her sister 40 years ago — and what led her recently to found the Promise Fund of Florida, with the goal of eliminating barriers to quality health care and creating a community-based continuum of care for all.

"I have committed the rest of whatever my life will be to get this done," Brinker says. "At the end of the day, I honestly believe that sometimes, to be an advocate, you have to be a bit of a maverick and just go off and do what you think is the right thing to do."



» KELLI MCCONNELL'S advocacy focuses around speaking openly about breast cancer and urging others to get tested if they suspect something isn't right.

KELLI MCCONNELL BY KRISTIN KARCH

# Spreading the Word

## *Breast cancer patient advocacy removed the stigma associated with the disease in the early 20th century, but what does it do for the advocates themselves?*

**JANE PERLMUTTER HAS** been an active breast cancer patient advocate since she received a diagnosis of mucinous carcinoma of the right breast in 1985. That was followed by diagnoses of intraductal and infiltrating ductal carcinomas of the left breast in 1988 and metastatic esophageal cancer, caused by radiation, in 2015.

"There is a great personal reward knowing that you're doing something to put some meaning to this experience that is so negative and traumatic," she says. "My advocacy is treatment for my post-traumatic stress."

Although Perlmutter uses her education in cognitive psychology to focus on clinical trials, advocacy looks different for every participant, in both the areas of emphasis and timing.

"Patients need to decide when they're ready," says Dian "CJ" Corneliussen, founder of METAvivor, which focuses on research, support and awareness on behalf of patients with metastatic breast cancer. "Some just want to get going — I did immediately after my diagnosis — and some people need time."

For patients with a new diagnosis who are interested in advocacy, Perlmutter and Corneliussen recommend taking it slow, starting in a peer-support setting and learning about all the ways to get involved.

"We always need fundraisers. The research is entirely dependent on raising money," Corneliussen says. "Some people may have a business where they want to give a percentage of sales or they want to hold an event. There are many areas where people can get involved."

For patients who are dipping their toes into the world of advocacy, sharing their stories and learning to advocate for themselves is a great way to start.

In May 2019, Kelli McConnell noticed a change in her right nipple. After her gynecologist assured her that nothing was wrong, McConnell felt relieved, but she still couldn't shake the feeling that her body was telling her something. She waited seven months to go back, and the second time around, she was diagnosed with stage 3c invasive ductal carcinoma of the right breast at the age of 37.

"For me, being an advocate is having really open and supportive dialogue around experiences," McConnell says. "Taking something at face value almost killed me, so my message is this: If you know your body and you know that something isn't quite right, get checked. And then get checked again. Before you trust your doctor, you have to trust yourself."

McConnell's advocacy journey has led to feelings of empowerment, along with the hope of helping other people feel more empowered themselves. "I've been able to find strength inside myself that I didn't even know I had," McConnell says. "Anybody I meet, I strike up conversations and say, 'Let's talk about this. Let's pull any shame and discomfort around this out of the shadows. These experiences we're having as cancer patients are valid, and they deserve to be seen and upheld. When we have power within ourselves, we can be better advocates for our own care.'"

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# Facing Metastatic Breast Cancer — Together

*Those with breast cancer that has spread to other parts of the body often feel misunderstood. Support from others walking the same road can make all the difference, five people living with the condition explain.* By BETH FAND INCOLLINGO

**BREAST CANCER CAN BE** scary and life altering at any stage, but those with metastatic disease, which has spread to areas beyond the breast and nearby lymph nodes, live a unique experience. Their perspective and decisions are shaped by the knowledge that their illness is incurable and that they'll need treatment for the rest of their lives.

Patients facing this diagnosis often say that only others in the same situation can truly understand what they're going through. *CURE*® talked with five people living with the disease, all ambassadors for Facing MBC Together, an Athenex Oncology program that includes a website and app designed to provide practical and emotional support. The excerpts of their stories presented here paint a picture of life with metastatic breast cancer.

## *Kathleen Friel*

Kathleen Friel is no stranger to having a misunderstood health condition. Being teased in school as a child with cerebral palsy prepared her well for having metastatic breast cancer, she says. "People don't understand, and the same is true of metastatic breast cancer," says the 46-year-old scientist and lab director at the Burke Neurological Institute of Weill Cornell Medicine, who learned in May 2018 that she had the disease and it had reached her spine.

"Most kinds of breast cancer are potentially curable, but metastatic breast cancer is not," the Hartsdale, New York, resident says. "People assume, 'Oh, you must be fine because you look fine.' It puts a lot of expectations on us that, if somehow we're strong enough, then we'll beat this disease. But with cancer, you can try everything and it might not work."

**On working full time with metastatic breast cancer:** "I really love my job and the people I work with, so in some ways it was almost like emotional therapy to stay involved. We're creating new therapies for children with cerebral palsy, so I feel like it's not just a job — it's really a passion. The people in my lab have been so good to me. One time I had radiation and my doctor told me I shouldn't drive, so I asked a co-worker for a ride. All four of them went, waited for me and took me out to eat afterward."

**On finding emotional support:** "I have a strong support system with other metastatic breast cancer patients who understand what I'm going through. Thank God for social media and support groups. Now that I know those people, I don't feel isolated, even if some others I know aren't supportive. Facing MBC Together is also cool because I got to meet all the other ambassadors, and we're really close friends now."

**On being there for those with the disease:** "If somebody in your life gets a diagnosis of metastatic breast cancer, really listen to them and don't try to sugarcoat things. People think it's helpful, but it isn't. At least for me, the most helpful thing is to talk about what's really going on. Even if you say, 'I don't know what to say, but I'll listen,' that's enough."

## *Pam Haldeman*

Self-advocacy has helped Pam Haldeman thrive through five lines of treatment for metastatic breast cancer.

"I felt like I needed to really dig in, because when you have metastatic disease, you've kind of lost control of your life," says the 66-year-old wife and mother who lives in a Philadelphia suburb. She received a diagnosis of stage 2/3 triple-negative breast cancer in 2016 and learned in 2018 that it had metastasized to her liver. "The future is not yours," she says. "A way to get back a little bit of control is to be your own advocate and get aggressive in researching and going to every conference or retreat available."

**On working full time:** "I've worked for the owner of multi-franchise car dealerships for 38 years. Maintaining my normal work schedule allows me to continue to feel both comfortable and productive. My bosses are flexible and understanding when I have to miss work for cancer care, and the cancer center is conveniently located nearby. So, at this time, I am still able to keep my job, my family commitments and most outside activities (except exercise class) without too much disruption or stress."

**On keeping mum about metastatic breast cancer:** "If I explained it to people, they always wanted an update. And somebody always saw an ad on TV and wanted to know why I wasn't taking that drug. It hit a point of ridiculousness, so I just decided to go cold with them and make it very easy, because it's draining and time-consuming to keep explaining. When I'm with my friends, I just want them to have fun, and if I ever want to talk about it, I want to be the one to control it. Instead, the MBC support group I attend twice monthly has given me the venue to discuss and share more of the physical, mental and emotional issues of MBC among women facing the same challenges."

**On leaving a legacy:** "I've always been an upbeat person, and through this I've tried to continue to be positive and hopeful, yet

» **SUSAN SWANSON,** right, spends time with a friend.

realistic, as well. People who talk to me or see me carrying on with my regular life have told me I'm an inspiration and that they look to me for my courage and strength. In a way, it's kind of a legacy that I can leave. You can leave a couple of kinds of legacies: an advocacy legacy and a role model legacy. I hope to do both."

## *Kirby Lewis*

Looking back at the night in 2012 when he found a lump in his chest and knew in his gut that it was breast cancer, Kirby Lewis easily finds the silver lining: When he underwent preliminary exams for mastectomy, doctors found that he needed open-heart surgery.

"I tell a lot of people that breast cancer saved my life," says the married 60-year-old resident of West Virginia, who received a diagnosis of stage 2 disease in March 2012 and of metastatic disease in March 2016. "My oncologist and thoracic surgeon and cardiologist all agree that, had I not found the breast cancer, the heart issues would not have been detected, and I would have probably just been walking down the street one day and that would have been it. So, I feel like, in a way, it was quite a blessing."

**On adjusting to life with metastatic disease:** "My wife's first words to me were 'How are we going to plan anything ever again?' It ate at my core, but my answer was simply 'What did we do yesterday?' Because, yes, it's not a good prognosis, but you just move on. Plans sometimes are going to be interrupted, but it comes back to my core belief that we don't get to pick and choose what happens to us. We just get to learn how to live with it."

**On being shunned as a man with breast cancer:** "I was at a conference in Philadelphia, hosted by a patient advocacy organization, at a group class teaching how to become a patient advocate in the metastatic breast cancer community, and a woman came up to me and got right in my face — not knowing that I have metastatic breast cancer — pointing her finger and hollering. She said, 'You have no right to be here.' It really took the wind out of my sails and made me very anxious, because I was trying to do the best I could."

**On helping others:** "Five months after the advocacy group class, we had lost five of the 28 members. I'm sure everybody was wondering: 'Am I going to be next?' So, I contacted everybody and said, 'If you're feeling like I am, we need to talk.' I couldn't live with the thought that somebody might be so depressed because of this that they would maybe consider taking their own life. That experience was the catalyst that pushed me to say, 'I want to go back to school for a master's in psychology, and this is what I want to focus on.' "

## *Susan Swanson*

Susan Swanson's diagnosis of stage 1 breast cancer in 2012 came at a particularly inopportune time. "My mom had died three weeks earlier and we had sold our house three days prior," recalls the 56-year-old Sea Girt, New Jersey, resident, who received a diagnosis of metastatic breast cancer in 2014. "My twins were graduating from high school and my oldest from college. We were packing, and my husband was going back and forth trying to get our kids through school while I was trying to figure out what had happened to me and where I was going to be treated. It was a very challenging time."

**On self-advocating:** "You don't know what questions to ask because you don't even know what the words mean, so you have to get up to speed quickly. I read and talked to anybody I could. I met a woman from a pharmaceutical company through a friend of a friend, and she ended up being this amazing source of information, so I tell people they have to connect and network."

**On handling the emotions that come with cancer:** "I don't see my therapist much anymore, but at the time, he got me out of my funk. When we moved, I lost my support network. I used to say to my husband, 'If I died today and you weren't here, no one would even know I was in the house.' What has really saved me is walking. I probably walk five to seven miles a day, and it's what keeps me sane. It has helped my side effects, and mentally, it keeps me in a good place." »

PHOTOS COURTESY OF ATHENEX

**KIRBY LEWIS** and **STEPHANIE WALKER** research an issue together.

**On advice for other patients:** "People need to have a good network around them if they possibly can, and sometimes that means losing friends. Some people can't handle it, and that's OK. If you don't have support, you've got to find it on social media. I always reach out to Living Beyond Breast Cancer because they're a trusted source and always seem to have the information I need. You can't think you're going to walk this walk alone. It's a very lonely walk."

### *Stephanie Walker*

When Stephanie Walker first heard that her mammogram looked abnormal, she repeatedly hung up on the person delivering the news. "I was not being rude, but I kept thinking she had the wrong person, because I had been doing this for over 25 years and never had an abnormal mammogram," says Walker, 61, of Tarboro, North Carolina.

After more tests, the married mother of adult children and career nurse received a call on July 9, 2015, confirming that she had breast cancer; it was determined to be metastatic two weeks later. "I rolled over and went back to sleep because I had to work that night," recalls Walker, who has had no evidence of disease since 2016. "When I got up, I thought, 'Man, that was a wack dream,' until I turned my phone over and saw that I did have that conversation."

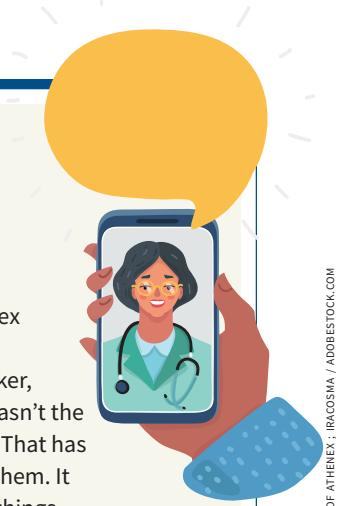
**On having cancer after working as a critical and hospice care nurse:** "When I worked in pediatrics, the children had leukemias and Hodgkin's disease and multiple brain tumors, (and the way they handled their) chemotherapy and side effects helped me through my chemo. When I wanted to feel really crappy and not do anything or mope around or cry, I would always think about those little kids who would get chemo, throw up, their hair would fall out, and all they would want me to do was to set them on their little IV pole and roll them to the playroom. I thought, 'If those kids can do it, why can't I?'"

**On retiring because of a blood clot and ministroke:** "That news of having to stop working was worse than a cancer diagnosis. It still makes me tear up. Being a hospice nurse is a calling, and I loved what I did. Cancer takes everything that you've ever known; it pulls the rug out from under you. You have a job on Tuesday and find out that you don't have a job on Wednesday, and by Friday, you have no insurance. It was devastating."

**On handling financial challenges:** "Cancer not only wrecks your body, it financially ruins you. My husband was retired, so he was getting Social Security and Medicare, but I had nothing. I didn't qualify for Medicaid. We finally got food stamps, but it was hard. I was encouraged to file for permanent disability through Social Security, and that was approved in less than two weeks. But during the five months that I got nothing, every day, for eight hours a day five days a week, it was my job to find organizations that could help pay our bills. Tons came through for me, and I found organizations that other people didn't know, so I compiled a lengthy list. What I do now is share those resources."

## Finding Support Online

*Isolation, anxiety, depression: These concerns are common among people with metastatic breast cancer.*



**ATHENEX ONCOLOGY, WHICH** is testing a drug to treat metastatic breast cancer, also wants to help patients cope emotionally. That's why it launched Facing MBC Together, a website that shares the stories of nine people living with metastatic breast cancer and offers patients an opportunity to create personalized pages for sharing news and photos and receiving support from family and friends. The website and a Facing MBC Together app "give voice to the roller coaster of emotions people experience with MBC," Athenex writes on the site.

"It has helped me a lot," says Stephanie Walker, whose story appears on the site. "I realized I wasn't the only one going through dark times when I did. That has allowed me to address them and to deal with them. It makes anybody feel a lot better to unload the things that are on their heart and on their mind."

Visit **facingmbctogether.com** to learn more.

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# Simple Test Helps Predict Recurrence

*Blood-based biomarkers reliably indicate if disease will return after treatment for triple-negative breast cancer, new findings show.* By CONOR KILLMURRAY

**DNA FRAGMENTS AND CELLS** from tumors, which can circulate in the blood of women treated with chemotherapy and surgery for stage 1, 2 or 3 triple-negative breast cancer (TNBC), are major indicators of anticipated disease recurrence, according to data recently published in *JAMA Oncology*.

TNBC is not fueled by hormones or the protein HER2. For about one-third of patients, chemotherapy followed by surgery will eradicate it (called a complete pathological response), whereas the other two-thirds will have residual disease that puts them at high risk of relapse.

Researchers hypothesized that circulating tumor DNA (ctDNA) and circulating tumor cells (CTCs), which are shed from tumors and then move through the blood, can help detect any cancer that may remain after treatment but elude standard imaging and other tests. Finding this so-called minimal residual disease could help oncologists assess a patient's likelihood of recurrence. Detection of ctDNA and CTCs was independently associated with TNBC recurrence, the researchers found, making this a marker to use on its own.

> **"The discovery and utilization of circulating tumor DNA and circulating tumor cells to better predict recurrence … has provided a huge step forward toward more certainty for treatment decision-making."** — MARY LOU SMITH, co-founder of the Research Advocacy Network

"A diagnosis of triple-negative breast cancer is very scary to the patient. The discovery and utilization of circulating tumor DNA and circulating tumor cells to better predict recurrence … has provided a huge step forward toward more certainty for treatment decision-making," Mary Lou Smith, co-founder of the Research Advocacy Network, said in a press release. "This significant scientific advancement will help personalize treatments for those still battling residual disease."

The study included 196 women with early-stage TNBC who had significant residual disease after chemotherapy and surgery. The women had been part of BRE12-158, a phase 2 randomized clinical trial that assigned participants to treatment based on either their cancer's genomics or physician's choice, which could simply entail observation.

The researchers looked at distant disease-free survival, disease-free survival and overall survival. Those measurements relate to the length of time from the start of treatment until disease spreads or grows and until death.

In all three areas, detection of ctDNA was associated with inferior outcomes. At 24 months from the completion of post-chemotherapy surgery, the probability that disease had not spread was 56% for patients who were positive for ctDNA compared with 81% for those who were negative. Similar trends were observed when combining ctDNA and CTCs. At 24 months, the probability that disease had not spread was 52% for patients who were both ctDNA- and CTC-positive. In contrast, those who were negative in both categories had an 89% likelihood of being free of distant disease spread at 24 months.

"Since uncovering these findings in women diagnosed with triple-negative breast cancer, we have learned that others are applying this stratification of patients based on ctDNA and CTCs to other cancers, including breast and colon," said the study's lead author, Milan Radovich, who holds a postdoctoral degree and is co-director of the Indiana University Health Precision Genomics Program, in the release.

Circulating tumor DNA was sequenced using the FoundationOne Liquid CDx assay, a minimally invasive cancer DNA analysis. The authors suggested that tests such as this could identify patients with a high likelihood of recurrence, giving them the opportunity to undergo targeted treatments chosen based on the genetic makeup of the tumor cells.

"This is an important step forward in the treatment of women with triple-negative breast cancer, who have not had much scientific evidence to point to — until now — for treatment of their disease," said Dr. Bryan P. Schneider, the study's senior author and the Vera Bradley Chair of Oncology at Indiana University School of Medicine, in the release. "We are going to use these findings and continue on until we find a treatment that works for each individual woman. This effort … involves finding the best way to (not only) kill cancer but (also) minimize side effects."

# Helping Patient Navigators Help You

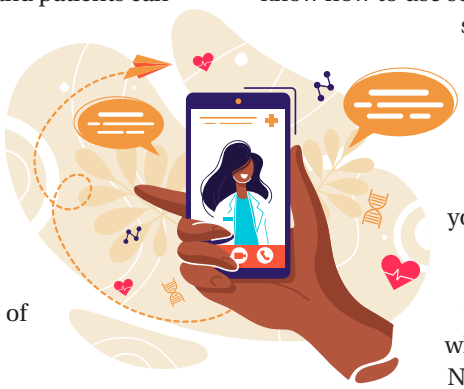
*Susan G. Komen Greater New York City, in partnership with CURE®, hosted its fourth annual Patient Navigation Town Hall to help these health care professionals overcome COVID-19-related obstacles.* By KRISTIE L. KAHL

**PATIENT NAVIGATORS PLAY** a crucial role in the management of those with breast cancer, guiding individuals through the health care system and helping them communicate with care teams.

The most recent challenge for these professionals involves navigating uncharted territory with the emergence of the COVID-19 pandemic and everyday use of telemedicine.

Partnering with *CURE®*, Susan G. Komen Greater New York City addressed these issues at its fourth annual Patient Navigation Town Hall. Its theme: "Empowering and Mobilizing Our Patient Navigation Workforce." At the virtual meeting, held June 23, oncologists, community health workers and patient navigators gathered to discuss the pandemic's impact on the cancer landscape and how professionals and patients can handle those factors moving forward.

During the event, *CURE®* spoke with one of the meeting's steering committee members, Dr. Jennifer Klemp, a professor and director of cancer survivorship at the University of Kansas Medical Center, about addressing the pandemic and racial disparities, as well as using telemedicine to help patients and health care workers shape the future of breast cancer care.



**Q: *CURE®*: How can navigators implement appropriate strategies in the new reality of the COVID-19 pandemic?**

**A: Klemp:** You need innovation and practicality together to really make some solutions. We need to be surveying both our teams and our patients as to what they can and can't do. For example, technology is new for a majority of our patients in this capacity, so how do we build those quick-start guides and help them? How do we help them leverage technology? Because that's not going away.

And then how do we continue to provide needs-based professional education and push in a bidirectional conversation? What is needed? How do we push that education out to the field? There needs to be this ability to have a conversation that happens every day and is relevant.

**Q: How far would you say we've come with technology in breast cancer care, and what can we look forward to?**

**A:** Technology has accelerated like a rocket ship, and the reality is, that's not going away. We need to streamline our use of technology and figure out the balance. We need to maximize the security of technology. We need to empower our aging workforce in oncology. How do we streamline some of the onboarding and quick-start it so that people don't feel so overwhelmed and shut down? We need to develop digestible information that is reliable.

**Q: How can we work to negate racial disparities in the early diagnosis of cancer and help patients with breast cancer navigate their care? Can we offer any resources to help bridge this gap?**

**A:** Most of the states that I interact with are underusing screening programs. So, how do we empower our local clinics, community providers or primary care providers to know how to use screening programs to get patients in for screening? How do they use risk-stratified screening? When do they start? How often do they screen?

There is some conflicting messaging, depending on if you're getting screening recommendations from your professional organization or from the U.S. Preventive Services Task Force. The important part is that we need to better use existing programs. We need to identify where those gaps and limitations are. Navigation can really help us fill in those gaps. Many of those are underused because people don't know about them. People don't know how to access them, and they don't know how to use a lot of the programs that are out there.

**Q: What do you think is next, and where do we go from here for patient navigators?**

**A:** There is a need for education and scope of practice, as well as the need to come together to continue the conversation, because there will be speed bumps. That could be COVID-19. It could be changes in someone's insurance status. There are lots of barriers that happen. We have to be able to pivot as a health care delivery system for patients.

My two biggest themes are that we need to be better at having expectation management — being transparent with roles, responsibilities and expectations. Then we need to work on how we communicate and use that team and those resources so that we can identify those gaps and work toward common goals.

We have a lot of work to do, but we have a lot of key stakeholders, and we're bringing them together.

ANNA / ADOBESTOCK

# CANCER

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# Accelerating Radiation

*Just one week of radiation therapy after surgery for early-stage breast cancer is as safe and effective as longer courses, researchers report.* By BETH FAND INCOLLINGO

**RADIATION THERAPY FOR** early-stage breast cancer once stretched out over many weeks; the current international standard involves higher doses spaced out over three weeks. Now a team of researchers says that giving even higher doses of radiation across only five sessions in select cases, completing the therapy in one week, is equally effective.

In addition, the scientists found the safety profile of the weeklong treatment to be as good as that of the standard three-week course, which is administered in 15 sessions.

The findings, based on five-year results of the randomized phase 3 FAST-Forward trial conducted in the United Kingdom, were published in *The Lancet*.

After surgery, many patients with early breast cancer undergo whole- or partial-breast radiation therapy to help prevent recurrence. The radiation is directed at the whole breast or, after mastectomy, the chest wall. In many countries, hypofractionated, or accelerated, radiation treatment has replaced longer courses of therapy for most patients, according to the study's authors. Sometimes a supplemental, or boost, dose of radiation to the conserved breast follows this treatment.

Patients may prefer a shorter radiation schedule because it involves fewer trips to the clinic and is more convenient. In addition, an abbreviated course may be beneficial during the COVID-19 pandemic because it limits opportunities for exposure to the virus. "The one-week schedule has major benefits over the three-week or five-week regimens in terms of convenience and cost for patients and for health services globally," the researchers wrote.

Conducted at 97 centers, the study included adults who had recently undergone lumpectomy or mastectomy for early-stage invasive carcinoma of the breast. Tumor size had to be 5 centimeters or less, and the cancer could have spread to no more than three lymph nodes. Patients who were receiving hormonal therapy for breast cancer at the time they received radiation were permitted to participate. Enrolled between Nov. 24, 2011, and June 19, 2014, the 4,096 participants were divided into three roughly equal groups to receive one of three regimens:

- 40 gray (Gy) given in 15 treatments, or fractions, of 2.67 Gy over three weeks.
- 27 Gy in five treatments of 5.4 Gy over one week.
- 26 Gy in five treatments of 5.2 Gy over one week.

Participants who had undergone lumpectomy were eligible to receive a boost dose to their conserved breast following radiation therapy.

The study's main goal was to measure the rate of local tumor recurrence in the originally affected breast five years after radiation therapy, with the rate of relapse in the weeklong treatment groups not significantly exceeding the 2% recurrence rate expected over five years of follow-up after the standard 40-Gy, 15-treatment dose.

At a median follow-up of nearly six years, relapse had occurred in 31 patients in the 40-Gy group, 27 in the 27-Gy group and 21 in the 26-Gy group, giving five-year recurrence rates of 2.1%, 1.7% and 1.4%, respectively. Statistically, the results were considered similar. Relapse was more likely to arise in patients who had higher-grade primary tumors, the authors found.

At five years after treatment, changes at the radiation site (scarring or hardening) were observed in 98 of 986 patients (9.9%) who received 40 Gy of radiation, 155 of 1,005 (15.4%) who got 27 Gy, and 121 of 1,020 (11·9%) treated with 26 Gy. The most common side effect was breast shrinkage, which happened in 5.5%, 8.2% and 6.8% of people treated with 40, 27 and 26 Gy, respectively. Breast distortion was also more likely in those who received 27 Gy compared with 26 Gy.

"Patient and photographic assessments showed higher risk of normal tissue effects for 27 Gy versus 40 Gy but not for 26 Gy versus 40 Gy," the authors wrote. In addition, although they hypothesized that the heart should not be more sensitive than other soft tissues to radiation intensity, the researchers noted that longer follow-up is needed to draw conclusions about the effect of the radiation schedules on cardiac outcomes; they plan to conduct patient follow-up until at least 10 years after treatment. There were no deaths due to radiotherapy, and there was no difference in the rate of secondary cancers between the groups.

"(Giving) 26 Gy in five fractions over one week is noninferior to the standard of 40 Gy in 15 fractions over three weeks for local tumor control and is as safe in terms of normal tissue effects up to five years for patients prescribed (postsurgical) local radiotherapy after primary surgery for early-stage breast cancer," the researchers concluded. "The consistency of FAST-Forward results with earlier hypofractionation trials supports the adoption of 26 Gy in five daily fractions as a new standard for women with operable breast cancer requiring (postsurgical) radiotherapy to partial or whole breast."

ROMASET / ADOBESTOCK

# Family Matters

*How does a metastatic cancer diagnosis affect families, especially children? CURE® spoke with Kate Watson, a patient ambassador for METAvivor, about the tricky balance of protecting and empowering kids.* By KRISTIE L. KAHL

**A PATIENT RECEIVING A** diagnosis of metastatic breast cancer might immediately worry about how the disease will affect their family dynamics. Among the many challenges: how to discuss the diagnosis with children of any age.

In partnership with METAvivor, a group dedicated to research, awareness and support focused on the needs of women and men living with metastatic breast cancer, *CURE*® spoke with patient ambassador Kate Watson about how a diagnosis of breast cancer that has spread to distant parts of the body affects everyone in the family. She also offered advice for parents facing this situation.

**Q: *CURE*®: What are some ways that a breast cancer diagnosis makes an impact on the whole family?**

**A: Watson:** First you're shocked that this is the diagnosis that you're facing. There's fear, there's anxiety. And you might be the one who's going through all the physical changes and the treatment, but that doesn't mean that it's not weighing heavily on your family — your parents, your partner, your spouse, your kids. From the get-go, it's important to open the lines of communication and make sure that everybody is on board with … knowing that they're going to be sharing how they're feeling openly and letting the patient drive how the conversations will go. But the patients also have to be respectful that this has an impact on the whole family's life.

**Q: Do you have any advice on how to have conversations with children about a metastatic breast cancer diagnosis?**

**A:** When I received my diagnosis, my daughters were 2 and 4. I really struggled with (these questions): What's the right way to tell them? What's too much? What's too little? It's going to be a lifetime experience for them, but at the same time, they don't really know any different when they're that young. So, my first piece of advice would be to wrap your head around what the likely treatment plan will be before you even talk to your kids. Are you going to be on a type of drug where you'll lose your hair? Are you going to have surgeries that have a long recovery period? Once you know what it is that you need to explain to your kids, you can break it down into what's age-appropriate, because you don't want to scare them into thinking that Mom's going somewhere tomorrow and that this is imminent; but it is a lifelong disease. So, my kids were involved. When I started to lose my hair, we had a hair-shaving party to make it a little less scary. I didn't want to walk into the house one day and all of a sudden be bald, with my 2-year-old having no idea about what was going on.

I would suggest that if you're going to treatment, use the same caregivers so you continue to make the routine as normal as possible in a very abnormal situation. That was helpful for us.

**Q: Can you recommend any particular resources?**

**A:** Have a conversation with your hospital system's oncology social worker. That was where I first started when searching for programs for my kids. When something arose while I was going through treatment, I was often in touch with them to ask for their advice: How do I frame this conversation with a kid who's this age?

It's also difficult because, when you're raising kids, you never know if the behavior that they're exhibiting is because Mom has cancer or if it's just a normal kid thing. That's what I found difficult and kept going over in my head: Is this cancer related? The social workers in the hospital system were really great at connecting me with local resources. That helped me think about the way that I was going to talk through what was happening before I actually sat down with my children.

**Q: Do you have any advice for other parents?**

**A:** The (experts I consulted) made it very clear not to say that Mom's going for medicine. You don't want a kid to think that anytime they come down with an ear infection or cold or flu, taking over-the-counter stuff is the same thing. This is not the same as what Mom is taking.

And just like every person is different, every cancer is different. So, when you are out and about and see somebody who looks sick, that cancer is different from Mom's or Dad's cancer. You need to keep them from fearing the absolute worst from the day you get the diagnosis. C

***This interview has been edited for clarity.***

PHILIP STEURY / ADOBESTOCK

# Overcoming Social Barriers

*Helping underserved women at the community level can be a crucial step toward reducing deaths from late-stage breast cancer. A grassroots initiative in Florida aims to contribute to that change and inspire the formation of similar groups.* By NANCY G. BRINKER

**THIS MONTH MARKS** the 35th anniversary of Breast Cancer Awareness Month, the first organized effort to bring widespread attention to this devastating disease. When the annual recognition started, 1 in 11 women received the diagnosis, and there was no national organization dedicated to representing patients with breast cancer; you could not even say the word "breast" in mainstream media. When my sister Suzy was dying from breast cancer in 1980, I promised her I'd do everything I could to stop the disease and the social stigma that surrounded it, even if it took the rest of my life.

We've come a long way in 35 years, raising billions of dollars for breast cancer research and awareness. But this year, our nation is reeling from a global pandemic, economic downturn and rising racial tensions — all of which have amplified barriers to health care and further exposed the troubling health disparities among at-risk and underserved populations across the country.

As someone who has devoted her life to fighting for better and more accessible health care for women, I believe that systemic change in how we prevent and treat breast cancer is necessary now more than ever, as racial disparities in mortality from the disease continue to persist. Let's look at the facts.

NANCY G. BRINKER

According to the Centers for Disease Control and Prevention, breast cancer incidence rates between 1999 and 2013 were higher among Black women younger than 60 compared with White women in general. Additionally, Black women were 40% more likely to die from breast cancer, due at least in part to lack of early diagnosis, compared with White women.

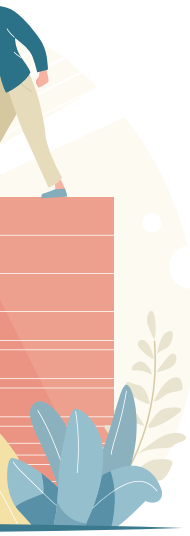
The persistence of breast cancer disparities is not just a medical issue. In fact, the growing number of disparities in breast cancer outcomes is a result of social determinants that desperately need to be addressed. This includes poor access to care and health education, a fragmented system with minimal public hospitals, lack of health insurance and financial resources, transportation and language barriers, and culturally inadequate service providers.

> **"The persistence of breast cancer disparities is not just a medical issue. In fact, the growing number of disparities in breast cancer outcomes is a result of social determinants that desperately need to be addressed."**
>
> — NANCY G. BRINKER

The years I spent building Susan G. Komen and our extensive network of results-oriented affiliates offered me invaluable insights into both the assets and challenges of running a strong, nationally focused organization. Although we made tremendous strides in resource acquisition, advocacy and cause marketing among public and private sector allies, I also learned that, in other respects, a large, national charity is not always the optimal solution for providing personalized treatment to the women who need it most. It was on this premise that I co-founded the Promise Fund of Florida (promisefundofflorida.org), a grassroots and community-driven organization that aims to reduce deaths from late-stage breast and cervical cancer through early detection, diagnosis and treatment for underserved women in Palm Beach County.

At the Promise Fund, every dollar we raise from the community stays in the community. We are mobilizing our mission by developing a continuum-of-care delivery model that guides patients through the health care system, ensuring quality completion of their care and alleviating costs and other barriers to treatment, such as transportation and child care. The Promise Fund

PHOTO OF BRINKER COURTESY OF THE PROMISE FUND OF FLORIDA; VECTOR ART: ZAIE / ADOBESTOCK.COM



provides health education and support services; navigation for breast and cervical health guided by culturally skilled navigators; and screenings, diagnostics and treatment at free or reduced cost through an established network of providers. Unlike the traditional continuum of care for breast cancer, which includes four components — screening, diagnosis, treatment and survivorship — the Promise Fund's continuum is designed to better help our community and break through social barriers to ensure we are meeting the needs of the underserved; specifically, Palm Beach County residents with a household income at 200% of the federal poverty level or lower. We have accomplished this by partnering with the local health care district, an independent taxing district that provides an array of health care services, and a federally qualified health care center — a public-private partnership that allows for the expansion of services in women's health.

The Promise Fund currently serves Palm Beach County, but the need we are addressing exists in every community across the nation. My goal is for the Promise Fund's continuum-of-care model to serve as a foundational framework that can be replicated nationwide to stop the progression of this horrible disease.

A failure to institute a new model of care for our underserved communities will halt the progress we've made over the past 3½ decades in reducing breast cancer incidences. So, this October, as we wear pink to support Breast Cancer Awareness Month, I encourage you to learn more about how your community can more effectively improve and expand breast cancer care, bringing health equity and social justice to all.

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***Nancy G. Brinker**, founder of Susan G. Komen, is a 2009 Presidential Medal of Freedom recipient and an author whose journey began with a promise to her dying sister that she would do everything possible to end the shame, pain, fear and hopelessness caused by breast cancer. In 2018, Brinker spearheaded creation of the Promise Fund of Florida, a nonprofit organization that aims to improve outcomes and reduce deaths from breast and cervical cancers in Palm Beach County. In August 2020, she was selected as one of USA Today's "100 Women of the Century" for her lifetime of volunteerism, public service and advocacy in the fight against breast cancer.*

**SHARE YOUR STORY!**

Whether you are a patient, survivor, caregiver or health care provider, we want to publish your stories about cancer and the people, places and moments of the experience. They can be funny, poignant or practical. Send stories to **editor@curetoday.com,** or share on our Facebook page at **facebook.com/curemagazine**. Submissions should be no more than 600 words and include your name, phone number and email.

# Flat-Out Determined

*One woman recounts her decision to forgo reconstruction after a bilateral mastectomy, joining women all over the world in advocating for the choice of a smooth, breastless chest.* By MARISSA HOLZER

**MARISSA HOLZER** is a 40-something flattie in sunny SoCal living with metastatic breast cancer, her boyfriend (and high school sweetheart) and her not-so-mini Schnauzer, Heidi. She enjoys reading, stress baking and roller skating. She hopes to inspire others with her dry humor and zest for life.

**IN THE SUMMER OF 2015,** I turned 40 and became a "flattie" just days after my milestone birthday. At that time, I was still fairly new to breast cancer and had no idea what to expect.

I am a smaller person and always have been. I met with the surgeon, and I can still remember our conversation about my size and not having enough skin to reconstruct; he said he could use skin from other parts of my body. I had friends tell me I should gain weight, but that wouldn't help; it wouldn't create extra skin.

Turns out my oncologist was the one running the show, not the surgeon. Because I was metastatic, he did not want me to have reconstruction. His concern was that my recurrences would be harder to see if I had reconstructive surgery. The surgical oncologist and the oncologist came to an agreement: mastectomy without reconstruction.

If I was going to have a mastectomy without reconstruction, I wanted both breasts removed, which I was told was OK at the beginning of the process. But, about a week before surgery, I was told that they would be doing a unilateral mastectomy. I felt that I would be much happier with both breasts removed, even though I was told this wouldn't increase my survival.

For symmetry and the hopes that I wouldn't have to go through any other surgeries, this was my choice. I had to do a little bit of letter writing and cajoling, but it was decided that I could have a double mastectomy. I was unknowingly advocating for myself and learning to speak up. So … back to the surgeon to figure this all out.

I was a little nervous at first because the surgeon was younger than I am and I didn't know him. I told him (OK, more like pleaded with him), "Just make my scars flat, even and straight. Please just make it look nice."

> **"My young surgeon did exactly as I asked, aesthetic flat closure, even before that was considered a reconstructive option."**
> — MARISSA HOLZER

Little did I know, there are surgeons out there who leave extra skin, called a skin-sparing mastectomy, just in case the patient decides later to reconstruct. Imagine waking up like that. I've seen pictures, and it's not pretty. I was one of the lucky ones. My young surgeon did exactly as I asked, aesthetic flat closure, even before that was considered a reconstructive option.

Now, five years later, women all over the world are advocating for flat closure and starting nonprofits to put flat on the menu and make it a viable choice for mastectomy. These organizations include Flat Closure Now, Not Putting on a Shirt, Flat Retreat and Flatties Unite.

Some of these women hosted a ball, which I attended, and it happened to be the last normal event I attended before the COVID-19 pandemic. These women make me proud to be a flattie. How inspiring it was that night to be surrounded by so many who had been through the process of going flat and still looked and felt beautiful!

If I had to do it all over again, I would still go flat and make it a double. C

ILLUSTRATION BY RAY PELESKO; VECTOR ART, CIENPIESNF / ADOBESTOCK

# We are helping to move mountains for myeloma patients

**Moving Mountains for Multiple Myeloma**, (MM4MM), is an award-winning collaboration between CURE Media Group and the Multiple Myeloma Research Foundation (MMRF) which raises funds and awareness for myeloma research.

Since its inception in 2016, Moving Mountains for Multiple Myeloma teams have climbed Mt. Kilimanjaro, hiked the Grand Canyon, summited Mount Fuji, trekked the Inca Trail to Machu Picchu, reached Everest Base Camp and conquered Iceland's many landscapes. Our team members have raised over $2.9 million, 100% of which goes directly to the MMRF, which spearheads and funds critical myeloma research. These amazing journeys are captured via blogs, social media posts, and video.

**Due to COVID-19 the 2020 program has shifted - all 2020 teams will continue fundraising and training this year and will hike in early 2021.**

Patients, caregivers, myeloma loved ones, and others impacted directly by multiple myeloma will take on the Alaskan Kenai Peninsula, summit Mount Washington, explore the terrain of Greenland, and more! They will raise funds for multiple myeloma research and demonstrate that the advancements being made in recent years, led by the MMRF, are helping patients live longer with a higher quality of life than ever before.

To learn more and join a MM4MM team visit:
**MovingMountainsForMultipleMyeloma.com**

To learn more about the MMRF, visit **TheMMRF.org**

## LEARN MORE ABOUT OUR CLIMBS!

### 2020 TREKS IN 2021!

**Mount Washington Hike**
July 9-12, 2021

**Greenland Trek**
To be determined

**Alaskan Kenai Peninsula Trek**
June 20-26, 2021

**Kilimanjaro Trek**
March 6-16, 2021

**Machu Picchu Trek**
May 1-11, 2021

**New 2021 hikes & dates coming soon!**
Email **teammanager@themmrf.org** to get on our waitlist!

MOVING MOUNTAINS for MULTIPLE MYELOMA

MMRF cure Bristol Myers Squibb gsk SANOFI GENZYME


FACING MBC
TOGETHER

## Introducing a new support and educational program for people living with metastatic breast cancer (MBC)

Facing MBC Together was created *with* the MBC community, *for* the MBC community. It gives a voice to the roller coaster of emotions people experience while living with MBC. On FacingMBCTogether.com, you can find stories, resources, and a mobile app that addresses isolation and provides meaningful support for people diagnosed with MBC.

**Connect to a world of support**

Visit FacingMBCTogether.com to watch powerful stories and find helpful resources

Create your own support community at FacingMBCTogether.app

Brought to you by Athenex oncology