

# CONQUER™

the patient voice™



## BREAST CANCER

special issue series

IN THIS ISSUE: an interview with Jamie Larson of the Young Survival Coalition

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**AONN** Official patient magazine of  
Academy of Oncology  
Nurse & Patient Navigators  
— Paid for in part by AONN+ Membership Dues —

For those facing **high-risk early-stage triple-negative breast cancer (TNBC)**,

# START WITH KEYTRUDA + CHEMOTHERAPY

**The first and only immunotherapy used with chemotherapy before surgery, then alone after, to treat high-risk early-stage TNBC.**

KEYTRUDA is a prescription medicine used to treat a kind of cancer called triple-negative breast cancer (TNBC). KEYTRUDA may be used with chemotherapy medicines as treatment before surgery and then continued alone after surgery when you have early-stage breast cancer, **and** are at high risk of your breast cancer coming back.

## IMPORTANT SAFETY INFORMATION

KEYTRUDA is a medicine that may treat certain cancers by working with your immune system. KEYTRUDA can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become severe or life-threatening and can lead to death. You can have more than one of these problems at the same time. These problems may happen any time during treatment or even after your treatment has ended.

**Call or see your health care provider right away if you develop any signs or symptoms of the following problems or if they get worse. These are not all of the signs and symptoms of immune system problems that can happen with KEYTRUDA:**

- **Lung problems:** cough, shortness of breath, or chest pain.
- **Intestinal problems:** diarrhea (loose stools) or more frequent bowel movements than usual; stools that are black, tarry, sticky, or have blood or mucus; or severe stomach-area (abdomen) pain or tenderness.
- **Liver problems:** yellowing of your skin or the whites of your eyes; severe nausea or vomiting; pain on the right side of your stomach area (abdomen); dark urine (tea colored); or bleeding or bruising more easily than normal.
- **Hormone gland problems:** headaches that will not go away or unusual headaches; eye sensitivity to light; eye problems; rapid heartbeat; increased sweating; extreme tiredness; weight gain or weight loss; feeling more hungry or thirsty than usual; urinating more often than usual; hair loss; feeling cold; constipation; your voice gets deeper; dizziness or fainting; changes in mood or behavior, such as decreased sex drive, irritability, or forgetfulness.
- **Kidney problems:** decrease in the amount of your urine; blood in your urine; swelling of your ankles; loss of appetite.
- **Skin problems:** rash; itching; skin blistering or peeling; painful sores or ulcers in your mouth or in your nose, throat, or genital area; fever or flu-like symptoms; swollen lymph nodes.
- **Problems can also happen in other organs and tissues.** Signs and symptoms of these problems may include: chest pain; irregular heartbeat; shortness of breath; swelling of ankles; confusion; sleepiness; memory problems; changes in mood or behavior; stiff neck; balance problems; tingling or numbness of the arms or legs; double vision; blurry vision; sensitivity to light; eye pain; changes in eyesight; persistent or severe muscle pain or weakness; muscle cramps; low red blood cells; bruising.
- **Infusion reactions that can sometimes be severe or life-threatening.** Signs and symptoms of infusion reactions may include chills or shaking, itching or rash, flushing, shortness of breath or wheezing, dizziness, feeling like passing out, fever, and back pain.
- **Rejection of a transplanted organ.** Your health care provider should tell you what signs and symptoms you should report and they will monitor you, depending on the type of organ transplant that you have had.
- **Complications, including graft-versus-host disease (GVHD), in people who have received a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic).** These complications can be serious and can lead to death. These complications may happen if you underwent transplantation either before or after being treated with KEYTRUDA. Your health care provider will monitor you for these complications.



Talk to an oncologist about KEYTRUDA  
[keytruda.com/high-risk-early-stage-TNBC](https://www.keytruda.com/high-risk-early-stage-TNBC)

If you need help with medication costs,  
call 855-257-3932 or visit [keytruda.com](https://www.keytruda.com)

### IMPORTANT SAFETY INFORMATION (continued)

**Getting medical treatment right away may help keep these problems from becoming more serious.** Your health care provider will check you for these problems during treatment with KEYTRUDA. They may treat you with corticosteroid or hormone replacement medicines. They may also need to delay or completely stop treatment with KEYTRUDA if you have severe side effects.

**Before you receive KEYTRUDA, tell your health care provider if you** have immune system problems such as Crohn's disease, ulcerative colitis, or lupus; have had an organ transplant or have had or plan to have a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic); have had radiation treatment in your chest area; have a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome.

If you are pregnant or plan to become pregnant, tell your health care provider. KEYTRUDA can harm your unborn baby. If you are able to become pregnant, you will be given a pregnancy test before you start treatment. Use effective birth control during treatment and for at least 4 months after your final dose of KEYTRUDA. Tell them right away if you think you may be pregnant or you become pregnant during treatment with KEYTRUDA.

Tell your health care provider if you are breastfeeding or plan to breastfeed. It is not known if KEYTRUDA passes into your breast milk. Do not breastfeed during treatment with KEYTRUDA and for 4 months after your final dose of KEYTRUDA.

**Tell your health care provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Common side effects of KEYTRUDA when used alone include feeling tired; pain, including pain in muscles; rash; diarrhea; fever; cough; decreased appetite; itching; shortness of breath; constipation; bones or joints and stomach-area (abdominal) pain; nausea; and low levels of thyroid hormone.

Common side effects of KEYTRUDA when given with certain chemotherapy medicines include feeling tired or weak; nausea; constipation; diarrhea; decreased appetite; rash; vomiting; cough; trouble breathing; fever; hair loss; inflammation of the nerves that may cause pain, weakness, and paralysis in the arms and legs; swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina; mouth sores; headache; weight loss; stomach-area (abdominal) pain; joint and muscle pain; and trouble sleeping.

These are not all the possible side effects of KEYTRUDA. Talk to your health care provider 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](https://www.fda.gov/medwatch) or call 1-800-FDA-1088.

**Please read the adjacent Important Information About KEYTRUDA and discuss it with your doctor.**

Having trouble paying for your Merck medicine?  
**Merck may be able to help. [www.merckhelps.com](https://www.merckhelps.com)**

**KEYTRUDA**<sup>®</sup>  
(pembrolizumab) Injection 100 mg

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US-0BR-00940 02/22



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**Important Information About KEYTRUDA® (pembrolizumab) injection 100 mg.** Please speak with your healthcare professional regarding KEYTRUDA (pronounced key-true-duh). Only your healthcare professional knows the specifics of your condition and how KEYTRUDA may work with your overall treatment plan. If you have any questions about KEYTRUDA, speak with your healthcare professional. **Rx ONLY**

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

KEYTRUDA is a medicine that may treat certain cancers by working with your immune system. KEYTRUDA can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become severe or life-threatening and can lead to death. You can have more than one of these problems at the same time. These problems may happen anytime during treatment or even after your treatment has ended.

**Call or see your healthcare provider right away if you develop any new or worsening signs or symptoms, including:**

#### **Lung problems**

- cough
- shortness of breath
- chest pain

#### **Intestinal problems**

- diarrhea (loose stools) or more frequent bowel movements than usual
- stools that are black, tarry, sticky, or have blood or mucus
- severe stomach-area (abdomen) pain or tenderness

#### **Liver problems**

- yellowing of your skin or the whites of your eyes
- severe nausea or vomiting
- pain on the right side of your stomach area (abdomen)
- dark urine (tea colored)
- bleeding or bruising more easily than normal

#### **Hormone gland problems**

- headaches that will not go away or unusual headaches
- eye sensitivity to light
- eye problems
- rapid heartbeat
- increased sweating
- extreme tiredness
- weight gain or weight loss
- feeling more hungry or thirsty than usual
- urinating more often than usual
- hair loss
- feeling cold
- constipation
- your voice gets deeper
- dizziness or fainting
- changes in mood or behavior, such as decreased sex drive, irritability, or forgetfulness

#### **Kidney problems**

- decrease in your amount of urine
- blood in your urine
- swelling of your ankles
- loss of appetite

#### **Skin problems**

- rash
- itching
- skin blistering or peeling
- painful sores or ulcers in your mouth or in your nose, throat, or genital area
- fever or flu-like symptoms
- swollen lymph nodes

**Problems can also happen in other organs and tissues.**

**These are not all of the signs and symptoms of immune system problems that can happen with KEYTRUDA. Call or see your healthcare provider right away for any new or worsening signs or symptoms, which may include:**

- chest pain, irregular heartbeat, shortness of breath, swelling of ankles
- confusion, sleepiness, memory problems, changes in mood or behavior, stiff neck, balance problems, tingling or numbness of the arms or legs
- double vision, blurry vision, sensitivity to light, eye pain, changes in eyesight
- persistent or severe muscle pain or weakness, muscle cramps
- low red blood cells, bruising

**Infusion reactions that can sometimes be severe or life-threatening.**

Signs and symptoms of infusion reactions may include:

- chills or shaking
- dizziness
- itching or rash
- feeling like passing out
- flushing
- fever
- shortness of breath or wheezing
- back pain

**Rejection of a transplanted organ.** Your healthcare provider should tell you what signs and symptoms you should report and monitor you, depending on the type of organ transplant that you have had.

**Complications, including graft-versus-host-disease (GVHD), in people who have received a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic).** These complications can be serious and can lead to death. These

**Continued on next page.**

complications may happen if you underwent transplantation either before or after being treated with KEYTRUDA. Your healthcare provider will monitor you for these complications.

**Getting medical treatment right away may help keep these problems from becoming more serious.** Your healthcare provider will check you for these problems during treatment with KEYTRUDA. Your healthcare provider may treat you with corticosteroid or hormone replacement medicines. Your healthcare provider may also need to delay or completely stop treatment with KEYTRUDA if you have severe side effects.

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

- have immune system problems such as Crohn's disease, ulcerative colitis, or lupus
- have received an organ transplant
- have received or plan to receive a stem cell transplant that uses donor stem cells (allogeneic)
- have received radiation treatment to your chest area
- have a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome
- are pregnant or plan to become pregnant. KEYTRUDA can harm your unborn baby.

**Females who are able to become pregnant:**

- Your healthcare provider will give you a pregnancy test before you start treatment with KEYTRUDA.
- You should use an effective method of birth control during and for at least 4 months after the final dose of KEYTRUDA. Talk to your healthcare provider about birth control methods that you can use during this time.
- Tell your healthcare provider right away if you think you may be pregnant or if you become pregnant during treatment with KEYTRUDA.
- are breastfeeding or plan to breastfeed. It is not known if KEYTRUDA passes into your breast milk. Do not breastfeed during treatment with KEYTRUDA and for 4 months after your final dose of KEYTRUDA.

**Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements.

**How will I receive KEYTRUDA?**

- Your healthcare provider will give you KEYTRUDA into your vein through an intravenous (IV) line over 30 minutes.
- In adults, KEYTRUDA is usually given every 3 weeks or 6 weeks depending on the dose of KEYTRUDA that you are receiving.
- In children, KEYTRUDA is usually given every 3 weeks.
- Your healthcare provider will decide how many treatments you need.
- Your healthcare provider will do blood tests to check you for side effects.

- If you miss any appointments, call your healthcare provider as soon as possible to reschedule your appointment.

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

**KEYTRUDA can cause serious side effects. See “What is the most important information I should know about KEYTRUDA?”**

**Common side effects of KEYTRUDA when used alone**

**include:** feeling tired, pain, including pain in muscles, rash, diarrhea, fever, cough, decreased appetite, itching, shortness of breath, constipation, bones or joints and stomach-area (abdominal) pain, nausea, and low levels of thyroid hormone.

**Side effects of KEYTRUDA when used alone that are more common in children than in adults include:** fever, vomiting, upper respiratory tract infection, headache, and low levels of white blood cells and red blood cells (anemia).

**Common side effects of KEYTRUDA when given with**

**certain chemotherapy medicines include:** feeling tired or weak, nausea, constipation, diarrhea, decreased appetite, rash, vomiting, cough, trouble breathing, fever, hair loss, inflammation of the nerves that may cause pain, weakness, and paralysis in the arms and legs, swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina, mouth sores, headache, weight loss, stomach-area (abdominal) pain, joint and muscle pain, and trouble sleeping.

**Common side effects of KEYTRUDA when given with**

**chemotherapy and bevacizumab include:** tingling or numbness of the arms or legs, hair loss, low red blood cell count, feeling tired or weak, nausea, low white blood cell count, diarrhea, high blood pressure, decreased platelet count, constipation, joint aches, vomiting, urinary tract infection, rash, low levels of thyroid hormone, and decreased appetite.

**Common side effects of KEYTRUDA when given with axitinib**

**include:** diarrhea, feeling tired or weak, high blood pressure, liver problems, low levels of thyroid hormone, decreased appetite, blisters or rash on the palms of your hands and soles of your feet, nausea, mouth sores or swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina, hoarseness, rash, cough, and constipation.

These are not all the possible side effects of KEYTRUDA.

Call your healthcare provider 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 KEYTRUDA**

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

Based on Medication Guide usmg-mk3475-iv-2112r048 as revised December 2021.

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**With the ongoing COVID-19 pandemic,  
we would like to remind breast cancer survivors to  
work closely with their healthcare team to determine  
appropriate safety measures when receiving care.**

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EDITORIAL CORRESPONDENCE should be addressed to EDITORIAL DIRECTOR, CONQUER, 1249 South River Rd, Suite 202A, Cranbury, NJ 08512. E-mail: [editorial@conquer-magazine.com](mailto:editorial@conquer-magazine.com). Phone: 732-992-1892. Correspondence regarding permission to reprint all or part of any article published in this journal should be addressed to REPRINT PERMISSIONS DEPARTMENT, The Lynx Group, LLC, 1249 South River Rd, Suite 202A, Cranbury, NJ 08512.

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Executive Vice President  
Russell Hennessy  
[russell.hennessy@amplity.com](mailto:russell.hennessy@amplity.com)

Director, Client Services  
Samantha DiClementi  
[samantha.diclementi@amplity.com](mailto:samantha.diclementi@amplity.com)

Guest Editorial Director  
Kristin Siyahian

Vice President, Senior Editorial Director  
Dalia Buffery  
[dalia.buffery@amplity.com](mailto:dalia.buffery@amplity.com)

Senior Associate Editor  
Lara J. Lorton

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Copy Editor  
Adam Buffery

Editorial Assistant  
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Senior Production Manager  
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President/CEO  
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Executive Vice President  
John W. Hennessy  
[john.hennessy@amplity.com](mailto:john.hennessy@amplity.com)

Executive Vice President  
Philip Pawelko  
[phil.pawelko@amplity.com](mailto:phil.pawelko@amplity.com)

Executive Vice President  
Shannon Sweeney  
[shannon.sweeney@amplity.com](mailto:shannon.sweeney@amplity.com)

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## A Word of Encouragement



By **LILLIE D. SHOCKNEY, RN, BS, MAS, HON-ONN-CG**

University Distinguished Service Professor of Breast Cancer  
Professor of Surgery, Johns Hopkins University School of Medicine  
Co-Developer of Work Stride—Managing Cancer at Work, Johns Hopkins Healthcare Solutions  
Co-Founder, AONN+  
Co-Founder, ACCCANN

As a breast cancer survivor, I know first-hand how terrifying it is to hear the words “you have breast cancer.” Almost immediately after hearing those words, fear and anxiety set in. Fear and anxiety—the natural companions to a cancer diagnosis. While these emotions are completely understandable, if left unchecked, they can and will negatively impact your quality of life. So, the question is, what can we do as survivors to lessen the impact of these emotions?

As an oncology nurse navigator (and a survivor), I'd like to offer advice in the hope of giving you a sense of empowerment and calm. Although my advice may seem obvious or oversimplified, I can promise that embracing a few of these strategies can help you to lessen or overcome those negative emotions. In fact, I would encourage you to think of these strategies as part of your treatment plan. In doing so, you may be able to regain some peace of mind.

### Learn Everything You Can

There is power in having *accurate* information. I emphasize the word “accurate,” because it is so important to ensure you are gathering information from reputable sources. Start with your oncologist's office and your nurse navigator; they will provide excellent educational resources and direct you to reputable websites so you can read and learn about this disease, the treatments, side effects, and long-term care.

I also encourage you to learn as much as you can about your particular case. Understand the type of breast cancer you have been diagnosed with, the stage of the cancer (how far the cancer has spread), and the grade of the cancer (how

quickly the cancer is growing). Understand your treatment options and ask questions about what you can expect from those treatments. Understand the typical side effects of treatment so you can prepare for them. Having a clear picture of what to expect can help to ease your fear.

UNDERSTAND YOUR  
TREATMENT OPTIONS AND  
ASK QUESTIONS ABOUT WHAT  
YOU CAN EXPECT FROM  
THOSE TREATMENTS.

### A Second Set of Ears

I'm sure you have heard this before, but I cannot stress enough how important it is to bring someone to your consultation who can take notes for you. When you are first diagnosed, it can be difficult to concentrate on the details of the conversation with your oncologist, let alone retain this information. Having someone you trust with you to be a second set of ears is a great idea. In some cases, you also might consider asking your oncologist if it is okay to record your conversation so you will have access to everything that was said once you are back at home.

### Understand Your Risk of Recurrence

It is a very common fear among survivors that the cancer will return. In talking with survivors, this fear seems to be pervasive regardless of the stage,

grade, or the suggested risk of recurrence. I have known women who worry excessively each and every day about the return of a breast cancer. They check their breasts daily and fret about every ache and pain. I know it is difficult (if not impossible) to fully and completely put your mind at rest; but allowing the disease to fully and completely steal your peace of mind is not healthy for you either.

It is a good idea to talk with your oncologist about your personal risk of recurrence and the tests they can use to determine your risk. Having accurate information from your doctor about your risk, as well as a plan to check for recurrence, may prevent needless or excessive worry.

## Participate in Decisions

Your treatment team wants you to actively engage and participate in shared decision-making. Once you have a good understanding of your exact diagnosis, the treatment options, and their related side effects, you should be able to voice your preferences. You should think of yourself as part of the treatment team and then come to the decision-making table with your input. You may be surprised by how many decisions there are to make at all the various phases of treatment: whether they be related to surgery, chemotherapy, immunotherapy, radiation therapy, hormonal therapy, or if you

should participate in a clinical trial. I know this may sound intimidating or overwhelming at the moment, but when you are well-educated, you will have opinions to share. I want you to know that your opinions and preferences are important and should be shared with your treatment team.

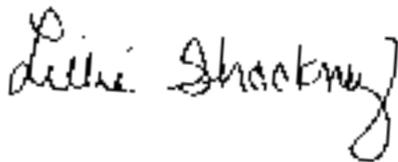
## Soothe Your Nerves

Continue to do the things that you enjoy as you are able. Perhaps you can introduce some new, soothing activities to your daily life. There is value in meditation, listening to music, or reading.

## Connect with Others

Other women who are going through treatment for breast cancer can be a great source of encouragement and support to you, as you will be to them. I highly recommend joining a support group—there are many options available to you. You may find a great support group through your local hospital. If you do not have a group in your area, several organizations host online groups. See the article in this issue about the Young Survival Coalition (page 9) to read about their expansive network of in-person and online support groups.

I truly hope the information provided here is valuable to you. I wish you all the best for a successful treatment journey. Most of all, I wish you peace. ♦



Co-Founder

 Academy of Oncology  
Nurse & Patient Navigators

## Young Survival Coalition: Focused on the Needs of Young Adults with Breast Cancer

By **KRISTIN SIYAHIAN**

Over 20 years ago, the Young Survival Coalition (YSC) was founded. It was 1998 in New York City, where a group of young women gathered and established a group unique to them. What was unique about these survivors? Each was diagnosed with breast cancer before the age of 40 years.

Through their connection, they realized they shared many of the same challenges and that these challenges were related to their phase of life. They also recognized that young adults were underrepresented in breast cancer research, in breast cancer communities, and in conversations about breast cancer. They acknowledged that young adults with breast cancer face higher mortality rates, fertility issues, and ramifications of early menopause unlike their older counterparts. And finally, they realized the need for an organization to address these needs of young adults; and now, more than 20 years later, these needs still define YSC's work.

I was fortunate to have the opportunity to speak with Jamie Larson from the YSC about the many programs offered by their organization and the important work they are doing to improve the lives of young adults diagnosed with breast cancer as well as the people who support them. What follows is our thoughtful exchange.

### How would you describe the mission and goals of the YSC?

Our mission is to work toward a world in which no young adult faces breast cancer alone. We do this by creating a community to address the unique needs, amplify the voice, and improve the quality of life of young adults affected by breast cancer.

---

Jamie Larson is the director of marketing and communications for the Young Survival Coalition.



**Jamie Larson**

### What are some of the support programs YSC offers?

We are so pleased to facilitate in-person support groups called the Face2Face Network—or F2F for short. We facilitate more than 170 F2F groups in 34 states. These groups provide support and resources for young adults at all stages of a breast cancer diagnosis, treatment, or recovery.

Survivors and their caregivers are welcome to join a group in their area; a listing of groups is available on our site ([youngsurvival.org/meet-in-person](https://youngsurvival.org/meet-in-person)); but if an in-person group is not an option, I can tell you that we have a vibrant online community that so many young adults take advantage of.

# interview with the advocate



**Above: An attendee at the YSC Summit expresses her appreciation for the Young Survival Coalition.**

**Below: Making connections at the YSC Summit is a great source of empowerment and support for survivors.**

Photo credit: Ryan Stephens Photography



For example, YSC Virtual Hangouts allow young survivors and thrivers to connect with others from the comfort of their own home. They can connect with their peers, who may share a similar diagnosis, life experiences, or treatment type. Joining a Virtual Hangout is really easy! You just need a computer, tablet, or phone with a webcam and an Internet connection. Groups include Virtual Hangouts for all survivors and thrivers, those living with metastatic breast cancer, African American survivors and thrivers, male co-survivors, and survivors and thrivers part of the LGBTQ+ communities.

We also have private Facebook groups with active communities where young adults support each other and share their experiences. This is a great place to ask questions or share personal stories with people who get it. We have 4 private groups: one for all young adults diagnosed with breast cancer age 40 years and under, one for those living with metastatic breast cancer, one for the LGBTQ+ community, and one for co-survivors.

We also have our YSC Peer Mentoring that connects young adults one-on-one with a peer mentor who shares a similar diagnosis, life experience, or treatment type.

## You also host conferences, right?

Yes, in fact, we host the YSC Summit, which is the largest breast cancer conference dedicated exclusively to the young adult breast cancer community. This 3-day conference features inspirational speakers, workshops addressing their unique issues, and interactive wellness activities. Attendees will have access to the most up-to-date, evidence-based information and tools and have the opportunity to connect with a community of other young thrivers and co-survivors from across the world.

## What are some of the unique challenges young women face when diagnosed with breast cancer?

There are many. Just off the top of my head, young women in general tend to have more aggressive forms of cancer. They are underrepresented in research studies. There can be unique challenges concerning finances, insurance, and

# interview with the advocate

child-rearing. Their quality of life can be impacted by early-onset menopause. There can be fertility issues, body image issues, and relationship and dating issues.

It's for all these reasons that YSC exists. Our community focuses on the issues facing young adults and helps to raise awareness, improve representation in research studies, and just to encourage all young adults with a breast cancer diagnosis.

**YSC offers many educational materials on its website. We are very interested in the "Navigator" booklet series. Can you talk about the creation of these materials and how breast cancer survivors are benefiting from them?**

The Navigator Series was created to provide a comprehensive guide to the different phases of a breast cancer diagnosis. The series includes 4 separate guidebooks.

The first in the series is called the Newly Diagnosed Navigator. It was created to educate and empower newly diagnosed young adults and includes an easy-to-understand breast cancer glossary, a list of questions to ask healthcare teams, and inspiring messages from young adults who have already been down this road.

The Post-Treatment Navigator was designed for those who have completed their active breast cancer treatment. It provides tips to manage the posttreatment phase with a survivorship care plan to use with their healthcare team. It also includes practical information about sex and intimacy concerns, family planning options, and long-term side effects like "chemo brain" and lymphedema.

The Metastatic Breast Cancer Navigator promotes a greater understanding of living with stage IV breast cancer. It includes various treatment options and provides advice on working with healthcare teams, along with forms and tools to help stay organized.

The Long-Term Navigator was developed specifically for young adults with a history of breast cancer and includes tips and information about how to manage long-term side effects and move forward with life after diagnosis and treatment. This guide-



**The "Breastie Girl Gang" enjoys a moment of camaraderie at the YSC Summit.**

Photo credit: Ryan Stephens Photography

book is especially useful for individuals who completed treatment 5 or more years ago.

**YSC also focuses on the caregiver, or the co-survivor. Can you define the term "co-survivor?" What advice do you have for them?**

Yes, YSC definitely touts the importance of caring for co-survivors. A co-survivor is anyone who offers the crucial emotional, physical, financial, or spiritual support to a young adult diagnosed with breast cancer. This can include partners, parents, siblings, friends, extended family, or others. Co-survivors need support just as much as the person diagnosed with cancer. Their needs are often overlooked in their caregiving role, but it's necessary that they take care of themselves in order to provide the support their loved one needs.

**How can a young adult diagnosed with breast cancer connect with YSC?**

Simply visit our site. They will find a wealth of resources there and many opportunities to connect with other survivors. We can be found at [youngsurvival.org](http://youngsurvival.org).

**Thank you very much for your time today, and best of luck with your mission. ♦**

## A Family in the Future: For Young Adults Diagnosed with Breast Cancer

By **CAROLINE S. DORFMAN, PhD<sup>1,2</sup>**; **JACKLYN BALLIOT, BSN, RN, OCN<sup>1</sup>**;  
**JULIANN M. STALLS, PhD<sup>1,2</sup>**; **CHEYENNE CORBETT, PhD<sup>1</sup>**

<sup>1</sup>Supportive Care and Survivorship Center, Duke Cancer Institute, Durham, NC

<sup>2</sup>Department of Psychiatry and Behavioral Sciences, Duke University Medical Center, Durham, NC

**C**ase: Sarah is a 28-year-old female who was recently diagnosed with early-stage breast cancer. Her oncology team has recommended that she receive TCHP (Taxotere + carboplatin + Herceptin + Perjeta) and have a mastectomy with reconstruction, followed by 5 years of tamoxifen. She was told that chemotherapy may impact her ability to have a child in the future. Sarah is recently engaged, and she and her fiancé strongly desire having biological children. Sarah's oncologist refers her to a reproductive endocrinologist to discuss options for preserving fertility prior to starting treatment.

For premenopausal women like Sarah, treatments for breast cancer can pose a risk to their fertility—their ability to have biological children—in the future. With other things on your mind like finishing school, building your career, or finding a partner, you may not be thinking about having children before your cancer diagnosis. While fertility may not be on your radar, it is a topic that may be important to discuss with your oncologist at the time of diagnosis and treatment planning. Advances in reproductive medicine allow for patients to take steps to preserve their fertility in a timely fashion that is in line with their time frame for starting cancer treatments.

### What Treatments for Breast Cancer May Impact My Fertility?

Not all cancer treatments impact fertility in the same way. Some treatments have minimal risk to fertility, while others are much more likely to have an impact. Chemotherapies classified as alkylating agents, such as the carboplatin that Sarah will re-

ceive with her TCHP treatment, are associated with a higher risk to fertility than other types of chemotherapies. Oncologists and reproductive endocrinologists can help you determine what your personal risk to fertility may be based on your treatment plan and age.

Age is an important factor when determining your risk for infertility when beginning treatment for breast cancer. Women are born with all of the eggs they will ever have, and chemotherapy can significantly decrease that number of eggs. Generally, younger patients will have a higher ovarian reserve—a higher number of eggs—prior to starting treatment than older patients, so even if their egg count drops because of their treatment, it may not drop low enough to put them into menopause. Menopause is when the ovaries stop releasing eggs and menstrual periods stop. Patients may become menopausal earlier than they would have without cancer treatment, but they may still have many fertile years after completing treatments. An older but still premenopausal patient will have a naturally lower egg supply because of her age. When they begin chemotherapy, their egg count may drop to a level low enough to induce early menopause more quickly.

Many breast cancer treatment plans include 5 to 10 years of hormone therapy (eg, tamoxifen). It is

generally not recommended to get pregnant while on these medications due to potential impacts to the unborn child. Although these drugs do not directly impact fertility, the length of time that a patient needs to delay having a child while on these medications may come with a natural, age-related decrease in fertility. Depending on age, many women consider fertility preservation prior to starting these medications.

## What Options Exist to Preserve My Fertility?

Oncofertility is a term coined in 2007 to describe a field that joins oncology and reproductive medicine to improve patients' options for biological parenthood through fertility preservation. In the field of oncofertility, there are a number of fertility preservation options that patients like Sarah might consider. These include embryo cryopreservation, oocyte cryopreservation (egg freezing), use of medications to help protect the ovaries, and ovarian tissue cryopreservation.<sup>1-3</sup> It is important to speak with your medical team, including your oncologist and a reproductive specialist, about your potential interest in fertility preservation early, and ideally before beginning treatment, so that your options might be explored.

### Embryo Cryopreservation

Embryo cryopreservation involves taking medications to cause the ovaries to release more eggs and then surgically retrieving mature eggs. Recent advances in reproductive medicine mean that patients do not have to wait for their menstrual cycle to begin the process of embryo cryopreservation. While this process previously took as long as 4 weeks, it now may take as little as 2 weeks. Next, mature eggs are fertilized in a lab with a male partner's or donor's sperm and cryopreserved (frozen) for later use through procedures like in vitro fertilization (IVF).

### Oocyte Cryopreservation

Oocyte cryopreservation also involves taking medications to cause the ovaries to release more eggs, followed by surgical retrieval of mature eggs. As with embryo cryopreservation, this process may

now be completed in as little as 2 weeks. Mature eggs are cryopreserved for later use through procedures like IVF.

### Gonadotropin-Releasing Hormone (GnRH) Agonists

Medications called GnRH agonists (eg, goserelin, leuprolide) may also be recommended for use during treatment to help protect the ovaries. The goal with these medications is to reduce the chance that the ovaries stop working before they typically would (eg, premature ovarian insufficiency).

### Ovarian Tissue Cryopreservation

A newer option, which may not yet be available at all sites, called ovarian tissue cryopreservation involves surgical removal of ovarian tissue and cryopreservation for later use. This procedure does not require any pretreatment medications and can be completed as soon as the procedure is scheduled, making it a useful procedure for patients who need to start treatment quickly. The cryopreserved ovarian tissue can be stored for many years and later re-implanted in the body to make pregnancy possible.

### How Do I Find a Fertility Clinic?

While many large health systems have an affiliated fertility clinic, community cancer centers and other health systems may not. Talk with your oncologist to see if they have recommendations for, or have partnered with, a fertility clinic. The Alliance for Fertility Preservation and Livestrong have search functions on their websites, and the Oncofertility Consortium has a hotline (866-708-FERT) to help patients locate a fertility clinic in their area.

### Who Can Help Me Think Through My Options?

Fertility preservation is a complex process with many decision points. On top of an already emotionally stressful time with navigating a recent cancer diagnosis, fertility-related decisions are further complicated by the emotional distress a patient may experience after learning that their cancer treatments may impact their ability to have biological children. Patients may experience feelings of grief or loss, rage, injustice, fear, sadness, frustration,

# fertility preservation

shock, anger, worry, nervousness, uncertainty, and a loss of control over their ability to build their families.<sup>4</sup> It is important for patients to feel like they are making an informed decision about fertility preservation, including whether to preserve or not. It may be helpful for you to connect with a multidisciplinary care team who can provide you with accurate fertility information and decision support and validate any fertility-related concerns you may have.

In addition to your cancer care team, your fertility care team may involve a reproductive endocrinologist, psychosocial provider, and/or an oncofertility navigator.

AS OF JUNE 2022,  
ONLY 12 STATES HAVE  
MANDATED INSURANCE  
COVERAGE OF  
FERTILITY PRESERVATION.

## **Reproductive Endocrinologist**

Reproductive endocrinologists are fertility specialists. In conjunction with a patient's oncologist, reproductive endocrinologists will review a patient's treatment plan and provide them with a personalized estimate of their risk for infertility and their options for fertility preservation. If a patient chooses to preserve their fertility, reproductive endocrinologists will manage and conduct any fertility preservation-related medical procedures (eg, egg retrieval).

## **Psychosocial Providers**

Psychosocial providers, like a mental health counselor, family therapist, social worker, or psychologist, can help patients process the emotions they are experiencing and assist with making a fertility preservation decision that best matches their goals and values.

## **Oncofertility Navigators**

Some institutions may also have oncofertility navigators. These individuals provide fertility-related educa-

tion and support and reduce barriers to preservation by coordinating fertility-related appointments and providing patients with information and resources.

Sarah and her fiancé are unsure about what steps to take after learning her fertility may be impacted by her breast cancer treatments. Sarah's oncologist helped to connect her with an oncofertility navigator who got her scheduled for a consultation with a reproductive endocrinologist. Sarah and her fiancé also set up an appointment with a psychosocial provider, who helped them to evaluate their goals for family building and talk through Sarah's fertility preservation options.

## **How Much Does Fertility Preservation Cost?**

The cost for fertility preservation varies depending on procedure type. Costs can range from \$11,000 to \$15,000 for embryo cryopreservation, \$10,000 to \$15,000 for oocyte cryopreservation, and \$500 to \$1800 per injection for GnRH agonists (eg, leuprolide) without insurance.<sup>5</sup> Patients may face additional costs associated with embryo or oocyte storage (\$300-\$600 per year) and to use preserved embryos or oocytes in the future through IVF or through the use of a gestational carrier (eg, surrogate).

As of June 2022, only 12 states have mandated insurance coverage of fertility preservation. It is important to contact your insurance provider to learn whether any portions of the fertility preservation process are covered. For many patients, fertility preservation is an out-of-pocket cost.

## **What Resources Exist to Help Me Pay for Fertility Preservation?**

Some resources exist to help patients pay for fertility preservation. Livestrong Fertility partners with fertility clinics to provide discounted services and fertility medications to patients undergoing fertility services due to a cancer diagnosis. It is important to ask your fertility clinic if they have a partnership with Livestrong or a similar organization. There are other programs that can also help provide free fertility medications to patients with cancer undergoing fertility preservation. Heartbeat and ReUnite, offered by Ferring Pharmaceuticals and MDRx Fertility Pharmacy, respectively, are 2 examples.

There are also grants that patients can apply for to help decrease the cost of fertility preservation or storage. Verna's Purse is a grant for people with cancer storing embryos or oocytes through ReproTech, a popular storage facility. Patients are eligible for discounted storage if they meet certain income criteria. Team Maggie's Dream is a nonprofit organization that provides grants to people between the ages of 15 and 37 years pursuing fertility preservation ahead of cancer treatment. They award grants based on need and available funding, and awards can be used for embryo or oocyte cryopreservation, or a year of storage fees. The fertility clinic staff or oncofertility navigator may have access to additional resources to assist in paying for fertility preservation. When a patient is ready to use a preserved embryo or oocyte to build their family through IVF or the use of a gestational carrier, organizations like The Samfund have grants that patients can apply for to help cover some of the costs.

## If I Do Not Preserve My Fertility, What Are My Options for Building a Family?

When a patient is not able to, or chooses not to, undergo fertility preservation, there are a number of potential options for family building after cancer treatment if this is important to them. Some patients will conceive naturally after breast cancer treatment, without medical intervention. If medical intervention is needed, there are a number of assisted reproductive technologies that may be useful. These may include IVF using a patient's own oocytes and a partner or donor's sperm, using donor oocytes or embryos and carrying the pregnancy themselves, or using a gestational carrier. Adoption is another important option that may be the best fit for some families.

If you are interested in family building after treatment, it is important for you to bring this up with your medical team early, even if you are not yet ready to begin building your family. Your medical team

## Resources

- Alliance for Fertility Preservation  
[www.allianceforfertilitypreservation.org/](http://www.allianceforfertilitypreservation.org/)
- Oncofertility Consortium Fertline  
<https://oncofertility.msu.edu/>

## Financial Resources

- Livestrong Fertility Discount Program  
[www.livestrong.org/what-we-do/program/fertility](http://www.livestrong.org/what-we-do/program/fertility)
- ReUnite Oncofertility  
[www.mdrusa.com/oncofertility/reunite-oncofertility/](http://www.mdrusa.com/oncofertility/reunite-oncofertility/)
- Heartbeat  
[www.ferringfertility.com/patient-resources/](http://www.ferringfertility.com/patient-resources/)
- Team Maggie's Dream  
[www.teammaggiesdream.org/](http://www.teammaggiesdream.org/)
- Verna's Purse  
[www.reprotech.com/vernas-purse/](http://www.reprotech.com/vernas-purse/)
- The Samfund  
[www.thesamfund.org/](http://www.thesamfund.org/)

may recommend a referral to a fertility specialist so that you may have an evaluation of your fertility. Bringing up potential interest in family building early will better help your medical team to connect you with information and support to make informed decisions. ♦

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## Insurance, Benefits, and You: From Financial Assistance Programs to the Family Medical Leave Act – Are You Taking Advantage of These Resources?

By **CLARA N. LAMBERT, CPH, BBA, OPN-CG**

Five years ago, when I was working as a financial navigator at a community cancer center in Michigan, a breast cancer patient entered my office with an all-too-familiar dilemma. She had recently started treatment and was struggling with the physical effects of chemotherapy. She was also dealing with the emotional toll of her diagnosis,

which was not only weighing on her but also on her partner and their 3 young children. But her most urgent concern was how she and her family could afford the astronomical costs of her care. Her chemotherapy drugs alone cost more than \$50,000 per dose. Between medication, travel to and from our facility, and other expenses—as well as lost income

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Clara Lambert is the director of financial navigation at TailorMed, a leading healthcare technology company dedicated to removing financial barriers to care. Driven by its best-in-class platform, TailorMed is building the largest network of patients, providers, pharmacies, and life science companies focused on ensuring all patients can afford treatment. Prior to joining TailorMed, Clara served as a financial navigator at the Borhade Cancer Center at Advocate Good Samaritan Hospital in Illinois and the Cowell Family Cancer Center in Michigan, where she helped pioneer a nationally recognized financial navigation program.

A frequent speaker at healthcare conferences nationwide, Clara is a recipient of the Academy of Oncology Nurse & Patient Navigators Leadership Council Award: Putting Evidence into Practice. She is a past chair of the Association of Community Cancer Centers Financial Advocacy Network Advisory Committee. Clara holds a BA in integrated professional studies (business, healthcare administration, and information technology) from Davenport University and a graduate certificate of public health from Loyola University. Having personally experienced the financial burden of a family member's cancer diagnosis, Clara is passionate about helping patients and caregivers secure the resources they need.

due to her inability to work—the financial burden had become unmanageable. She faced a decision no one should have to make: Should she pay for necessary living expenses, including her family's mortgage, food, and childcare, or pay for lifesaving treatment?

Sadly, her story is not uncommon. Far too often, patients must overcome steep financial obstacles to get the care they need. In the United States, skyrocketing healthcare costs across all conditions have led to \$140 billion in medical debt.<sup>1</sup> Last year, nearly 20% of Americans—more than 46 million people—said that they did not seek treatment for a health problem in the last year due to costs.<sup>2</sup>

For patients facing an acute, rare, or chronic disease such as breast cancer, the financial impact can be even more devastating. The National Cancer Institute reported that in 2019, the patient cost of cancer care in the United States was more than \$21 billion.<sup>3</sup>

Fortunately, cost-saving resources are available to help breast cancer patients manage the burden and avoid what is known as “financial toxicity.”<sup>4</sup> The challenge is that many patients are unaware of these resources or unable to access them.<sup>5</sup> Here are 4 ways to ensure you have the benefits and funding you need to afford care:

## 1. Make Sure Your Insurance Is Optimized

Whenever I meet with a new patient, the first step is to review their healthcare coverage and make sure they are enrolled in a plan that helps them lower their out-of-pocket costs.

If you have employer-based insurance, take advantage of your company's open enrollment period to reevaluate your existing coverage and change your plan as needed. Open enrollment typically occurs once per year, but employees who have life-changing events—such as moving out of their plan area, loss of employment, or shifting from full- to part-time work—may be eligible for special enrollment. Speak to your human resources representative and find out if you qualify.

If you have Medicare, the open enrollment period takes place between October 15 and December 7 each year.<sup>6</sup> Medicare beneficiaries with low incomes<sup>7</sup> can qualify for the Social Security Admin-



Clara N. Lambert, CPH, BBA, OPN-CG

istration's Low-Income Subsidy program, also known as Extra Help. This federal program provides support for prescription drug premiums, deductibles, and cost-sharing for eligible patients with annual incomes at 150% of the federal poverty level. Ask your provider to connect you with a financial navigator who can determine whether you qualify and help you complete the enrollment process.

WHENEVER I MEET WITH  
A NEW PATIENT, THE  
FIRST STEP IS TO REVIEW  
THEIR HEALTHCARE  
COVERAGE.

In addition, open enrollment for 2023 Affordable Care Act (ACA)-compliant individual and family health plans begins on November 1, 2022.<sup>8</sup> Until the end of 2022, patients can expect to find more aid and lower premiums compared with years past,

thanks to the American Rescue Plan Act. To enroll in the most cost-effective plan, be sure to report any income changes to ACA administrators as soon as possible. Doing so may reduce expenses, either in the form of lower premiums or greater cost-sharing assistance. Visit [Healthcare.gov](https://www.healthcare.gov) and click “Find local help” to get ACA-certified enrollment support in your area.

MANY BREAST CANCER PATIENTS STRUGGLE TO COVER THEIR GENERAL LIVING EXPENSES AFTER PAYING FOR MEDICATION AND TREATMENT.

## 2. Explore Patient Assistance Programs and Funds

There are a number of programs and funds created to alleviate the financial stress people with cancer face. These resources help cover the costs of medical care, cancer treatments, and prescription drugs.

Many drug manufacturers offer copay assistance programs, also known as copay cards or copay savings programs. These programs may cover all or part of your out-of-pocket costs for the treatment you need, including chemotherapy infusions. Most patients with private health insurance, no matter their income, are eligible for these programs. Once you're enrolled in a copay assistance program, your insurance will pay their portion of the drug cost, and the drug manufacturer will pay some or all of your portion. Speak to your doctor or pharmacist or contact the pharmaceutical company directly to learn more.

If you have government health insurance, such as Medicare and TRICARE, a number of charitable foundations offer disease-specific grants. Eligibility criteria vary from program to program, but most require information about your household income and family size. Many also require information from your healthcare provider about your diagnosis and

treatments before approving your application. The Patient Advocate Foundation and the Patient Access Network Foundation, for example, provide copay grants on a first-come, first-served basis to breast cancer patients who meet specific medical and financial criteria.

Some funds may have a wait-list, but do not be discouraged. It is best to apply and get on the wait-list, as some funds provide retroactive reimbursement once you are approved into the program. CancerCare's Assistance Fund, for example, considers retroactive reimbursement for applicants who are actively receiving breast cancer treatment or have received treatment within 60 days of the applicant's approval.

If you are uninsured and have an immediate need for financial assistance and cannot otherwise afford your prescriptions, many pharmaceutical companies offer patient assistance programs (PAPs). PAPs provide free or low-cost medications to cancer patients who are experiencing financial hardship and/or have no third-party insurance coverage.<sup>9</sup>

In addition, local, regional, and community-based assistance programs, as well as hospitals' internal funds, can help cover treatment-related costs. Talk to your healthcare provider about the options that may be available to you.

## 3. Beyond Treatment: Get Help with Living Expenses

Many breast cancer patients, like the woman I worked with in Michigan, struggle to cover their general living expenses after paying for medication and treatment. For these patients, there are organizations that provide funding to cover costs such as transportation, childcare, mortgage and rent, utilities, and groceries.

The Pink Fund, for example, provides 90 days of nonmedical expenses to breast cancer patients in active treatment. The Susan G. Komen Foundation's Komen Treatment Assistance Program provides funding for daily living expenses to breast cancer patients who meet the program's eligibility criteria. The Provision Project offers financial relief to patients in active treatment for breast cancer, so no family is ever put in the impossible predicament of choosing between lifesaving cancer care and day-to-day expenses.

## 4. Lean on the Family Medical Leave Act and Other Government Protections

If you need to take time off work for cancer treatment and recovery, you may qualify for financial assistance through your employer's disability coverage plans or government programs. The Family and Medical Leave Act is a federal law that allows eligible employees to take up to 12 weeks of unpaid leave for medical or specific family reasons.<sup>10</sup> You do not need to take 12 weeks off all at once; leave can be intermittent, so you can take time off as needed.

SHORT-TERM DISABILITY  
BENEFITS—KNOWN AS PAID  
MEDICAL LEAVE—SUPPLEMENT  
A PORTION OF YOUR INCOME  
FOR UP TO 26 WEEKS.

If you are unable to work after you have used your paid time off (eg, vacation and sick days), your employer may offer short- and long-term disability plans that provide a continuation of income and benefits for employees who are medically disabled.

Short-term disability benefits—known as paid medical leave—supplement a portion of your income (usually 50%-80% of your salary) for up to 26 weeks.<sup>11</sup> To qualify for short-term disability, you must be unable to work due to your diagnosis, treatment, or treatment side effects. Most short-term disability plans are managed by insurance companies, and eligibility requirements vary. Generally, you must show proof that you are unable to perform your job or carry out your work activities due to your cancer diagnosis and treatments.

Once short-term disability payments end, you may qualify for long-term disability (LTD) benefits under your employer-sponsored plan. Similar to short-term disability, LTD benefits pay a portion of your income—usually 60%—until you have recovered. Speak with your employer's human resources

department to learn more about your workplace short- and long-term disability coverage.

Social Security Disability Insurance (SSDI) is a federally run benefit program for those who have worked and paid Social Security taxes on their earnings in the past 10 years.<sup>12</sup> To qualify for SSDI, you must have a diagnosis that meets the Social Security Administration's standard for disability (eg, metastatic breast cancer).<sup>13</sup> Approval may take 3 to 5 months, but some patients with advanced breast cancer may qualify for a Compassionate Allowance, which expedites the approvals process.<sup>14</sup>

For those who lose their employer-sponsored health benefits due to job loss or reduced work hours, the Consolidated Omnibus Budget Reconciliation Act (COBRA) gives workers the right to continue receiving benefits from your employer's health plan for a limited period. If you opt for COBRA, you will be required to pay the entire premium for coverage up to 102% of the cost of the plan.<sup>15</sup> If this presents financial hardship, disease-specific funds may help cover the cost of your health insurance premiums. The HealthWell Foundation, for example, offers funding for insurance premiums to assist breast cancer patients who meet certain financial criteria.

## Resources

### **For healthcare coverage:**

Affordable Care Act Marketplace Coverage:

[healthcare.gov](https://healthcare.gov)

Centers for Medicare & Medicaid Services: [cms.gov](https://cms.gov)

### **For charitable funds:**

CancerCare: [cancercares.org](https://cancercares.org)

The HealthWell Foundation:  
[healthwellfoundation.org](https://healthwellfoundation.org)

The Patient Advocate Foundation:  
[patientadvocate.org](https://patientadvocate.org)

The Patient Access Network Foundation:  
[panfoundation.org](https://panfoundation.org)

The Pink Fund: [pinkfund.org](https://pinkfund.org)

The Provision Project: [provisionproject.org](https://provisionproject.org)

The Susan G. Komen Foundation's Komen  
Treatment Assistance Program:

[komen.org/treatment-assistance-program](https://komen.org/treatment-assistance-program)

## Take Advantage of Available Resources— and Do Not Go It Alone

For many breast cancer patients, the costs associated with medical care and treatment can quickly become overwhelming. By optimizing your insurance, exploring funding options to finance your medical and living expenses, and leaning on government protections, you can ease the financial burden.

RESEARCH SHOWS THAT  
PATIENTS WHO WORK WITH  
FINANCIAL NAVIGATORS  
HAVE AN INCREASED  
QUALITY OF LIFE.

You may have concerns about your family's financial health but not know where or how to look for help. The good news is, you do not have to go through this alone. Oncology financial navigators are on staff at many healthcare facilities. They can help with insurance optimization and discuss payment options for any out-of-pocket expenses you incur related to cancer care and treatment. In recent years, new technologies have been developed that enable these professionals to quickly and efficiently connect patients with resources to reduce financial barriers.

Research shows that patients who work with fi-

nancial navigators have an increased quality of life and higher survival rates.<sup>16</sup> Essentially, navigators are there to help relieve any finance-related stress so that you can focus on what matters most: your treatment and recovery. ♦

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