Many patients with cancer who have limited financial resources have started to use crowdfunding campaigns to pay for the daunting bills associated with their treatment and subsequent care.
KEYTRUDA is a breakthrough immunotherapy.

**FOR TODAY**

KEYTRUDA is a potential first treatment for 3 out of 4 patients with advanced non–small cell lung cancer (NSCLC).

KEYTRUDA is also used to treat more patients with advanced lung cancer than any other immunotherapy.

KEYTRUDA may be your first treatment for advanced NSCLC, either in combination with chemotherapy or used alone as a chemotherapy-free option. Ask your doctor if KEYTRUDA is right for you.

**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 blistersing 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;

Important Safety Information is continued on the next page.
KEYTRUDA is a breakthrough immunotherapy.

ALK = anaplastic lymphoma kinase.

PD-L1 = programmed death ligand 1;

If you received an “EGFR” or “ALK” inhibitor medicine that contained an abnormal “EGFR” or “ALK” gene, you have also received KEYTRUDA if your tumor tests positive for “PD-L1” and your tumor tests positive for “PD-L1” or your NSCLC has spread (stage III) and you cannot have surgery or your lung cancer has not spread outside your chest. It may be used alone as your first treatment when your lung cancer has spread (advanced cancer (NSCLC)).

KEYTRUDA is a prescription medicine used to treat solid tumors that express PD-L1 and have metastasized, or solid tumors that express PD-L1 and cannot be surgically removed, or solid tumors that express PD-L1 and have spread to nearby tissue or spread to other parts of the body. KEYTRUDA is used in combination with chemotherapy or used alone as a chemotherapy-free option. 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 if you are breastfeeding or plan to become pregnant. 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 while receiving KEYTRUDA, 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.

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

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.

Having trouble paying for your Merck medicine? Merck may be able to help. www.merckhelps.com
Important Information About KEYTRUDA® (pembrolizumab) injection 100 mg. Please speak with your healthcare professional regarding KEYTRUDA (pronounced key-truh-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.

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
- itching or rash
- flushing
- shortness of breath or wheezing

**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.

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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FIRSTLINE

Sheryl Crow, Cross-Country Walk and More

HEAL AT HOME

Caring for a Port
As part of CURE®'s Heal at Home series, we provide a helpful guide for patients on how to care for their ports to prevent infections.

EXTRAORDINARY HEALER®

Margaret Campbell, B.S.N., RN, Wins CURE®’s 2022 Extraordinary Healer® Award
For the first time in three years, CURE® welcomed 500 attendees in person and hundreds more virtually to honor the 2022 Extraordinary Healer® award recipient.

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Stopping the Walls From Closing In
Many patients with cancer who have limited financial resources have started to use crowdfunding campaigns to pay for the daunting bills associated with their treatment and subsequent care.

GYNECOLOGIC CANCERS

Uncovering New Ways to Make Surgery Safer
The use of newer tools and techniques may be reducing the risk of surgical site infections and other complications in patients receiving treatment for gynecologic cancers.

LUNG CANCER

A Paradigm Shift
Researchers have begun analyzing the effects of immunotherapy in earlier treatment lines in patients with lung cancer.
An unexpected side effect of a cancer diagnosis is the financial burden that comes with fighting the disease. If you own a life insurance policy, Whitestone Life will help you access immediate cash that can assist you and your family through this difficult time.

Whitestone Life is your partner during this process. As a licensed advocate, we will help you sell your existing life insurance policy for the highest amount possible. The funds received can be used however you choose and will provide financial peace of mind for you and your loved ones when you need it most.

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**PLEASE CALL FOR MORE INFORMATION**

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72 BREAST CANCER
In the Driver’s Seat
In CURE®’s “Speaking Out” video series, on behalf of Living Beyond Breast Cancer, Dr. Nancy Lin discusses treatment planning for brain metastases in breast cancer and how patients can take part in driving their care.

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Receive CURE® at home for FREE!
CURE® is FREE to patients with cancer, survivors or caregivers who live in the U.S. FREE bulk subscriptions are available for physicians, cancer centers and other organizations.
Patients Turn to an Unconventional Way to Fund Cancer Care

I AM ALWAYS ASTONISHED to see the sky-high prices of cancer treatment. For many Americans, receiving a cancer diagnosis comes with the daunting question of “How can I afford this?”

Some patients may ultimately consider forgoing treatment altogether knowing that without proper insurance and adequate savings, they and their families may accumulate crippling debt.

Let’s face it: Many patients can’t afford cancer care. In 2018, according to data from the American Cancer Society, patients with cancer in the United States paid more than $5 billion in out-of-pocket costs for cancer treatments.

That same American Cancer Society report indicates that certain individuals with cancer are more likely to be affected by financial hardships. People who are under the age of 55, are of color, have obtained less than a high school degree and are considered to live in a low- to middle-income household are most likely to struggle under the weight of cancer costs.

As these costs have become unmanageable, many patients have turned to an unconventional method to raise funds for their treatments: crowdfunding through strangers.

In this issue of CURE®, we detail the lengths to which some patients go to ensure they can afford their care by seeking help from people they don’t even know. Crowdfunding, which was once traditionally used by startup businesses seeking to raise money to grow their capabilities, is now being used by people to seek help from the outside world to fund their medical care.

“The fact that people have to go this route tells me we’re not doing as good a job as we could be — it really puts an asterisk on our current health care system,” an expert from Johns Hopkins Medicine in Baltimore said in an interview for our cover story.

And it’s true, as evidenced by the patient stories in this issue, that many patients in these situations find themselves facing the toughest challenge of their lives: going through cancer treatment while worrying about the financial burden of their disease.

“I just felt so overwhelmed and I broke down in my living room. I remember thinking, ‘I can’t do this alone. I’m going to need help,’” said a patient who received a diagnosis of endometrial cancer and eventually shared her story on the crowdfunding platform GoFundMe.

The problem that many patients face with crowdfunding, however, is that they feel embarrassed being unable to pay for their care.

“I hate asking for money,” one caregiver said. “It makes me uncomfortable. I don’t even ask my parents for money, let alone friends or strangers.

But ultimately, they all said the decision to turn to crowdfunding was necessary to ensure they received appropriate care.

As always, we hope you find our stories inspirational and informative. Thank you for reading.
editor's note

SUMMER 2022

Using Effective Therapies Earlier — Does It Always Work?

IF YOU HAVE AN effective tool, should you always use it more often or in more situations? It all depends on the specifics — and in the case of medical issues, it requires careful thought and well-designed clinical trials. Lung cancer was one of the earlier beneficiaries of the cancer immunotherapy revolution that is now at the 20-year mark. For cancers that do not have a genomic target that can be addressed with an EGFR, ALK/ROS1 and other such inhibitors, immunotherapy has made significant impacts on survival in advanced lung cancer. With increased awareness, better imaging technology and the advent of low-dose screening CT scans for those at risk for lung cancer, earlier detection is becoming more common. Surgery has long been the mainstay for localized and operable lung cancer. However, recurrences due to residual microscopic disease that cannot be seen on scans are common, and usually not curable. Preventing recurrences with “adjuvant” chemotherapy became a standard treatment to address this, and was complemented with radiation for stage 3 cases, but the reductions in risks were modest. As immunotherapy became the standard of care for many cases of metastatic lung cancer because it was much more effective than chemotherapy alone, the natural question was whether this could be moved to the adjuvant setting. But immunotherapy is not without its consequences — side effects that are sometimes severe and may be fatal. Where should the line be drawn so that the improvement in mortality would clearly outweigh the harms of treatment? The only way to answer this was with clinical trials — and not just one, but several with different designs and using various immunotherapies. Through the deliberate and innovative designs of these studies, as you will read about in this issue of CURE®, recurrences have been cut by more than one-third with this approach. And there is the potential to go even further as refinements in harnessing the immune system against cancer continue with more discoveries in the lab and newer agents that home in on more recently discovered modulators of the immune system. The stories of the patients in our feature on this topic illustrate how they have become partners in therapeutic advances by, in some cases, participating in trials, or simply taking the time to understand their disease, the powerful treatments involved, and appreciating what they could do to help their own cause by learning the protocol and knowing what side effects to report to their care team. The field is changing more quickly than it ever has — immunotherapy being a big part of the latest successes but aided greatly by the migration of successful therapies to earlier in the disease process.

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How do I manage chemo rash?

Skin toxicity, also known as “chemo rash,” is a common side effect for patients with colorectal cancer. Luckily, there are ways to manage and lessen the symptoms of skin toxicity.

Skin toxicity resources are available for free in Fight Colorectal Cancer’s resource library. Find them at fightcrc.org/skintoxicity.
Sheryl Crow Urges Women to Get Screened for Breast Cancer

COUNTRY MUSICIAN AND pop artist Sheryl Crow received a diagnosis of invasive breast cancer in 2006 at the age of 44. In a recent interview with CBS Los Angeles, she recalled how she received her diagnosis following a routine mammogram that she almost postponed.

Crow urged women to get screened and to resume screening if they have skipped their recent yearly checkups because of COVID-19.

“My message to women is it can happen to anyone. One in 8 women now are being diagnosed with breast cancer and until we have a cure, early detection is our best weapon,” she said in the interview. “I’m happy to say that at least our technology is advancing even though we don’t have a cure yet.”

Cancer Survivor Walks from New York to Los Angeles

CODY O’CONNOR, a 26-year-old cancer survivor who was diagnosed with Ewing sarcoma at 14 years old, recently completed a 3,700-mile walk. The Cincinnati native trekked from New York to Los Angeles to raise awareness of the ongoing mental and emotional toll a cancer diagnosis can have on patients and their family members.

O’Connor started his Walk for Hope journey in New York on June 17, 2021. He averaged 20 to 25 miles per day with a goal of raising $300,000 for Champions Do Overcome, the nonprofit he founded in 2018 that provides financial and emotional support to families facing cancer.
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

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.

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

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
  - 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.

Pfizer Oncology together™

CALL 1-844-9-IBRANCE
(Monday–Friday 8 AM–8 PM ET)
VISIT PfizerOncologyTogether.com

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PP-IBR-USA-5073-01
Pediatric Osteosarcoma Survivor Continues to Play Baseball Through Pain and Chemotherapy Treatments

AFTER THEN-8-YEAR-OLD NOLAN MADSEN heard a pop when playing with his friends in 2018, he underwent a series of medical tests that revealed his diagnosis: osteosarcoma, a type of bone cancer.

Madsen, a Georgia native, received 29 rounds of inpatient chemotherapy before undergoing surgery in 2019 to remove the bone at the top of his femur, where the cancer was located. But throughout treatment, Madsen, who said he “revolves around baseball,” continued to play the game he loved, often playing with a walker and a chemo port in his chest. Now the 11-year-old continues to play baseball with a titanium femur that has a gearbox right below his right hip.

“I feel fine,” he told FOX 5 Atlanta. “I’m living life and I’m living it well.”

Drug Commonly Used to Treat HIV Shows Promise in the Treatment of Metastatic Colorectal Cancer

EPIVIR (LAMIVUDINE) is an antiviral drug that has been used to treat human immunodeficiency virus (HIV) for years, but now research has shown that it might be useful in the fourth-line treatment setting for metastatic colorectal cancer.

Trial findings that were published in Cancer Discovery showed that Epivir stopped disease progression in 25% of patients with colorectal cancer who have had four lines of treatment.

“After giving them only this one drug — nothing else — we saw signs of disease stability,” co-senior author Dr. David T. Ting of Mass General Cancer Center in Boston told the Harvard Gazette. “If we see this kind of response with just one HIV drug, the next obvious trial is to see what else we can achieve with HAART, or highly active antiretroviral therapy.”

Florida Fire Departments Receive Funding to Reduce Exposure to Cancer-Causing Contaminants

FLORIDA HAS AWARDED $500,000 to fire departments across the state to purchase new equipment that better protects firefighters against cancer-causing chemicals that may be present on the job.

According to data from the National Institute for Occupational Safety and Health, firefighters are at a 9% greater risk of developing cancer than the general public. Those statistics also show that firefighters are 14% more likely to die from their disease.

“What we’re finding in the fire service now is that the sooner we could get out of these contaminated clothes, get showered, get all this bad stuff off of us, the better we’re going to be in the long run,” Wayne Bernoska, president of Florida Professional Firefighters, said in an interview with FOX 13 Tampa Bay.
A PORT, ALSO known as a port-a-cath, among other names, is a device that is surgically implanted under a patient’s skin, typically on the right side of the chest. This allows cancer teams to draw blood and give treatments such as blood transfusions, intravenous fluids or drugs like antibiotics and chemotherapy without the need for constant pokes.

“I think ports are phenomenal, I really do,” Allegra B. Bell, M.S.N., RN, OCN, a clinical nurse manager in the Department of Solid Oncology at UCLA Santa Monica Hospital, said in an interview with CURE®. “Obviously (ports) come with their inherent risks, but I always say, ‘You have enough pain and suffering; you don’t need to be poked three times for your blood in the morning. You have it already accessed.’ We can just do a quick little flush, draw your blood and be out of your hair. That ease that it provides was really beneficial.”

CURE® spoke with Bell to learn more about ports and how patients can take care of them to prevent infection and other complications.
What are ports typically used for?

Ports can be used for chemotherapy (which can be damaging to small veins), blood draws, continuous IV fluids, continuous antibiotics or a medication delivery system for long-term use.

How long do patients typically have a port implanted?

Patients usually have a port implanted for the duration of their chemotherapy treatment. If the port isn’t being actively used, guidelines recommend that nurses flush it every four weeks with heparin to make sure it is still functioning. Once it has been shown that a patient’s chemotherapy treatment was successful, the port can be removed.

Are there any issues associated with ports?

A port is used as a delivery system that goes directly into a patient’s central system and the tip of the port stays right outside their heart. Bacteria on a patient’s skin may get introduced into their system, which can cause widespread infection.

Can patients feel where the port is placed?

Patients shouldn’t feel any discomfort with the port, which is about the size of a quarter. If anything, it feels like a little pin cushion underneath the skin. Otherwise, it lies flat on a patient’s body.

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How can patients help keep their port clean?

When the port is in use with the dressing, nurses own that responsibility, which can include keeping the area clean at all times with an antimicrobial wipe. At home, the patient should maintain good hygiene and monitor for any signs of change near the port such as redness, inflammation, fever, pus, peeling or signs that it may be infected.

Are there times when a patient should call their cancer team about port complications?

Even in (patients who are) most diligent, whenever something foreign like a port is placed inside the body, it can cause infections, although it is uncommon. Be sure to monitor the area where a port is placed, especially after it is implanted.

Should patients avoid certain products like perfumes?

Avoiding scents and detergents is more of a personal preference. Port care is more about being conscious of a patient’s body and what it may respond to.
The landscape of MPN blood cancers is shifting, with emerging treatments and evolving perceptions that are bringing newfound hope to patients, caregivers, and clinicians. Sole 2 Soul for MPN is an innovative collaboration between Canadian MPN Research Foundation, the MPN Research Foundation, and Cure Media Group and is dedicated to supporting and uplifting the MPN blood cancer community in both Canada and the USA. We empower those who are closely impacted by MPN blood cancers to challenge their inner adventurer while raising funds to fuel change for those who are facing a debilitating incurable blood cancer.

Waterton Lakes National Park
August 3-7, 2022
The inaugural trek of Sole 2 Soul for MPN will take place with teams across Canada and the United States trekking through Waterton Lakes National Park in Canada which borders Montana’s Glacier National Park. Team members are currently raising funds to fuel research and to amplify the voices of those living with an incurable blood cancer. These life-changing experiences offer participants an opportunity to redefine what’s possible during a MPN diagnosis while joining a welcoming team that challenges their personal preconceived limits and widens their circle of support.

Supported by:

For more information and to get involved, visit curetoday.com/cure-adventures/sole2soul

To learn more about Canadian MPN Research Foundation, visit cmpnrf.ca

To learn more about MPN Research Foundation, visit mpnrf.org

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SIERRA ONCOLOGY
MARGARET CAMPBELL, B.S.N., RN, Wins CURE®’s 2022 Extraordinary Healer® Award

For the first time in three years, CURE® welcomed 500 attendees in person and hundreds more virtually to honor the 2022 Extraordinary Healer® award recipient. 

CURE MEDIA GROUP recognized Margaret “Peg” Campbell, B.S.N., RN, as the winner of its 2022 Extraordinary Healer® award, which honors nurses in the cancer community who strive to go above and beyond their call of duty.

Essays were submitted by colleagues, patients and family members identifying Campbell, two finalists and almost 100 other Extraordinary Healer® nominees, all detailing the noble acts of oncology nurses, from staging a last-minute wedding for a patient who had days to live to spending more than a decade guiding a patient through their breast cancer journey.

The Extraordinary Healer® award was given on April 27, 2022, during a hybrid celebration held in conjunction with the 47th Annual Oncology Nursing Society Congress. The night featured a keynote address from award-winning actor, producer and cancer advocate Patrick Dempsey. During his speech, Dempsey, who is best known for his portrayal of Dr. Derek Shepherd on the hit ABC series “Grey’s Anatomy,” discussed his mother’s journey with ovarian cancer as well as...
what led him to launch the Dempsey Center in Lewiston, Maine, in 2008. Of note, the Dempsey Center is not a cancer treatment facility. It provides services that support healing and symptom management to patients with cancer and their families free of cost.

Dempsey talked about being live in person again for the first time in several years and expressed his gratitude to all in attendance, both in Anaheim, California, and those watching around the world.

"Why are we here? What is our purpose in life? (It is) to lift up the people who are in need to give them the love (and) compassion (that) they so deserve.

– PATRICK DEMPSEY

She advocates for her patients in ways big and small. In short, she cares for the whole person.”

The other finalists for the Extraordinary Healer® award were Livia Szeto, B.S.N., RN, OCN, a research nurse at the University of Chicago Medical Center, and Tammy Allred, RN, OCN, a nurse navigator at UNC Lineberger Comprehensive Cancer Center in Chapel Hill, North Carolina.

ACHIEVING A CHILDHOOD DREAM

Allred was nominated by Darlene Burns, of Hampstead, North Carolina. In her nominating essay, Burns wrote that Allred dreamed as a child to have a mobile clinic to help treat children in indigent communities around the United States.

Although the allure of driving a mobile clinic faded after her graduation in 1985, Allred became interested in the newly emerging specialty of cancer care. Burns wrote that Allred saw oncology care as an opportunity to heal the human spirit, if not the disease.

And for 16 years, Allred has been doing just that as a nurse navigator at UNC Lineberger Comprehensive Cancer Center.

“It’s my dream job,” Allred said. “I look at every one of my patients as if they were my family members and I treat them as I would (want to) be treated. I build close relationships with patients, and they know they can call me day or night if they need anything. One of my patients with metastatic cancer and kidney failure totaled his pickup truck while driving to dialysis. He talked to me about ending his life the day he totaled his car because he felt like he was fighting a losing battle, having cancer, kidney disease and now, no way to get to dialysis. We are working to arrange for in-home peritoneal treatment and I’m working with agencies to get him a new truck. We saved him by showing him we care.”

DRIVING RESEARCH WITH COMPASSION

Szeto was nominated by her colleague Dr. Christine Bestvina of the University of Chicago, who highlighted Szeto’s dedication and loyalty to her patients there, where she has worked since 1987.

“For the majority of her career, she has served as an oncology nurse navigator, working primarily in thoracic oncology,” Bestvina wrote in her essay. “I have been at the University of Chicago on faculty for less than five years and having Livia’s foundational knowledge of the university, and those who work here has been essential. Throughout her years, she has facilitated strong relationships across disciplines, from interventional radiology to intravenous therapy to bed access. She is able to use all of these relationships

"Why are we here?"

“Why are we here?” he asked.

“What is our purpose in life? (It is) to lift up the people who are in need to give them the love (and) compassion (that) they so deserve.”

‘QUIET HERO’

Campbell, a research nurse who has worked at Dana-Farber Cancer Institute in Boston since 2003, was nominated by her colleague Dr. Nancy Lin, associate chief of the Division of Breast Oncology in the Susan F. Smith Center for Women’s Cancers at Dana-Farber.

Lin referred to Campbell as a “quiet hero” who, despite very little recognition — she is often not included as an author on published studies and doesn’t present medical data to an audience of her peers — balances patient obligations with the demands of the trials that have led to advances in the breast cancer space.

“I have witnessed how Margaret always goes above and beyond in communicating with patients and delivering outstanding clinical care,” Lin wrote in her nominating essay. “She takes extra care to make sure that all trial requirements are met, while also asking patients about other commitments (vacations, graduations, weddings) so that the scheduling can be adjusted to accommodate important events in patients’ lives.

Of note, the Dempsey Center is not a cancer treatment facility. It provides services that support healing and symptom management to patients with cancer and their families free of cost.

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to improve care of her patients by enabling early access to services our patients desperately need.”

Bestvina also commended Szeto's ability to connect to her patients in a manner that allows her to elicit a patient's sensitive information, from illicit drug use to fears at the end of life. Bestvina said that by enabling her patients to express their needs and sensitive information, the providers can take better care of the patients.

Originally a clinical trial nurse, Szeto became a nurse navigator six years ago and now helps care for patients enrolled in trials and those who are not.

“That way the patient doesn't have to interact with so many different nurses,” Szeto explained. “There's just one primary nurse taking care of the patient. The navigator role can be pretty complex. You're not only taking care of the patient, but the family as well, helping them find their way through the health care system. They encounter many different specialties and need someone to help them understand them all.”

HEROES
Kristie L. Kahl, vice president of content at MJH Life Sciences®, the parent company of CURE Media Group, spoke from the heart and highlighted a personal experience that spotlighted the effect oncology nurses have on their patients as well as their loved ones.

“As I sat down to think about what I wanted to say to highlight how far we've come in the cancer space in just 20 years, I'd be remiss not to share my own story and appreciation for every one of you in this room,” she said.

Kahl was referencing the cancer space over the past two decades as 2022 marks CURE®’s 20th year in circulation. She recalled her childhood friend Krista, who had received a diagnosis of Ewing sarcoma at age 15 years in 2003 — just one year after CURE®’s founding. Although doctors gave Krista a poor prognosis, she had no evidence of disease eight months later. But the disease returned in 2005 and it had spread to her lungs. Kahl said she and her friends would spend their weekends visiting Krista at Children’s Hospital of Philadelphia, where, she said, she learned how valuable oncology nurses were.

“It was then, to me, each and every single one of you in this room became a hero to me,” she said. “Before working for CURE®, before anything, you all in this room wore a cape in my eyes. I was only 15, but the impact that Krista’s nurses had on my life, in addition to hers, is indescribable.”

Krista died from her disease in 2007, and Kahl said she couldn't help but look back at how far the space has come since.

“And a large part of that success is each and every one of you sitting in this room tonight,” she concluded.

The event was sponsored by Bristol Myers Squibb and Janssen Oncology, which is a wholly owned subsidiary of Johnson & Johnson. Peg Esper, region associate director in the U.S. Field of Medical Oncology at Bristol Myers Squibb, noted that not everyone can fulfill the responsibilities of an oncology nurse.

“Being an oncology nurse is really not for the faint of heart. I believe that you give a small portion of your soul to every patient and caregiver that you touch, you become their confidant, their resource person, the person they yell at, complain to, cry with and hug every time they come to the clinic or the hospital,” said Esper, who spent several decades as an oncology nurse before joining the pharmaceutical company. “They trust you. They depend on you.”

Christine McDonough, marketing director for multiple myeloma at Janssen Oncology, said oncology nurses fulfill a larger purpose in life.

“You speak up for your patients when they don’t have a voice,” she said. “You support your health care team and despite burnout and frustrations, you somehow figure out a way to soldier on, giving it all you have, because to you, it’s worth it. … For you, oncology is not just a job; it’s a purpose in life.”

Erik Lohrmann, vice president of CURE Media Group, acknowledged those who made the event possible: “Our industry partners, BMS and J&J. On behalf of MJH Life Sciences® and all attending, thank you for making tonight possible,” he said. “My CURE® staff, who work unbelievably hard to bring our events to fruition, thank you. Lastly, and the reason we're here tonight: the oncology nursing community. CURE® is proud to shine a spotlight on a profession that routinely goes above and beyond for cancer patients. Thank you for all you do.”

“(This event) provides (us) an opportunity to recognize those who dedicate their careers (and) their lives to helping patients,” Lohrmann said, “renewing perspective, reminding us why we entered the health care field.”

“I speak on behalf of myself and CURE® in that we appreciate those who serve on the front line during what can be one of the scariest and most overwhelming experiences a patient and their loved ones can face,” Kahl said during the ceremony. “I would like to thank all of the frontline workers with us tonight for everything you have done in the last two years, never skipping a beat to ensure your patients could continue treatments as the COVID-19 virus turned many of our worlds upside down. From the bottom of our hearts, we thank you.”
THANK YOU FOR AN Extraordinary Evening!

*CURE* magazine would like to thank everyone who attended the 2022 Extraordinary Healer® award celebration!

Congratulations to Margaret (Peg) Campbell, B.S.N., RN, of the Dana-Farber Cancer Institute in Boston, who received *CURE*’s 2022 Extraordinary Healer® award at a celebration in Anaheim, California, on April 27, before more than 600 of her nurse peers. Peg was nominated by Dr. Nancy Lin. As the winner, Peg received a spa trip for two to the Eden Roc Miami Beach resort.

*CURE* would also like to recognize our finalists and the readers who nominated them:

**Tammy Allred, RN, OCN**  
UNC Lineberger Cancer Center  
Nominated by Darlene Burns

**Livia Szeto, B.S.N., RN, OCN**  
University of Chicago Medicine  
Nominated by Dr. Christine Bestvina

THANK YOU TO OUR SPONSORS

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Congratulations to All Nominees

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Norwalk, Connecticut

Tammy Allred, RN, OCN
Chapel Hill, North Carolina

Christine Amoroso, B.S.N., RN, OCN
Philadelphia, Pennsylvania

Wendy Austin, M.S., RN, AOCN, COA, NEA-BC, FACHE
Irving, California

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Brick, New Jersey

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Findlay, Ohio

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Hackensack, New Jersey

Margaret Campbell, B.S.N., RN
Boston, Massachusetts

The Cancer Team at Bellin Health
Green Bay, Wisconsin

Katherine Caprinolo, B.S.N., RN
Baltimore, Maryland

Diane Cope, Ph.D., APRN, BC, AOCNP; and Sandra Molina Leahy, B.S.N., RN, OCN
Fort Myers, Florida

Rebecca Crane-Okada, Ph.D., RN, CNS, AOCN
Santa Monica, California

Tuesday Crews, B.S.N., RN, OCN
Santa Monica, California

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Chicago, Illinois

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Springfield, Missouri

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Forest Hills, New York

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East Hills, New York

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Keene, New Hampshire

Maribel Lopez, B.S.N., RN
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Provvidence, Rhode Island

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Markham, Ontario, Canada

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Branson, Missouri

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Michael Wojcik, RN
Hastings, Michigan

Laura Wood, M.S.N., RN, OCN (retired 2021)
Cleveland, Ohio

Christine Wylie, M.S.N., RN, OCN
St. Louis, Missouri

Kimberly Zwibel, B.S.N., RN, BMTCN
Mineola, New York
COVER STORY crowdfunding
Until the 1990s, there was no such thing as crowdfunding. Financially compromised patients with cancer relied on help from friends and relatives, bake sales, art and craft fairs, garage sales and other in-person events to raise money for their treatments.

But in 2010, GoFundMe was established and is now the largest crowdfunding platform in the world. It changed the way many patients with cancer raise funds for their care.

One reason so many patients resort to crowdfunding is the ever-rising cost of cancer treatment, says Dr. Benjamin N. Breyer, chief of urology at Zuckerberg San Francisco General Hospital and Trauma Center, who co-authored a 2019 study of crowdfunding for cancer care. 

Many patients with cancer who have limited financial resources have started to use crowdfunding campaigns to pay for the daunting bills associated with their treatment and subsequent care.
“There are really innovative and groundbreaking technologies here in the United States,” notes Breyer. “Those surgical techniques and advanced medical care can lead to prolonging the life of or even curing cancer patients.”

The downside, of course, is the expense.

And it’s not just the uninsured who are affected, according to Dr. Andrew J. Cohen. “Even when patients have insurance, there are co-pays and coinsurance fees that need to be covered,” says Cohen, director of trauma and reconstructive urologic surgery at Johns Hopkins Medicine in Baltimore and lead author of the 2019 study.

“Here at Johns Hopkins, we see patients from all over the country with rare cancers,” he explains. “To come here, they have travel expenses, hotel fees, child care expenses, and have to deal with the time taken off work.”

**DESPERATE TIMES, DESPERATE MEASURES**

Cohen reveals that many patients who turn to crowdfunding have already tried every other avenue of fundraising and have reached the limit of their energy and resources.

“These are individuals who are at the end of their rope, facing the toughest challenge of their lives,” he says. “Some have had to sell their possessions and declare bankruptcy. Others have eliminated all leisure activity, and still others have had to cut back on food purchases.”

The need for crowdfunding, Cohen notes, is a commentary on society and how the public takes care of those who are ill.

“The fact that people have to go this route tells me we’re not doing as good a job as we could be — it really puts an asterisk on our current health care system.”
One of the unfortunate findings of the study Cohen and Breyer led is that most cancer campaigns don’t reach their goals. The study, which examined 1,035 campaigns, found that the median fundraising goal was $10,000, while the median total donation was $2,125 — only about a quarter of the requested goal. One reason may be the increasing competition for dollars, says Breyer.

“Contributions come from a somewhat limited pool, and people can only give so much, so campaigns really end up jostling for attention,” he explains. “But one of the great aspects of it is that a site like GoFundMe is massive, so you get to tap into a very large pool of people who can potentially help you.

“Those who are technologically literate, who are in tune with social media and who have large social networks are more likely to reach their goals. Unfortunately, sometimes we Americans have trouble asking for help.”

DOUBLE WHAMMY

That was the case for Susel Gonzalez, a 46-year-old elementary schoolteacher from Austin, Texas, who never imagined she’d have to ask anyone for financial assistance. Although she chose teaching rather than one of the more lucrative careers selected by her college classmates, it paid the bills and helped her feel she was making a difference.

But in January 2022, she began feeling so exhausted that she made a doctor’s appointment and learned she had a massive paraesophageal hiatal hernia — which is when the upper part of the stomach protrudes through an opening in the diaphragm into the chest — that was causing esophageal bleeding. Gonzalez needed three blood transfusions to restore her hemoglobin level and underwent a hernia repair procedure in April.

But that wasn’t the end of it. During a physical before her surgery, Gonzalez told her internist that she’d had painful menstrual cramps for years, so she was referred to a gynecologist specializing in pelvic pain. The doctor prescribed tests to check for pelvic dysfunction, including a pap smear and ultrasound. She also ordered an endometrial biopsy.

When the test results came in, Gonzalez learned she had endometrial cancer. “If it hadn’t been for the pain, they wouldn’t have found the cancer until it was too late,” she says.

With two upcoming surgeries to pay for in addition to post-surgical care, Gonzalez’s friends urged her to set up a crowdfunding campaign. Although she had donated to others’ campaigns, she resisted because the prospect of requesting money for herself was daunting.

“I felt very exposed, vulnerable and embarrassed,” she remembers. “It’s pretty terrifying because you’re a teacher, you’re educated, you’re supposed to be a productive member of society.”

A RELUCTANT CAMPAIGN

But because of a number of factors beyond her control,
such as the skyrocketing rent at her apartment complex and the cost of the special diet required in the lead-up to surgery, Gonzalez felt as if the walls were closing in. She recalls coming home on a Friday to no hot water in her apartment because of an unresponsive management company, only to find another stack of bills in the mail. “I just felt so overwhelmed and I broke down in my living room. I remember thinking, ‘I can’t do this alone. I’m going to need help,’” she says.

Her friends and co-workers immediately rallied. Her best friend, knowing she was reluctant to ask others for money, reminded Gonzalez of the donations she had made in the past. “She asked me if I thought less of the people who’d reached out for help,” says Gonzalez.

The last thing someone newly diagnosed with cancer needs is more stress, but Gonzalez said she found the campaign setup process relatively straightforward. “I had to upload a photo, and I was still feeling guilty about it, so I thought, ‘If you’re going to go full grifter, put up a cute photo of you and the dog,’” she says. “Then I wrote up my story and uploaded it. I had to prove my identity by uploading a picture of my driver’s license and give them a bank statement to prove it was my account. It was actually surprisingly simple to set up.”

AN UNWELCOME SURPRISE
Leslie Hughes also found the process easy when creating a campaign for her 30-year-old photographer boyfriend.
Elliott Howell. The 34-year-old writer met Howell four years ago when she, as Howell puts it, “slid into my DMs.”

Hughes said they met in person and then connected on Instagram, which was “so millennial of us.” She recalls picking Howell up at the airport when he returned from a five-day trip on March 13 only to awaken to him having a seizure around midnight. “It was absolutely terrifying,” she recalls. “I didn’t really understand what was going on.”

At UCLA Health’s emergency department, a scan showed a tumor in Howell’s brain, but doctors believed it was benign. When the couple were referred to a surgeon a week and a half later, however, they learned it was anything but. “He said that from the scans, it looked like stage 3 cancer, and he wanted to get Elliott into surgery as soon as possible,” says Hughes.

A DIFFERENT SET OF CONCERNS
Younger patients face a unique set of challenges after a cancer diagnosis, says Lauren Ghazal, a research fellow at the University of Michigan School of Nursing’s Department of Systems, Populations and Leadership. Ghazal, herself a cancer survivor, led a 2022 study of young patients with cancer to determine their perceptions of medical crowdfunding.

“We looked at young adults 20 to 39 years old,” she says. “The good news is that due to treatment advances, young adult cancer survivors are living longer than ever before. But they also face unique hurdles and are burdened by those challenges.”

Their diagnoses come at a time of milestones such as completing their education, living on their own, establishing employment and romantic relationships and sometimes starting a family, Ghazal explains. A cancer diagnosis short-circuits that process.

“It creates a pretty big financial shock to your quality of life and then you have to struggle through our complicated health care system,” she notes.

As with most patients who turn to crowdfunding, younger people are often averse to asking for help. Perhaps they’ve recently moved out of their parents’ house, are finally on their own and are looking forward to taking care of their own affairs.

“You’re trying to be financially independent but then you get sick and have to lean on others for help. Our study showed that there are huge psychological implications in having to ask others for money,” Ghazal says.

PUSHING THROUGH THE RESISTANCE
Hughes explains how she has experienced what Ghazal was referring to.

“I hate asking for money,” she says. “It makes me uncomfortable. I don’t even ask my parents for money, let alone friends or strangers. It felt really weird for me, even though the GoFundMe campaign was on behalf of Elliott. But in the end, I realized we had to move forward because he needs the money to help him through this, and if other people can do it, so can we.”

The couple are fortunate to have an extensive friend network at home in Venice, California, and they made good use of it. One friend who knew someone who’d crowdfunded told them their original goal amount of $10,000 to $15,000 was way too low and suggested increasing it to at least $125,000.

Hughes put her travel writing on hold to care for Howell, but she put her writing experience to good use crafting Howell’s campaign. “At first I geared his story more toward friends,” she says, “but realized there would be donors who didn’t know Elliott, so I went further and told his whole story.”

Howell notes that he is grateful for all the help.

“Her skill set makes her very good at crafting the story,” he says. “I want to give her full credit for putting the story down and letting people follow along in my journey. And she’s been constantly updating it, which is something I probably wouldn’t be doing. My writing skills are terrible.”

Because wording is so crucial in telling a patient’s story, Hughes suggests retaining a writer if they’re unsure how to proceed. Patients may also look at other crowdfunding sites to get ideas on how others communicated their personal story.

Gonzalez highly recommends crowdfunding to anyone in financial distress from a cancer diagnosis and hopes telling her story will help those thinking of trying it. Although it may be difficult, Howell recommends trying to stay as positive as possible.

As he wrote in an Instagram post: “I’m setting my sights on the moon, the path we call life that is ahead of me, and whatever adventures, travels, friendships, and connections await. I hope that anyone reading this is moved to do the same.”
The potential to celebrate more of life’s everyday moments.

Living longer could start with LIBTAYO.

LIBTAYO will not work for everyone.

What is LIBTAYO?

LIBTAYO (Lib-TIE-oh) is a prescription medicine used to treat people with a type of lung cancer called non–small cell lung cancer (NSCLC). LIBTAYO may be used as your first treatment when your lung cancer has not spread outside your chest (locally advanced lung cancer) and you cannot have surgery or chemotherapy with radiation, OR your lung cancer has spread to other areas of your body (metastatic lung cancer), and your tumor tests positive for high “PD-L1,” and your tumor does not have an abnormal “EGFR,” “ALK,” or “ROS1” gene.

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

Important Safety Information

What is the most important information I should know about LIBTAYO?

LIBTAYO is a medicine that may treat certain cancers by working with your immune system. LIBTAYO 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, 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: headache 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, or 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, or loss of appetite
- Skin problems: rash, itching, skin blistersing or peeling, painful sores or ulcers in mouth or nose, throat, or genital area, fever or flu-like symptoms, or 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 LIBTAYO. 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 or 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, or bruising
- Infusion reactions that can sometimes be severe. Signs and symptoms of infusion reactions may include: nausea, chills or shaking, itching or rash, flushing, shortness of breath or wheezing, dizziness, feel like passing out, fever, back or neck pain, or facial swelling
- 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 complications may happen if you underwent transplantation either before or after being treated with LIBTAYO. Your healthcare provider will monitor you for these complications
In a study, LIBTAYO was proven to help patients with advanced NSCLC live longer versus chemotherapy

**Median overall survival (OS)**

- At 22.1 months, half of the patients taking LIBTAYO (178 out of 356 patients) were alive versus 14.3 months for patients taking chemotherapy (177 out of 354 patients)

*Median overall survival (OS) is the time in a trial—expressed in months or years—when half of the patients are still living.

**More patients were alive with LIBTAYO compared with chemotherapy**

- As of March 2020, results from the trial showed that 248 out of 356 patients (70%) taking LIBTAYO were alive, compared with 213 out of 354 patients (60%) taking chemotherapy

**Individual results may vary.**

*Patients were enrolled between June 27, 2017, and February 27, 2020. Patients were treated with LIBTAYO for an average of 27 weeks. The study is still ongoing, and patients will be followed up for up to 4 years.

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**Important Safety Information (continued)**

Getting medical treatment right away may help keep these problems from becoming more serious. Your healthcare provider will check you for these problems during your treatment with LIBTAYO. 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 LIBTAYO if you have severe side effects.

**Before you receive LIBTAYO,** tell your healthcare provider about all 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 a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome
- are pregnant or plan to become pregnant. LIBTAYO 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
- You should use an effective method of birth control during your treatment and for at least 4 months after your last dose of LIBTAYO. Talk with your healthcare provider about birth control methods that you can use during this time

- Tell your healthcare provider right away if you become pregnant or think you may be pregnant during treatment with LIBTAYO

- Females who are breastfeeding or plan to breastfeed. It is not known if LIBTAYO passes into your breast milk. Do not breastfeed during treatment and for at least 4 months after the last dose of LIBTAYO

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

The most common side effects of LIBTAYO include muscle or bone pain, tiredness, rash, and diarrhea. These are not all the possible side effects of LIBTAYO. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. You may also report side effects to Regeneron Pharmaceuticals and Sanofi at 1-877-542-8296.

**Please see additional Important Safety Information on the previous page and Brief Summary of full Prescribing Information on the following pages.**

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

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**IMPORTANT PATIENT INFORMATION ABOUT LIBTAYO® (cemiplimab-rwlc) INJECTION**

Please speak with your healthcare provider regarding LIBTAYO. Only your healthcare provider knows the specifics of your condition and how LIBTAYO may work with your overall treatment plan. If you have any questions about LIBTAYO (pronounced Lib-TIE-oh), speak with your healthcare professional. Prescription Only.

What is LIBTAYO? LIBTAYO is a medicine that may treat certain types of cancers by working with your immune system. LIBTAYO 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.

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**Lung problems.**
- cough
- chest pain

**Intestinal problems.**
- diarrhea (loose stools) or more frequent bowel movements than usual
- 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)

**Hormone gland problems.**
- headache that will not go away or unusual headaches
- eye sensitivity to light
- rapid heartbeat
- increased sweating
- extreme tiredness
- weight gain or weight loss
- feeling more hungry or thirsty than usual

**Kidney problems.**
- decrease in your amount of urine
- blood in your urine

**Skin problems.**
- rash
- itching
- skin blistering or peeling
- fever or flu-like symptoms

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 LIBTAYO. 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 or 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.** Signs and symptoms of infusion reactions may include:
- nausea
- chills or shaking
- itching or rash
- flushing
- shortness of breath or wheezing
- dizziness
- feel like passing out
- fever
- back or neck pain
- facial swelling

**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 complications may happen if you underwent transplantation before or after being treated with LIBTAYO. 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 your treatment with LIBTAYO. 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 LIBTAYO if you have severe side effects.

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- have received or plan to receive a stem cell transplant that uses donor stem cells (allogeneic)
- have a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barre syndrome
- are pregnant or plan to become pregnant. LIBTAYO 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 LIBTAYO.
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– Tell your healthcare provider right away if you become pregnant or think you may be pregnant during treatment with LIBTAYO.
• are breastfeeding or plan to breastfeed. It is not known if LIBTAYO passes into your breast milk. Do not breastfeed during treatment and for at least 4 months after the last dose of LIBTAYO.

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 LIBTAYO?
• Your healthcare provider will give you LIBTAYO into your vein through an intravenous (IV) line over 30 minutes.
• LIBTAYO is usually given every 3 weeks.
• Your healthcare provider will decide how many treatments you will 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 LIBTAYO?
LIBTAYO can cause serious side effects, including:
• See “What is the most important information I should know about LIBTAYO?”
The most common side effects of LIBTAYO include muscle or bone pain, tiredness, rash, and diarrhea.
These are not all the possible side effects of LIBTAYO. 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 LIBTAYO. Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. If you would like more information about LIBTAYO, talk with your healthcare provider. You can ask your healthcare provider for information about LIBTAYO that is written for health professionals.
Uncovering New Ways to Make Surgery Safer

The use of newer tools and techniques may be reducing the risk of surgical site infections and other complications in patients receiving treatment for gynecologic cancers.

By HEATHER STRINGER

When Nancy Tellez, 37, received a cervical cancer diagnosis in 2019, her oncologist was confident the surgery to treat the cancer would have no complications because Tellez was young and healthy.

Her cervix, uterus and a portion of her vagina were removed during a radical hysterectomy, and she was told to expect some discomfort during recovery after discharge from the hospital.

The pain in her pelvis worsened when she returned home, but Tellez, of Topeka, Kansas, assumed the throbbing was normal after surgery. During the following four days, her right pelvis became swollen, fluid started leaking out of her vagina and her level of discomfort surpassed labor pains. She also had a temperature of 104 degrees.

A friend rushed Tellez to the emergency room, where a CT scan showed a mass in her pelvis. During a second surgery, doctors drained the abscess.
The last thing Tellez remembered that day was shaking because she felt extremely cold in the recovery room, and then she lost consciousness. She went into septic shock due to an infection, and she awoke briefly at one point as a priest was reading her last rites. Tellez was treated with antibiotics and regained consciousness several days later, when doctors explained that she was lucky to be alive.

The infection was likely caused by urine leaking from a tear in her urethra. She also developed Clostridioides difficile (an infection commonly known as C. diff that can cause severe diarrhea and inflammation of the colon) while in the hospital, possibly as a result of the antibiotics.

Although Tellez eventually recovered and is grateful that her cancer is in remission, she wishes she had understood the risk of infection before undergoing surgery.

“The doctor briefly touched on one or two potential complications, but nothing about the risk of infection,” she says. “I had so many medical bills related..."
to the complications, and I was going through a divorce and raising four children.”

Surgery is a part of treatment for many patients diagnosed with gynecologic cancer, which includes uterine, ovarian, cervical, vaginal and vulvar cancers.

“Infections after surgery are a problem in the United States and worldwide,” says Dr. Oliver Zivanovic, director of innovative surgical technology at Memorial Sloan Kettering Cancer Center in New York City. “I’m taking care of patients with gynecologic cancer who are already suffering from a complex disease, and it’s important to try to minimize the risk of infections for these patients.”

The surgeries range from laparotomy — a large incision in the abdomen — to minimally invasive procedures such as a laparoscopy (use of a thin, lit tube with a video camera administered via a small incision) or robotic approaches to vulvar and vaginal procedures involving removal of tissue in a localized area. The risk of infection is lower with early-stage disease that can be treated with minimally invasive surgery, but women with advanced cancer are usually not candidates for laparoscopic or robotic procedures, says Zivanovic.

“I see many older patients who present with metastatic ovarian or uterine cancer who require large incisions, long operative times and blood transfusions, and all these factors increase the risk of infection,” he says.

Studies have shown that patients with gynecologic cancer who require a bowel resection (the removal of some or all of the large intestine) during surgery are at highest risk of surgical site infection (SSI), with rates ranging from 33% to 37% in recent studies. Patients may also have comorbidities, such as poorly controlled diabetes, obesity or compromised immune systems, that can elevate the chance of developing an infection, according to Zivanovic.

Infections may increase the length of stay in the hospital and the chance of needing additional interventions such as a repeat surgical procedure — and elevate the risk of death by as much as elevenfold.

Although infection after surgery is a complex problem, researchers are exploring strategies to reduce the risk of this complication.

“In gynecologic oncology, many researchers and surgeons are working to discover ways to make surgery safer,” says Dr. Amanda Nickles Fader, a professor of gynecology/obstetrics and oncology and vice chair of gynecologic surgical operations at Johns Hopkins Health System in Baltimore. “These strategies help patients experience a better recovery and transition more quickly to further cancer treatments, if needed.”

SUCCESS WITH INTERVENTIONS

Nickles Fader and colleagues previously studied the outcomes of more than 200 women who underwent cytoreductive surgery (a procedure to remove tumors in the abdominal cavity) for ovarian cancer, and the results demonstrated that a “bundle” of infection prevention strategies reduced SSIs from 20% to 3%, and the hospital readmission rate dropped from 13% to 3%.

The strategies included the use of a sterilizing soap known as chlorhexidine, which the patients applied at home before surgery and the medical team used during the surgery. Patients in the bundle group also received antibiotics prior to surgery, and those requiring bowel resection were prescribed laxatives the night before to clear the colon. During especially prolonged surgeries, patients received antibiotics during the procedure, and those undergoing colon resection received broader-spectrum antibiotics that acted on a wider range of bacterial types.

“Communication between the surgery, anesthesiology and nursing teams is critical during surgery to keep the patient safe,” explains Nickles Fader.

Before closing abdominal incisions in patients who underwent colon resection, the operating team changed gloves, gowns and medical instruments to avoid using surgical tools that could be contaminated with bacteria from the colon. In surgeries involving colon resection, these safety measures reduced the rate of infection from 33% to 7%.

While many hospitals are leveraging these strategies to minimize infections, not all are, notes Nickles Fader.

“Patients should speak to their surgeons about what will be done to mitigate perioperative risk,” she says. “If there is no clear plan, patients may wish to seek a second opinion.”

Of note, patients are advised to seek care from centers that routinely perform large numbers of procedures with a team of physicians and staff that specialize in gynecological or abdominal surgery and also provides adequate explanation and education.

Uncontrolled diabetes can also compromise the immune system and increase the risk of infection, according to Dr. Marcia Ciccone, a gynecologic oncologist at the Keck...
Infections after surgery are a problem in the United States and worldwide.

—DR. OLIVER ZIVANOVIC

School of Medicine of the University of Southern California in Los Angeles.

“I make sure the patient’s blood sugar is under good control pre- and postoperatively,” she says.

If patients are very obese, she places a drain in the subcutaneous fat during surgery because excessive depth and volume of subcutaneous tissue increase the risk of infection. Nutritional deficiencies are also a risk factor for poor wound healing, according to Ciccone.

“A lot of our cancer patients have diminished appetites or nausea, and they have increased metabolic demands due to the cancer,” she says. “Good nutrition and a balanced diet help the immune system, and patients who cannot eat should receive artificial nutrition and hydration after surgery.”

CLOSER MONITORING AT HOME

Researchers are also experimenting with electronic systems that give patients an opportunity to report their symptoms in the days following discharge from the hospital. Zivanovic recently led a pilot study in which patients recovering from minimally invasive gynecologic surgery answered questions daily to track eight symptoms: pain, nausea, vomiting, shortness of breath, fever, swelling, discharge and redness around the incision. Pain, nausea and swelling were the most commonly reported symptoms.

“If a patient still has moderate to severe pain three to five days after this type of surgery, something may be wrong,” notes Zivanovic.

In these cases, an email alert was sent to the medical team and the patient was told to call the doctor’s office immediately. Most of the participants in the study agreed or strongly agreed that electronic symptom tracking was helpful and easy to use and they would recommend it to others.

Investigators at Memorial Sloan Kettering Cancer Center are also developing a similar tool for patients who are in the hospital for more than three days after complex surgeries.

This type of tool could be beneficial for some patients like Andrea Brockway, 57, of Crestline, California, who received a diagnosis of uterine cancer in 2020 after she started spotting. The radical hysterectomy went smoothly, but a week later she noticed that the 5-inch abdominal incision was turning red, was starting to ooze and felt painful. She notified her doctor and the medical team confirmed that the wound was infected.

Her surgeon reopened the incision, drained the infection, prescribed antibiotics and gave Brockway a wound vacuum device that held the edges of the wound together and removed fluid from the area while she was recovering at home.

“Fortunately, my doctor had prepared me as far as what to look for related to signs of infection,” says Brockway. “When I called to report the symptoms, they told me to come in right away.”

The infection healed after two weeks, and she later underwent radiation therapy.

TACKLE PROBLEMS EARLY

Although studies are exploring strategies to prevent infections like the ones Brockway and Tellez experienced, Dr. Haider Mahdi, a gynecologic oncologist at UPMC Hillman Cancer Center at Magee-Womens Hospital in Pittsburgh, was curious about the level of risk associated with different types of gynecologic surgery.

He and colleagues studied more than 6,800 patients who were diagnosed with SSIs after procedures to treat endometrial, cervical or ovarian cancers. The study authors found that the risk of infection after a laparotomy was 3.5 times higher compared with minimally invasive surgery (7% versus 2%). In the laparotomy group, predictors of SSI included an endometrial cancer diagnosis, obesity, preoperative anemia, ascites (fluid in the abdomen) and perioperative blood transfusion. Patients who developed SSIs were five times as likely to need an additional operation to treat the infection.

“I am using these findings to counsel patients about their level of risk,” Mahdi says. “If someone is obese, for example, I will likely consider whether a minimally invasive procedure is possible, especially in endometrial cancer.”

While the risk of infection is lower with laparoscopy, new research suggests that it may no longer be the preferred option to treat early-stage cervical cancer. In a recent study, patients undergoing laparoscopic radical hysterectomy for cervical cancer were more likely to develop recurrences and peritoneal carcinomatosis (a rare cancer of the peritoneum, or the thin layer of tissue that

continued on page 38 »
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Danielle Glick, 38, was a candidate for minimally invasive robotic surgery after she received a diagnosis of cervical cancer in 2020, when she also learned that infections may occur months after a procedure. Her cancer journey began when she started feeling pressure in her lower abdomen and hip. Her Pap smear results came back abnormal, and she underwent a colposcopy (a procedure in which a provider closely examines the cervix, vagina and vulva for signs of disease). The biopsy findings showed that she had cancer in her cervix and a portion of her uterus. Glick, who lives in Connecticut, opted to have a radical trachelectomy to preserve her ovaries and most of her uterus in case she wanted to have children. During the three months following the robotic surgery, she experienced cramps, abdominal swelling and recurrent urinary tract infections.

She returned to the operating room for a dilation and curettage procedure to remove scar tissue, but in the following months she developed severe abdominal cramping. “I was so tired of going to the doctor and the hospital, but everything between my pelvic bones felt like it was being crushed,” she says. “I could not find relief, and I became suicidal.”

Glick was diagnosed with an infection known as pelvic inflammatory disease and was started on a 14-day regimen of antibiotics. The medication cured the infection and her pain subsided, but the complications were traumatic emotionally and physically.

She now encourages others not to remain silent and to immediately express what they’re experiencing. “I wish I had contacted my doctor earlier, but I was afraid that the pain was a sign that the cancer was back,” she says. “It’s important to be aware of the signs of an infection and speak up as soon as the symptoms begin.”
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A Paradigm Shift

Researchers have begun analyzing the effects of immunotherapy in earlier treatment lines in patients with lung cancer.

By TARA HAELE

Every day while stuck in traffic heading home from work, Denise Lee saw the American Lung Association billboard along the highway, informing the 54-year-old lawyer that she should get screened for lung cancer if she smoked. But when she brought it up to her doctor, she learned she was a year too young for screening recommendations. After she turned 55, Lee talked to her doctor again and this time they made an appointment. She would be retiring soon and was about to spend a month vacationing in Sicily, so she scheduled the lung scan for the Monday after she returned.

The day after her scan, the pulmonologist called Lee and told her to come in immediately.

“At that point, in my head, I knew,” Lee says. “I couldn’t breathe.” But despite her insistence on getting screening as soon as she could, the news was a surprise: “They told me I had a mass on my lung.”

By TARA HAELE
She received the results of a biopsy on Valentine’s Day 2018: The mass was lung cancer but fortunately, scans suggested it was stage 2b or 3a, meaning they had caught it early enough for surgery. It wasn’t until surgeons removed the upper lobe of her lung and 17 lymph nodes that her cancer was downgraded to stage 1b. But Lee had risk factors that increased her likelihood of the cancer returning, so her oncologist recommended chemotherapy after surgery to increase her likelihood of survival. During her chemotherapy treatments, he told Lee she qualified for the ALCHEMIST clinical trials, a group of studies exploring different experimental treatment options in people who had early-stage non-small cell lung cancer (NSCLC) completely removed by surgery and treated with chemotherapy, but who still had a high risk of recurrence.

The ALCHEMIST trial Lee joined was testing a treatment that was unheard of for early-stage NSCLC just five or six years ago: immunotherapy.

One of the ways cancer takes over the body is by blocking the immune system’s ability to attack the cancer. Immunotherapy drugs are lab-grown antibodies that work by removing those roadblocks and teaching the immune system how to fight back. But until recently, immunotherapy had been used only in stage 4 metastatic lung cancer.

“The research tends to start in the metastatic setting because those patients have incurable disease,” says Dr. Catherine A. Shu, a thoracic medical oncologist at Columbia University Cancer Center in New York City. “If there is something that’s really promising and is approved in the metastatic setting, it is often brought into the earlier-stage setting. This is the traditional paradigm for all cancer research.”

**SHIFTING THE PARADIGM**

For more than 30 years, the standard treatment for stage 3 NSCLC was daily radiation for six weeks plus chemotherapy,
features

lung cancer

explains Dr. Neal Ready, a professor of medicine at Duke Cancer Institute in Durham, North Carolina.

“All sorts of things were done to improve on that and basically none of them worked,” he says. But immunotherapy has been moving into metastatic NSCLC for nearly a decade now and “it’s transformed the field,” Ready says.

Of note, immunotherapy is a standard now for stage 3 after a patient has completed chemotherapy and radiation. As it moves into earlier stages now, “the care for early-stage lung cancer is changing pretty rapidly,” he adds.

“This (immunotherapy) is changing our treatment options for patients with early-stage disease and actually leading to more cures, so it’s a really exciting time,” says Dr. Heather Wakelee, chief of the Division of Oncology at Stanford University and deputy director of the Stanford Cancer Institute in California. “We think immunotherapy is really going to change overall survival because immunotherapy changes the whole body’s response to the disease. If you get the body to recognize the tumor and mount an immune response, that can be permanent even when the drug is stopped.”

Aside from skin cancer, lung cancer is the second most common cancer after breast cancer in women and prostate cancer in men. More than 236,000 new cases are expected in 2022 and about 130,000 people die from the disease each year. Most cases (84%) are NSCLC and although new cases have been declining, five-year survival rates remain low, particularly for later stages, making early detection paramount. “Early” can refer to anything before stage 3b or 4, when the cancer has spread too far for resection — surgical removal. Stages 1 and 2 are resectable, and stage 3a can be, Wakelee says.

“The first really definitive new treatment in early lung cancer was adding an immune therapy for the treatment of stage 3 lung cancer,” Ready says. “The PACIFIC trial was the first trial that moved immune therapy into standard treatment for potentially curable non-small cell lung cancer.”

The PACIFIC trial tested the immunotherapy Imfinzi (durvalumab) in patients with stage 3 unresectable NSCLC. All patients received radiation and chemotherapy before randomly being assigned Imfinzi or placebo. Imfinzi improved five-year overall survival rates by 31%, which were 33% with placebo and 43% with Imfinzi. The Food and Drug Administration (FDA) approved Imfinzi in early 2018 as the first NSCLC immunotherapy before stage 4.

Promising results from two other trials followed as researchers tested immunotherapy in patients with resectable cancer, both after surgery (adjuvant) and before surgery (neoadjuvant). The IMpower010 trial added Tecentriq (atezolizumab) after chemotherapy in people with resected stage 1b to 3a NSCLC. Researchers reported in October 2021 that Tecentriq improved event-free survival (time after primary treatment ends that a patient remains free of events treatment was intended to prevent or delay) by 21% for all patients at three years and by 34% for a subset of patients whose genetic testing shows tumor expression of PD-L1 above 1%. PD-L1 is a protein produced by some tumor cells that acts as a “stop” signal to immune cells and dampens their attack on cancer cells. Tecentriq, an anti-PD-L1 drug, blocks the protein, so it makes sense that a PD-L1 inhibitor would be more effective against tumors producing more PD-L1, although it is not a perfect biomarker. The FDA approved Tecentriq for patients with stage 2 to 3a NSCLC with tumors with at least 1% PD-L1 expression.

The CheckMate 816 trial tested Opdivo (nivolumab) as a neoadjuvant (presurgical) therapy: Patients with stage 1b to 3a resectable NSCLC received Opdivo with chemotherapy or chemotherapy alone before surgery. Adding Opdivo improved event-free survival (32 months vs. 21 months), with a complete pathologic response in 24% of patients compared with 2.2% receiving chemotherapy alone, leading the FDA to approve Opdivo plus chemotherapy for neoadjuvant use in people with stage 1a to 3a NSCLC.

With immunotherapy, I felt great. I had energy, I was functional. I’m not going to lie and say there aren’t side effects, but it’s not like chemo. I almost died from chemo.

– LINDA CIMINO
This (immunotherapy) is changing our treatment options for patients with early-stage disease and actually leading to more cures, so it’s a really exciting time.

– DR. HEATHER WAKELEE

Lung cancer is very aggressive and can involve microscopic spread below what tests can detect, Ready says, and that’s what immunotherapy appears to help with. “The medical treatment can potentially wipe out whatever microscopic disease is left” after resection, he says. Ready adds that lung cancer experts are optimistic that the improvements they’re seeing in clinical trials “will translate into clearly better outcomes at three to five years — the gold standard in early stage lung cancer.”

So far that’s the case for Linda Cimino, a 60-year-old nurse practitioner in New Jersey who developed a dry cough in March 2020. Cimino tested negative for COVID-19 and knew dry coughs aren’t common with most infections. Because she’s otherwise active with yoga, Pilates and daily 5-mile runs, she already suspected cancer when she called her doctor.

But the pandemic delayed each appointment, first more than five weeks to get an X-ray and CT scan because radiology centers were closed, and then another couple of weeks before she got a biopsy in late April. The diagnosis: stage 3a NSCLC. Cimino couldn’t begin chemotherapy until July, and when she asked about genomic testing, the doctor at her small community hospital said they didn’t have enough tissue for it. So she switched to Memorial Sloan Kettering Cancer Center in New York City and a full genomic work-up revealed she had high PD-L1 levels and a high tumor mutation burden, both advantageous for success with immunotherapy.

Meanwhile, the chemotherapy she was receiving wasn’t working. The tumor continued to grow into her middle and lower lobe and surgery would have required the removal of most of her lung. So instead of surgery, she underwent three weeks of radiation in December that shrank her tumor by half. Before the PACIFIC trial, Cimino’s only options would have been radiation, surgery and chemotherapy. Now, immunotherapy was an option for Cimino. Given her relatively high PD-L1 levels (42%), she followed her oncology team’s advice to opt for immunotherapy and began receiving Opdivo plus Yervoy (ipilimumab) in January 2021. A month later, Cimino had no evidence of disease. She continued immunotherapy for nine months until she developed pancreatitis, an autoimmune complication that, like other autoimmune complications, can happen with immunotherapy. It stopped in September.

“With immunotherapy, I felt great. I had energy, I was functional,” Cimino says. “I’m not going to lie and say there aren’t side effects, but it’s not like chemo. I almost died from chemo. It doesn’t kill the good cells. It boosts the body’s natural defenses to fight cancer.”

Cimino was frustrated that her first cancer center said she wasn’t eligible for immunotherapy. It was joining the support network LUNGevity soon after diagnosis that prompted her to switch providers to get genomic testing, which doesn’t drive all immunotherapy decisions in early-stage lung cancer but is recommended for all patients at any stage of diagnosis, Wakelee says. “It’s very important that we know the mutations and the PD-L1 level before making a decision,” she says.

All the immunotherapy drugs currently approved for early-stage lung cancer are PD-1 or PD-L1 inhibitors, so patients with high PD-L1 expression in their tumors typically respond better to immunotherapy. People with the EGFR mutations or ALK genetic translocations typically have fewer overall mutations and it can be harder for the immune system to recognize the cancer and attack. That means patients with EGFR or ALK can benefit less from immunotherapy and are instead treated with therapies targeting the abnormal proteins resulting from EGFR and ALK genomic anomalies.
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Many other trials are testing immunotherapy agents in early-stage lung cancer. In addition to testing Opdivo, the ALCHEMIST trial that Lee was in is testing Keytruda (pembrolizumab), as are the PEARLS/KEYNOTE-091 trial and KEYNOTE-671 trial. In July 2021, results from the IMPower030 trial — testing Tecentriq as both a pre- and postsurgery therapy — showed 90% of patients improved to the next lower stage. And the AEGEAN and MERMAID-1 trials are testing Imfinzi as pre- and postsurgery treatments. Other trials’ immunotherapy drugs have different targets, such as TIGIT, LAG3 and CTLA-4, which Yervoy inhibits.

**PROGRESS MARCHES ON**

The ultimate goal in using immunotherapy is to “improve cure rate and overall survival,” Shu says, but it takes years to collect those data, limiting disease recurrence and progression becomes a surrogate measure along the way. Meanwhile, the paradigm shift in treatment regimens has made it particularly important to have multidisciplinary oncology teams, including a medical oncologist, a pathologist, a radiation oncologist and a surgical oncologist, Shu says. A team looks at each person’s situation to determine the best treatment plan for them.

“It makes everything a little bit more complicated but also a lot more exciting” to individualize care for each patient, Shu says.

Among the barriers to immunotherapy use in early-stage lung cancer are patients’ lack of awareness of their options, inadequate insurance coverage for the drugs and not getting genomic testing done. Some patients may also struggle with a treatment schedule that involves coming in every week for infusions or taking a pill for several years, Shu says, “but most patients want the treatment if it’s been shown to work.” Side effects are usually less toxic than with chemotherapy, but toxicity may be an issue for some patients. Although rare, severe toxicities may prevent a patient from being able to undergo surgery.

But multidisciplinary teams help overcome other barriers. “Another challenge is that you’re changing a paradigm for surgeons: They usually take patients for surgery right away and now you’re telling them that you are going to give the patient this treatment first,” Shu says. “Sometimes there may be reluctance from the surgeons,” who worry the tumor will grow or they won’t be able to operate.

Patients can have those doubts, too. “A lot of patients just want their tumors out,” Shu says. “They don’t want to wait three months getting treatments before surgery.” She explains that presurgery treatment with chemo and immunotherapy can often improve cure rates. “We know that how necrotic (dead) the tumor looks at the time of surgery is much better with chemotherapy and immunotherapy, which we think means the cancer has less chance of spreading.”

And if the cancer does spread? Research and drug development are moving so quickly that patients may already have another option available to them by then.

“(With) all this research, we are actually seeing results in real time for patients,” Shu says. “Patients are always asking what’s next, and we’re coming up with it. I have patients who are on one line of treatment and by the time they’ve progressed, we’ve already come up with an FDA approval for another line of treatment for them. I have patients who have had metastatic disease for seven or eight years and are doing great.” That was unheard of in the past, she says.

“The addition of the immune therapy in early-stage diseases is going to be transformative; it’s going to lead to improved progression free-survival and overall survival,” Ready says. “There’s still going to be a lot of biomarker analysis to identify patients who will benefit the most and patients (who) won’t benefit at all, so that’s not clear yet, but it’s clear it’s going to have a major impact.”

Despite stopping immunotherapy early last September after the pancreatitis, Cimino still has no evidence of disease, which she credits partly to immunotherapy.

“I think immunotherapy has a bigger role to play in future cancer therapies, especially for patients with other issues, because chemo is tough,” Cimino says. “All the chemo is doing is telling the body to kill everything. It’s not teaching the body anything.”

Lee also has no evidence of disease and got her last CT scan at the end of January. The only side effect she had from Opdivo was some stomach upset. She thinks it’s “fantastic” that immunotherapy is being used earlier in lung cancer treatment. It is important to note that patients may experience more side effects associated with immunotherapy use, some of which can be serious and permanent, even fatal.

“That’s one of the reasons I wanted to do the clinical trial,” Lee says. “The people who were suffering from lung cancer or any type of cancer before me, they went through a lot to test various drugs and basically made it easier for me. Somebody’s got to help with the research, so I wanted to do that.”

Her reward has been seeing just how quickly progress is chugging along. “For people just diagnosed with lung cancer, it is scary,” Lee says, “but there have been so many advances in the treatment of lung cancer that there’s a lot more hope now than there was, say 10, 15, 20 years ago.”
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MAY 2022

TEACHING OTHERS THROUGH ADVOCACY

One patient turned her diagnosis of multiple myeloma into a way to educate others as an advocate. By DARLENE DOBKOWSKI, MA

EVEN THOUGH TREATMENT FOR multiple myeloma forced Cindy Chmielewski to retire from her 29-year career in teaching, she continues to be a lifelong educator, pivoting her focus from teaching science at an elementary school to educating others about multiple myeloma. As the self-proclaimed “Myeloma Teacher” on Twitter and Facebook, she shares resources from her home in Lawrenceville, New Jersey, with patients and families around the world.

She also uses social media to share her experiences with multiple myeloma, including the time when finding an effective treatment seemed nearly impossible. Chmielewski, 62, advises patients, including those around her age, to step out of their comfort zone and ask the questions to potentially lead them to a treatment plan that’s right for them sooner rather than later.

“This is important (that) I always share my story,” Chmielewski said in an interview with CURE®. “A lot of people are like me because the disease is a disease mostly of older patients. There’s a lot of people who were brought up in that age of ‘doctor knows best,’ so they don’t want to ask questions.”

NAVIGATING DIAGNOSIS AND TREATMENT

Starting in 2006, Chmielewski received treatment for degenerative disc disease, which provided her no relief for her severe back pain. It wasn’t until 2008 when X-rays indicated that she had compound fractures in her spine. Before undergoing surgery to potentially relieve the pain, Chmielewski had blood drawn, which came back “very abnormal.” This led to an appointment with a hematologist, who gave Chmielewski, then 49, a diagnosis of stage
3 multiple myeloma, the most advanced stage of this type of cancer.

“Myeloma attacks your bones, so all that back pain was (from) compression fractures,” Chmielewski said. “In that time, I lost 3 and a half inches of height due to the compression fractures.”

Chmielewski started treatment immediately with Revlimid (lenalidomide) and dexamethasone, although she went into it somewhat blindly.

“The reason I chose Revlimid and dexamethasone was because they were oral drugs, and I could continue teaching taking these drugs,” Chmielewski said. “I didn’t ask the questions I should have been asking, like: What’s the efficacy? What are the side effects? How much is it going to cost me? What were the trials? All those questions that were normal questions, (and) mine was, ‘Oh, it’s oral, I guess I could continue teaching.’ That’s how naive I was.”

The doublet therapy worked on Chmielewski’s multiple myeloma for three cycles, which led her cancer team to add a third drug — Velcade (bortezomib) — to her treatment regimen. This also didn’t help too much, so she underwent a stem cell transplant. Unlike Chmielewski, patients are often in remission when undergoing a stem cell transplant, and hers was aimed at putting her into remission. But 100 days after her stem cell transplant, she still had multiple myeloma.

“I was so devastated,” Chmielewski said. “That was a sadder day than the day I was diagnosed (with multiple myeloma) because the day I was diagnosed, I had never heard of multiple myeloma before. (I was) thinking, ‘I know nothing about it. It can’t be that bad.’ … So that was more devastating because now I thought I was completely out of options. I mean, this really barbaric type of treatment failed to put me into remission.”

It was at this time that Chmielewski, then 50, decided to retire from teaching so she could dedicate her time to exploring other treatment options, including clinical trials. After trying a few more regimens, including ones with Thalomid (thalidomide), she suddenly started to respond to her initial treatment with Revlimid, dexamethasone and Velcade. Over the next two years on that specific treatment, she started deriving a maximum response, although it was never a complete response (the disappearance of all signs of cancer from treatment). For the past 13 years, Chmielewski has been on Velcade maintenance therapy.

“[I’ve been living with this disease that, at the time of my diagnosis, they said maybe four to six years, and now]"
I’ve been living with this disease that, at the time of my diagnosis, they said maybe four to six years, and now it’s over 13 (years).

— CINDY CHMIELEWSKI

It’s around the entire world,” Chmielewski said. “If you look at my followers, they’re not just here in the United States; they’re global, and just helping some people in areas of the world that have no access to patient education and just sharing those resources with them, it’s incredible, and connecting them with maybe someone who could help them.”

This recently happened as a result of a Facebook post in a closed group, where a young patient with multiple myeloma living in Norway said she had no other treatment options. Chmielewski connected her with a doctor she had met at an International Myeloma Workshop meeting in Austria who was also from Norway. He gave Chmielewski his personal telephone number and his email address and told her to have the patient to contact him to see what he could do. Although she doesn’t know exactly what came out of that connection, Chmielewski said it’s rewarding to attend these meetings and make connections, in addition to sharing information with patients who may not be able to attend the meetings.

Chmielewski credits connections like these and the many others she has made throughout her multiple myeloma journey for bringing her out of the depression she was in after she retired because of her disease.

“I thought I was depressed back then, 10 years ago, thinking I was going to be bored and have nothing to do,” she said. “Now I have too much to do, but I enjoy it.”

EDUCATING OTHERS THROUGH EDUCATING ONESelf

In 2009, when Chmielewski was home from her stem cell transplant, she started gathering resources online and saving them to folders in her AOL account because “being a teacher, that’s what I like to do in educating myself,” she said. She wanted a way to share this information with other people, and that’s when she had her lightbulb moment. She was watching the “Today” show, and Kathie Lee Gifford and Hoda Kotb were promoting their Twitter accounts. Chmielewski created a Twitter handle just to follow the two hosts. While searching for “myeloma” on Twitter, she saw that people including doctors were tweeting about her disease. She started following the doctors and patients she came across during her research. Chmielewski changed her Twitter handle to @MyelomaTeacher and started using #MMSM (multiple myeloma social media) as a hashtag to make herself stand out with the resources she was sharing.

“When I started gaining followers on Twitter, I said, ‘Well, then I better start putting out really good stuff,’” Chmielewski said. “It became a game, like: Can I get the doctors to follow me, too? … Then it was no longer a game. I was like, ‘Well, I really have a purpose. I could start educating others using this.’ I started gaining more and more followers. I guess more and more people started to see me and what I was doing.”

Chmielewski also started a Facebook account to accompany her Twitter account since “people with myeloma tend to be older, and Facebook was more comfortable to them than Twitter,” she said.

She also looked at what advocates in the breast cancer space were doing on social media to potentially implement those tactics into the multiple myeloma social media space. Chmielewski joined Tweet chats and became friends with many patients within the breast cancer community. This is how she learned more about attending organizational meetings, volunteering and other programs to advocate in other ways (see sidebar).

Through Chmielewski’s activity on Twitter and Facebook, she has received messages from patients and family members alike, thanking her for sharing the information she has obtained about this disease.

“That’s the beauty with Twitter:

It’s around the entire world,” Chmielewski said. “If you look at my followers, they’re not just here in the United States; they’re global, and just helping some people in areas of the world that have no access to patient education and just sharing those resources with them, it’s incredible, and connecting them with maybe someone who could help them.”

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More than 2 people die from skin cancer every hour. See something new, changing or unusual? It could be skin cancer. Check yourself for The Big See today.
Be Honest and Open

It is incredibly important that patients with MPNs inform their health care team of any symptoms they are experiencing, according to an expert. By COLLEEN MORETTI

BECAUSE PATIENTS WITH ESSENTIAL thrombocythemia (ET) or polycythemia vera (PV) experience a range of symptoms that can significantly impact their quality of life, it’s important that patients communicate what they’re experiencing with their health care team.

Symptoms may include fatigue, symptoms from blood clots, abdominal discomfort (sometimes from spleen enlargement), fatigue, weight loss, fever and itching.

Dr. Ruben Mesa, executive director of The Mays Cancer Center at UT Health San Antonio MD Anderson Cancer Center, explained how symptoms of ET and PV impact patients and affect quality of life.

“Elevated (blood) counts can give you a risk of blood clots or bleeding, but you don’t necessarily feel them. So it’s really the PV- or ET-related symptoms that are the bigger driver in terms of quality of life,” Mesa said in an interview with CURE®. “We also know that these are chronic diseases. Patients can have them for many years, sometimes decades. So the control of these symptoms (becomes) incredibly important.”

Measuring symptoms of myeloproliferative neoplasms (MPNs) helps doctors quantify something that is inherently subjective. It has been shown that questionnaires result in more complete and honest assessments of how a patient is feeling compared with an in-person physician checkup.

“(It’s) critical to understand (symptoms and) to track them. They clearly have an impact on therapy, sometimes the choice of drug, sometimes the dose (and) sometimes the need to move to a different therapy,” he explained.

To further demonstrate how symptom burden assessment may help identify treatment efficacy, Mesa and researchers examined symptom burden prior to and after treatment. The aim was to see how treatment impacted symptom burden of patients using data from two clinical trials published in Lancet Hematology:

- 114 patients (64% with ET; 44% with PV) from the MPN-RC 111 study, which evaluated the drug Pegasys (pegylated interferon alfa-2a) in patients with ET or PV resistant to Hydrea (hydroxyurea).
- 166 patients (48% with ET; 52% with PV) from the MPN-RC 112 trial, which evaluated alfa-2a versus Hydrea in therapy-naive patients with high-risk ET or PV.

Specifically, treatment with Pegasys or Hydrea was associated with an improvement in symptom burden between three and 12 months in patients who entered each trial with a high symptom burden. These medications, according to Mesa, helped decrease blood clots and inflammation, two main symptoms experienced by patients with MPNs.
However, symptom burden worsened between three and 12 months in patients who had a low symptom burden at the start of the MPN-RC 111 study, and similar results were observed in the patients from the MPN-RC 112 study.

Mesa explained that some therapies don't reach both goals — control of blood counts (and hence decrease risk of blood clots) and the secondary goal of either improving prior treatment symptoms or not creating new symptoms as toxicity from the treatment.

“You can't make a patient who feels well feel any better,” he said. “And (for) individuals with low baseline symptoms, there is a trade-off of some slight increase in symptoms or side effects for the protection that these medicines (give) to decrease the risk of blood clots or bleeding.”

He emphasized the importance of patients honestly discussing the symptoms they are experiencing with their health care team. He explained that many of these symptoms may not be apparent externally but that patients still feel them — so their health care team needs to know about them.

“I think this is a prime example of where ... close cooperation between patients, patients’ groups and researchers in the field has been very helpful,” he said. “Really, all of this work started because patients ... were coming up to me saying, ‘My symptoms are worse than people really recognize. And although I may (look fine on the outside), if you see me in the mall, I really don’t feel well.’ So how do we better understand that?”

Mesa also noted that some skeptics thought these symptoms were caused by the stress of having the disease; however, research has shown they can also be caused by the treatments and the biology of the disease itself. “For many, the symptoms are caused by the biology of their MPN and a critical sign of the disease” he said. “And then when we treat the disease, things are better. They’re more stable. And hopefully then we’re able to have them in a less intensive mode where they’re on therapy, (and) they’re getting blood counts every two to three months. But overall, they’re able to really put (the) PV or ET in the rearview mirror — it’s there, but not a significant part of their day-to-day lives.”

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FOR PATIENTS WITH KIDNEY cancer, the use of immunotherapy (IO) agents in combination as a front-line treatment option offers the best response rates and median overall survival compared with single-agent tyrosine kinase inhibitors (TKIs) or a mix of TKIs and checkpoint inhibitors, according to an expert.

In a recent discussion during the CURE® Educated Patient® Kidney Cancer Summit, held virtually on April 9, Dr. Saby George, director of network clinical trials at Roswell Park Comprehensive Cancer Center in Buffalo, New York, highlighted the current and potential future use of IO combinations in patients with kidney cancer.

Before he delved deeper into the use of these agents, he noted that prior to the emergence of IO combinations, the most common first-choice treatment options for metastatic kidney cancer were either Sutent (sunitinib) or Votrient (pazopanib). But over time, as he explained, other agents and treatment regimens came into the mix.

During his presentation, George primarily highlighted the significance of the results of the CheckMate 214 trial. These findings showed that treatment with Opdivo (nivolumab) and Yervoy (ipilimumab) kept leading to better overall survival and objective response rates (percentage of patients whose disease responded to treatment) compared with Sutent in high-risk patients with advanced renal cell carcinoma, a type of kidney cancer.

The data emphasized that at a minimum follow-up of 42 months, the median overall survival of patients who received the combination was 47 months versus 26.6 months for those who received Sutent alone. “(There was) nearly doubling of survival based on this application of this regimen combining Opdivo and Yervoy,” George said during the presentation. “This was (a) very significant result.”

Moreover, George said that of the patients who achieved a complete response to treatment, 34% remained on therapy at the 42-month follow-up. Additionally, 47% of those complete responders were off treatment but did not require subsequent maintenance therapy because they continued to derive a benefit.

“It’s very interesting to note that a lot of those patients … did not require treatment for years,” he said. “Yet, (the) cancer did not progress, meaning they maintained the complete response.”

SALVAGE THERAPY

George also reviewed data from a trial that looked at the use of Opdivo and Yervoy in what is called the salvage setting, meaning treatment given to a patient after standard treatments have failed to induce a response. In that trial, he explained, patients with heavily pretreated disease achieved a response rate close to 17%, which he said could be promising for that patient population.

“If patients have gone through checkpoint inhibitors in the past — gone through multiple other treatments like TKI, mTOR inhibitors and when (and) if they run out of choices — this could be something that (they) can reconsider,” he said.

MAINSTAY

Ultimately, the use of IO combinations such as Opdivo and Yervoy has been established as a mainstay treatment option for patients whose disease has failed to respond to previous treatments. “(IO combinations provide) the longest median overall survival advantage compared (with) any other studies in the first-line (setting), and immune-related (side effects) from (IO combinations do) not necessarily mean that (they) will adversely affect survival,” George concluded. “Indeed, (this is indicating) that they may live longer. And long-term remissions or durable responses are possible in a fraction of patients from this regimen and a lot of patients did not require a second treatment. That’s the beauty of this regimen. And salvage (therapy) with the (IO) combinations is still possible even after prior exposure to (an IO) agent.”

Immunotherapy Combos Give Patients the Most Durable Responses, Longest Survival in Front-line Setting

Combining immunotherapy agents, particularly Opdivo and Yervoy, provides the most benefit in the front-line treatment of patients with kidney cancer, according to an expert. By RYAN MCDONALD
A Spotlight on Clinicians Showing Off Their Hobbies Outside of Work

After Hours showcases the exciting lives of healthcare providers outside their day-to-day practice, highlighting the hobbies that take them around the world—to speedways, art studios, wineries, and more.

Season 6 is streaming now!
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Patients With Advanced Melanoma May Benefit From Forgoing Surgery

Skipping the surgical removal of lymph nodes and instead moving to adjuvant therapy may become the standard of care for patients with advanced melanoma. By COLLEEN MORETTI

ADJUVANT THERAPY IN PATIENTS who did not undergo complete lymph node removal surgery for the treatment of stage 3 melanoma, a type of skin cancer, may provide better distant metastasis-free survival, according to recent data.

“I think (these) data provide some comfort to both physicians and patients that says it’s OK to skip that step and move on to the systemic therapy, which probably has more impact on the overall outcome,” Dr. Martin McCarter, a professor of surgery in the Division of Oncology at the University of Colorado School of Medicine in Aurora, said in an interview with CURE®.

He explained that because of a lack of survival benefit, more patients with stage 3 melanoma have skipped surgery to remove the lymph nodes. Instead, providers and patients are turning to adjuvant systemic therapy or additional treatment given after primary treatment to potentially lower the risk of the cancer coming back, which has been shown to improve survival.

“In contrast to the surgical removal of the melanoma involved in lymph nodes, the clinical trials with systemic therapies — either immunotherapy or targeted therapy for melanoma — did show a survival benefit in patients with metastatic disease,” he said.

COMPARING THERAPY WITH OBSERVATION McCarter and researchers evaluated the outcomes of 90 patients with stage 3 melanoma who skipped surgical removal of affected lymph nodes, of whom 56 patients received adjuvant therapy consisting of immunotherapy or targeted therapy, and the rest underwent observation alone.

A microscopic view of malignant melanoma.
Disease recurrence was observed in 12 patients in the observation group and 11 patients in the adjuvant therapy group. The most common first site of recurrence among patients in the group was distant recurrence alone, which occurred in five patients from the observation group. In addition, eight patients in the adjuvant therapy group had nodal recurrence alone. The 24-month nodal recurrence rate was not significantly different in patients from the adjuvant therapy and observation groups (26% versus 20%, respectively) despite more adverse nodal features in patients from the adjuvant therapy group. There was also no significant difference in recurrence-free survival during this time (75% versus 61%).

Patients with stage 3b/c melanoma treated with adjuvant therapy had a longer distant metastasis-free survival (time a patient is alive without disease spreading to distant organs) at 24 months compared with those who underwent observation alone (86% versus 59%).

“That suggests that there are microscopic melanoma cells in places that we cannot see at the time of surgery, and that by targeting those cells either with immunotherapy or targeted therapy, we can reduce the chance of the melanoma showing up at distant sites outside of the regional lymph nodes,” McCarter explained.

The overall data demonstrated that patients treated with adjuvant therapy are having better outcomes than those who are undergoing surgery to remove the lymph nodes.

“I think if you put the two pieces of information together, the one saying that a regional lymph node dissection did improve survival and that the systemic therapy did improve survival, the data we discovered or uncovered (support) that notion,” he said.

McCarter explained that having the option of skipping a surgery and moving to adjuvant therapy can be beneficial for some patients who are at high risk for recurrence.

“It avoids significant complications, but it also allows them to progress sooner to systemic therapy that might improve the long-term outcome,” he added.

**A POTENTIAL CHANGE IN STANDARD OF CARE**

Additionally, he said skipping this surgery and moving to adjuvant therapy may become the standard of care for patients in this setting. It is still an active area of investigation, in addition to newer therapies.

“With the newer therapies available, there are a lot of changes evolving, and sometimes the practice of medicine gets ahead of the actual clinical trial data that we have to support it. This is one of those scenarios where logically it makes sense, scientifically it makes sense and now at least we have some data to support the direction that things are heading,” McCarter said. “I think that just gives everybody more comfort in doing the treatment the way that things have now evolved.”

He concluded that data such as these would not be possible without patients participating in clinical trials and encourages patients to continue to do so to advance cancer care.

“I thank all the patients (who) have participated in prior clinical trials because that is the way we change in advanced care. If patients did not participate in those kinds of trials, then care would stagnate. I think most of all, it’s important that patients are willing to continue to contribute to our knowledge base,” McCarter concluded.
THE PAST 20 years have brought great advancements to cancer treatments, and people are living longer, healthier lives. But what has been depicted on the big screen does not always represent that. However, there has been some improvement compared with 20 years ago, according to some experts.

In honor of CURE®’s 20th anniversary, we dove deeper into the past two decades of cancer representation in television and movie culture, how it can be beneficial — and harmful — and where it will hopefully be going in the next 20 years.

Kate Folb said that there have been great strides to accurately depict cancer journeys. Folb is the director of Hollywood, Health & Society at the University of Southern California Annenberg Norman Lear Center in Los Angeles, where she partners with TV script writers to provide accurate information about medical storylines.

“It’s very important to have, first and foremost, accurate depictions … making sure that shows are not spreading misinformation that could lead to harm,” she said in an interview with CURE®. “And then beyond that they could offer information that may be beneficial to an audience member.”

John Sencio agrees, calling the advancement of simply including people with cancer and stories around cancer on the big screen “monumental” and “rapid.” Sencio is a two-time cancer survivor who has been in the TV/movie industry for some time as a producer and host on MTV, NBC, HGTV and more.

But Colleen McBride, a professor in behavioral sciences and health education at the Rollins School of Public Health at Winship Cancer Institute at Emory University in Atlanta, tends to disagree. While there may be benefits to depicting a cancer diagnosis in TV or movies, she said more needs to be done to accurately depict what it’s like to live with cancer and not just the tragedy of dying young from cancer.

DEPICTING TRAGEDY

“A Walk to Remember,” a 2002 film based on the 1999 novel of the same name by Nicholas Sparks, tells a story of young love and tragedy inspired by the cancer journey of Sparks’ sister. The movie grossed $47.5 million.

The 2012 film “Now Is Good” portrays a young girl with terminal acute lymphoblastic leukemia who sets off to finish her bucket list with the help of her love interest.
This movie grossed $2.3 million.

And in 2014, another teen love-tragedy story brought many to tears. “The Fault in Our Stars” follows two chronically ill teenagers who meet at a support group and fall in love. In the end, one dies from their cancer. The movie grossed $307.2 million.

All these movies and many more share the theme McBride mentioned: young love and tragedy.

“Cancer is (often) an old person’s disease,” McBride said. “And right now, for many people, it’s a chronic disease, so they take medications and are able to live for a long time after diagnosis — which I don’t think is dramatically as interesting (a storyline). (It’s) much more interesting if it’s a young person struck down — our greatest fear, basically.”

And although this idea of tragic, unfair death does sell — as shown by the box office receipts — McBride said it can raise unnecessary worry and fatalism about cancer.

“I think it can certainly do harm,” she said, “in the sense of giving people with cancer a very fatalistic view of it, and also may discourage individuals from wanting to find out they have cancer because (they think), ‘What difference does it make if I’m going to die anyways?’”

In some shows Folb has worked on, cancer is not a character’s defining characteristic. She mentioned the 2014 TV series “Chasing Life,” which followed a woman with a leukemia diagnosis through different journeys of life, including love, family and friends. Folb noted that the difference between this and shows or movies from 20 years ago is that this show didn’t depict cancer as a tragedy and instead showed someone with cancer who had a life outside of the disease.

“There were all kind of things going on in her life besides cancer. And we did go on her journey, but she was a three-dimensional person,” she said. “Cancer was only one facet of who she was.

“That benefits people who are living with cancer and it also helps change attitudes of the general public about what it’s like to live with cancer and that it doesn’t have to define your entire life.”

Another benefit of cancer representation in TV or movies, Folb said, is to spread awareness about the disease.

In 2013, one of the main characters on the “90210” reboot found out she had the BRCA breast cancer gene after her mother and aunt died from the disease. Folb noted that this was one of the first popular TV shows to have a storyline about the breast cancer gene.

After that episode aired, Hollywood, Health & Society conducted two complementary studies of adult women to evaluate how the public perceived the storyline. Results of both studies demonstrated that exposure to the episode increased knowledge on the BRCA gene and mastectomies.

IS SHOWING CANCER ON THE BIG SCREEN BENEFICIAL?

Folb said that 20 years ago, “if you got a cancer diagnosis on a TV show it was doom and gloom and by the end of the episode that person was usually dead.” But, she stressed, cancer representation in TV and movies can be beneficial.

John Sencio (left) stands with his surgeon, Dr. Elliot Abemayor.
“We see significant knowledge gains,” Folb explained. “People learn things they didn’t know, about treatment, about the disease, and their attitudes also shift. The more that audiences see people like themselves living with cancer, just living their lives, the more their attitudes can change about the disease.”

But one of the studies also showed that there was an increased fear regarding the consequences of the BRCA gene, a theme McBride previously discussed.

But McBride agrees with Folb that it may be beneficial and even motivational, if done correctly.

“Someone can look at living with cancer and see it as a positive outcome,” McBride explained. “And so they may be more willing to seek out information, to take preventive actions to reduce a risk of cancer,” she said. “So it really can go both ways. But a fuller representation of how cancer really happens is what is needed.”

Sencio noted the 2007 film “The Bucket List,” which depicts two men who are dying from lung cancer and go off to fulfill a wish list before they die. In the end, one of the men dies from his disease.

“I do believe cancer representation in TV and movies can be very beneficial, especially if it provides insight and inspiration,” Sencio said. “And I think it really depends on the patient because everyone is different. I’ve been through this chaos twice … and I know how meaningful it can be (to see something) authentic.”

QUANTITY OR QUALITY
Another good thing, Sencio added, is the sheer volume of representation over the past 20 years.

“I think the representation has grown at a staggering rate,” he said. “I think there is a lot more out there than when I was a kid in the ’80s. … It’s been monumental, rapid … and hopefully it becomes even more honest and accurate.”

Folb agrees, saying there are now more “well-rounded characters,” such as the main character in the 2014 TV series “Chasing Life,” and that there are more accurate depictions of a cancer journey, not just diagnosis and death.

She mentioned a 2017 two-part episode in the TV series “Grey’s Anatomy” in which the mother of a main character receives a diagnosis of inflammatory breast cancer after discovering a rash on her breast. The plot follows more than just her diagnosis and death, focusing instead on her journey with clinical trials, going to different institutions for different treatments and the reaction of a caregiving family member — things patients with cancer experience during the journey in the real world.

“We saw a little bit more of her journey and not desperation from her,” Folb said. “The desperation actually came from her daughter, who was desperate to save her mother. I think we’re seeing a lot more nuance.”

But that character still died in the end — which is why
McBride says not much has changed in 20 years. She compared the 1971 film “Brian’s Song” with the movie “The Fault in Our Stars,” and said that despite the more than 40 years between them, the ending is the same: young, tragic death caused by cancer.

“I’m a movie buff. I watch lots and lots of movies. And I don’t think it’s changed much,” she said.

THE NEXT 20 YEARS
McBride noted that she hopes that in the next 20 years there is a focus on cancer survivorship in film and TV to show that patients have a life after their diagnosis. It can be a part of their character, but not the only part.

“I think that could certainly give a more positive view that brings to light how many cancer survivors there are,” she said.

McBride added that the narrative must be flipped from dying to living, which could help normalize for patients and the general public that cancer is survivable. It could also be a teachable moment to portray a cancer survivor who is now living a full and healthier life compared with before their cancer diagnosis, she said.

“It doesn’t mean that even if you get cancer, your life isn’t going to be diminished. Your life could get even better post cancer,” she explained. “But these movies and TV shows are there to make money and attract. And I think that there’s a lot of work to get us beyond the fact that we’re still in the ‘Big C’ being one of the biggest worries and people still believing it’s a death sentence.

“I just wonder to what extent this would be a priority for these profitable movies,” McBride said. “How do you make cancer an interesting topic?”

Folb said she is proud to be part of the change underway to have cancer represented more often and more accurately on TV. As treatments and therapies have advanced over the past 20 years, so has the outlook for cancer.

She recalled that just hearing the word “cancer” 20 years ago was scary, and while it is still scary, more treatments and therapies are available. And as treatments advance and survival rates continue to rise, so should the representation of cancer in TV and movies.

“The more advances we make in treatment, mitigation and prevention, the more we’ll be able to depict cancer more like diabetes or HIV, or something that is a more chronic situation and not an immediate, terrible death sentence,” Folb explained.

“And I can see it going in that direction. And I can only imagine in 20 years, with more advances, that it will become an even less scary topic,” she said.

Sencio explained that he hopes to be a part of that change and bring a more authentic story of cancer to the small and big screens. Since his diagnosis, he has been working on “Thryvor,” a documentary about his journey, which will show viewers a real, raw depiction of what he went through with cancer.

“I’d imagine that cancer representation in TV and movies over the next 20 years will likely be much more common. Of course, with an increase in sheer volume, there will be an increase in misinformation — my doctors are already dealing with this — and it can be dangerous,” he said. “One safeguard is to collaborate with medical professionals … then these stories can be an extraordinarily valuable resource. That’s my belief. The goal is survival. Cancer patients (and families) need healthy skepticism as this takes shape over the next 20 years. I look to the future of cancer representation in TV/movies with cautious optimism.”

“I do believe cancer representation … can be very beneficial, especially if it provides insight and inspiration.

— JOHN SENCIO

Sencio (right) stands with a physician during filming of his documentary, “Thryvor.”
In patients with CSCC that has spread or cannot be cured by surgery or radiation:
LIBTAYO works with your immune system to help treat advanced CSCC

In 1 clinical trial of 137 patients with CSCC that had spread or could not be cured by surgery or radiation treated with LIBTAYO*: 46% saw an improvement in their advanced CSCC.

Responses to LIBTAYO lasted 6 months or longer in 50 out of 63 patients (79%) and 12 months or longer in 34 out of 63 patients (54%).

In the same clinical trial, in a separate group of 56 patients with CSCC that had spread who took LIBTAYO at the recommended dose†: 41% saw an improvement in their advanced CSCC.

Responses to LIBTAYO lasted 6 months or longer in 15 out of 23 patients (65%).

In this trial, responses lasted between 2 months and more than 2 years (24.2+ months); plus sign (+) denotes ongoing at last assessment.

*Patients were dosed by body weight.
†LIBTAYO 350 mg over a 30-minute infusion every 3 weeks.
CSCC = cutaneous squamous cell carcinoma.
LIBTAYO may not work for everyone.

What is LIBTAYO?
LIBTAYO (Lib-TIE-oh) is a prescription medicine used to treat people with a type of skin cancer called cutaneous squamous cell carcinoma (CSCC) that has spread or cannot be cured by surgery or radiation.

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

Important Safety Information

What is the most important information I should know about LIBTAYO?
LIBTAYO is a medicine that may treat certain cancers by working with your immune system. LIBTAYO 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, 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: headache 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, or 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, or loss of appetite
• Skin problems: rash, itching, skin blistering or peeling, painful sores or ulcers in mouth or nose, throat, or genital area, fever or flu-like symptoms, or 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 LIBTAYO. 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 or 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, or bruising
• Infusion reactions that can sometimes be severe. Signs and symptoms of infusion reactions may include: nausea, chills or shaking, itching or rash, flushing, shortness of breath or wheezing, dizziness, feel like passing out, fever, back or neck pain, or facial swelling

Please see additional Important Safety Information and Brief Summary of full Prescribing Information on the following pages.
Meet Dave.

Husband, father, and music lover.
Dave also lives with locally advanced cutaneous squamous cell carcinoma (CSCC). He was first diagnosed with CSCC in 2008 and underwent many forms of treatment, including surgery and radiation. When his CSCC became advanced and could not be cured by surgery or radiation, he and his doctor decided that LIBTAYO was the next appropriate treatment option.

“Having a good support system in place is important. My wife has really helped me a lot through my struggles with advanced CSCC.”

—Dave, living with locally advanced CSCC

To learn more about Dave and other patient stories, visit MeaningfulStories.com

Important Safety Information (continued)

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

• 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 complications may happen if you underwent transplantation either before or after being treated with LIBTAYO. 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 your treatment with LIBTAYO. 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 LIBTAYO if you have severe side effects.

Before you receive LIBTAYO, tell your healthcare provider about all 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 a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome
• are pregnant or plan to become pregnant. LIBTAYO 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
– You should use an effective method of birth control during your treatment and for at least 4 months after your last dose of LIBTAYO. Talk with your healthcare provider about birth control methods that you can use during this time
– Tell your healthcare provider right away if you become pregnant or think you may be pregnant during treatment with LIBTAYO
• are breastfeeding or plan to breastfeed. It is not known if LIBTAYO passes into your breast milk. Do not breastfeed during treatment and for at least 4 months after the last dose of LIBTAYO

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

The most common side effects of LIBTAYO include muscle or bone pain, tiredness, rash, and diarrhea. These are not all the possible side effects of LIBTAYO. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. You may also report side effects to Regeneron Pharmaceuticals and Sanofi at 1-877-542-8296.

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 Brief Summary of full Prescribing Information on the following pages.
IMPORTANT PATIENT INFORMATION ABOUT LIBTAYO® (cemiplimab-rwlc) INJECTION

Please speak with your healthcare provider regarding LIBTAYO. Only your healthcare provider knows the specifics of your condition and how LIBTAYO may work with your overall treatment plan. If you have any questions about LIBTAYO (pronounced Lib-TIE-oh), speak with your healthcare professional. Prescription Only.

What is the most important information I should know about LIBTAYO? LIBTAYO is a medicine that may treat certain types of cancers by working with your immune system. LIBTAYO 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.

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Lung problems.
• cough
• shortness of breath

Intestinal problems.
• diarrhea (loose stools) or more frequent bowel movements than usual
• stools that are black, tarry, sticky, or have blood or mucus

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)

Hormone gland problems.
• headache 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

Kidney problems.
• decrease in your amount of urine
• blood in your urine

Skin problems.
• rash
• itching
• skin blistering or peeling

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 LIBTAYO. 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 or 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

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• nausea
• chills or shaking
• itching or rash
• flushing
• shortness of breath or wheezing
• dizziness
• feel like passing out
• fever
• back or neck pain
• facial swelling

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 complications may happen if you underwent transplantation either before or after being treated with LIBTAYO. 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 your treatment with LIBTAYO. 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 LIBTAYO if you have severe side effects.

What is LIBTAYO? LIBTAYO is a prescription medicine used to treat people with a type of skin cancer called cutaneous squamous cell carcinoma (CSCC) that has spread or cannot be cured by surgery or radiation. It is not known if LIBTAYO is safe and effective in children.

Before you receive LIBTAYO, tell your healthcare provider about all 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 a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome
• are pregnant or plan to become pregnant. LIBTAYO can harm your unborn baby

Continued on following page
IMPORTANT PATIENT INFORMATION ABOUT LIBTAYO® (cemiplimab-rwlc) INJECTION

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

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 LIBTAYO?
• Your healthcare provider will give you LIBTAYO into your vein through an intravenous (IV) line over 30 minutes.
• LIBTAYO is usually given every 3 weeks.
• Your healthcare provider will decide how many treatments you will 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 LIBTAYO?
LIBTAYO can cause serious side effects, including:
• See “What is the most important information I should know about LIBTAYO?”

The most common side effects of LIBTAYO include muscle or bone pain, tiredness, rash, and diarrhea.

These are not all the possible side effects of LIBTAYO. 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 LIBTAYO. Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. If you would like more information about LIBTAYO, talk with your healthcare provider. You can ask your healthcare provider for information about LIBTAYO that is written for health professionals.

This is a brief summary of the most important information about LIBTAYO. For more information, talk with your healthcare provider, call 1-877-542-8296, or go to www.LIBTAYO.com
The decision by the Food and Drug Administration (FDA) to greenlight the first of several treatments within a particular drug class starting in the 2010s may have ultimately transformed the lives of many patients diagnosed with gynecologic cancers and altered how the disease is treated.

In 2014, the FDA approved Lynparza (olaparib) as the first PARP inhibitor to be used as a maintenance treatment option for women with recurrent BRCA-mutated ovarian cancer following three lines of therapy. Over the next three years, the FDA would approve two additional PARP inhibitors — Rubraca (rucaparib) and Zejula (niraparib). Of note, PARP inhibitors are approved for everyone either in the upfront or recurrent setting for maintenance — or after chemotherapy — treatment.

PARP inhibitors, according to Dr. Erin Medlin, have the best results in patients with BRCA genetic mutations (either germline or somatic). And although not every patient diagnosed with ovarian cancer can benefit from a PARP inhibitor, the development of this drug class has been monumental for patients. The reason, according to Medlin, a gynecologic oncologist at Colorado Permanente Medical Group in Denver, is that this advancement has resulted in every patient diagnosed with a gynecologic cancer undergoing genetic testing to determine whether they are a candidate for PARP inhibitors or other targeted therapies or immunotherapies.

"For patients who have (BRCA) gene mutations, we may see time without cancer (extended) by two to three years," Medlin said in an interview with CURE®. “And in the cancer world, that’s a long time.”
The added years of survival with a PARP inhibitor, she explained, are in comparison with the months patients would typically expect with the standard-of-care treatments of the past.

“We are hesitant often to use the word ‘cure’, especially in ovarian cancer, because it does come back frequently,” Medlin said. “But this is giving patients an opportunity for (a) cure, and at least an opportunity to have a much longer time without cancer therapy. In terms of their tolerance, we’re able to keep patients on these drugs for years; we have gotten very good at tackling some of the side effects and compensating for those to allow patients to continue therapy. So it’s now pretty uncommon for patients to have to discontinue (treatment) and now we can keep them on and see the full potential of these drugs.”

However, that wasn’t always the case.

A SHIFT IN STANDARD OF CARE
Fifteen years ago, platinum-based chemotherapy served as the standard-of-care treatment option for patients with gynecologic cancers. It first started with the use of Taxol in the 1990s, and then providers started combining chemotherapies such as carboplatin and Taxol.

Even before the arrival of PARP inhibitors, cytotoxic chemotherapy was not being used just in the front-line treatment of patients with gynecologic cancers, but also after a patient’s disease failed to respond to the initial treatment.

“In the ovarian cancer (space), we have lived (in a) platinum or bust (world) for so long,” she exclaimed.

But when PARP inhibitors burst onto the scene starting in the 2010s, they completely changed the treatment landscape, especially since PARP inhibitors are delivered orally and are a shift from the conventional chemotherapy delivery method.

“It’s less time for the patient to have to come into the clinic and be devoted to an infusion center for an entire day or multiple days in a row, which improves their quality of life,” she said. “And we don’t see the hair loss that we see with cytotoxic chemotherapy, (as well as) all the nausea that we see with other chemotherapy.”

That’s not to say that PARP inhibitors don’t come with their share of side effects, according to Medlin. But she noted that the side effects are much more tolerable with PARP inhibitors than with the standard-of-care cytotoxic chemotherapies, which has made a tremendous impact on the lives of patients.

FIRSTHAND EXPERIENCE
In 2013, Ruth Ann Ornstein, a 47-year-old mother of two teenagers — one just weeks shy of going to college — ran an overnight summer camp. In June, she noted that she started to experience spotting and some bloating.

At the time, though, she didn’t think much of her symptoms and continued on as if nothing were wrong, that is, until one day after the summer campers left.

Ornstein remembers that it was a Monday morning when she started developing a severe stomachache that although was subdued by a dose of Tylenol, the pain became unbearable to the point where she visited a walk-in clinic the next day.

Within a week, Ornstein received a diagnosis of stage 2c ovarian cancer and was in surgery for a full hysterectomy and to have several lymph nodes as well as a tumor removed. Ornstein, who is of Ashkenazi Jewish descent, received genetic testing and within weeks was informed she was positive for a BRCA1 mutation.

A few weeks after her surgery, Ornstein started chemotherapy and underwent the traditional six cycles of Taxol.

“...my best friend. To hold me up for four and a half years and (to be) on my fourth recurrence, I feel blessed for this PARP inhibitor that modern science created for ovarian cancer.”

— RUTH ANN ORNSTEIN

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rounds of treatment. During that time, she said, her family underwent genetic testing and they were able to identify where the mutation came from. After her six cycles of chemotherapy were finished, she was scanned and the results were good.

“My doctor said to me, ‘BRCA1, you did well. We’ll never see you again. It’s all good, you’ll go every three months for checkups,’” she recalled. “I went my three months, and (everything) was fine.”

By January 2015, she said she knew something was wrong.

A PET scan in spring 2015 revealed that the cancer had returned. She went in for a debulking surgery (the removal of any visible tumor larger than 1 centimeter) and received several rounds of chemotherapy.

“Then finally the chemo was starting to get to my joints,” she said. “I was tired of being like an old lady (if) I wasn’t an old lady.”

Since her scans were good, her doctor said they could stop the chemotherapy. However, 12 months later, in 2017, the cancer returned.

This time she would undergo another debulking surgery, but she wouldn’t be put on any chemotherapy. Instead, she was prescribed the PARP inhibitor Rubraca. But the drug made her feel very ill.

“I remember texting (her doctor) and saying, ‘I’m not going to live like this,’” Ornstein said. “There’s got to be something else. This isn’t acceptable for any human being to feel this way.”

Enter Lynparza.

“I have to tell you that I skated through my four and a half years on Lynparza,” Ornstein explained. “The only thing is my taste buds changed. I put on weight but I figured I could be fat and happy and not have cancer.”

After four and a half years, however, the Lynparza stopped keeping the disease at bay. But, as Ornstein explained, she was grateful for what the drug provided her with.

“The PARP inhibitor was such a freedom,” she said. In fact, Ornstein explained that the drug allowed her to remove the cancer world out of her head since she could just take a pill and not have to go for infusions.

“(The) PARP inhibitor was … my best friend,” she said. “To hold me up for four and a half years and (to be) on my fourth recurrence, I feel blessed for this PARP inhibitor that modern science created for ovarian cancer.”

**THE HOPE**

There is a tremendous amount of research looking at PARP inhibitors in combination with other targeted therapies as well as immunotherapies, according to Medlin. They’re being tested in patients whose disease has stopped responding to other treatments. But the hope, she said, is to move those regimens up to earlier treatment stages.

“Can we imagine a world where we see PARP inhibitors are the first-line treatment in combination with some other targeted therapy over chemotherapy?” she asked. “I think that is conceivable. The real hope is that we can … give patients a more tailored approach that will hopefully find a cure for that specific patient or at least give a lot more time in remission.”
Learn to Tell Which Online Health Information is Trustworthy.

When misinformation about health is shared, it can lead to harmful outcomes, including the spread of unproven cancer prevention and treatments.

FORCE, a national nonprofit dedicated to improving the lives of individuals and families facing hereditary cancer, has created a short, interactive tool and quiz to teach you how to spot unreliable health information online.

Take this short quiz to learn 3 key questions and 5 red flags to look for when viewing health information online.

FacingOurRisk.org/BOAST
ONE OF THE most significant challenges I have had to reconcile over the past decade is that I inherited Lynch syndrome from my abusive father. He had colon cancer when he was in his 40s, before my birth, and managed to survive cancer free for another 30-plus years until he died from cirrhosis of the liver in 1992.

Sadly, I had a fragmented relationship with him because of his alcoholism. He emotionally neglected and abused my siblings and me. His alcoholism worsened when my mother died suddenly in 1980. I was only 9 years old. My father was unpredictable, unloving, uncaring, explosive and verbally abusive. He was critical, judgmental and angry and could never see the positive in anything. We constantly walked on eggshells around him. Nothing we did was ever good enough.

My childhood after my mother’s death included a constant, high level of uncertainty and fear without much family support. I was a good kid with stellar grades until my sophomore year of high school when my anger toward my father and family finally emerged. I found my voice and became a rebel. I became a product of my dysfunctional environment and acted out. I was left to fend for myself; my pleas for help from my siblings were often ignored. I suppose they had had their share of misery from him and did not want to be bothered. I had only myself.

I moved away at age 18 to another state and started fresh. When my father died in 1992, I wept and grieved for the father I never had or deserved. My father managed to continue the emotional pillaging from the grave, though we did not realize it. I ended up back in Chicago and was stunned to learn that my eldest brother had been diagnosed with advanced colorectal cancer, though at the time we did not know it was Lynch related. He died in 1995 at 36.

Eventually, life was looking up for me, and I finally let go of my past and appreciated the good things happening. I managed to put myself through school, and after taking some biology and genetics courses, I knew there must be a genetic component to colon cancer within my family. I eventually met a man who would become my husband and the father to our beautiful son. Several years passed and I believed I had finally found some happiness. Then my other brother got colon cancer at 48. Six months later, cancer returned, and that is when his doctor suggested that he and I test for Lynch syndrome. This is how I discovered that I, too, carry the mutation.

My brother lost his entire colon and not long after, it was strongly recommended that I have my reproductive organs removed to prevent cancer. I reluctantly gave them up, which held all kinds of horrific, hellacious, negative implications for me. My father lives on through this horrendous mutation, not to mention that the removal of my reproductive organs held enormous implications for my well-being and femininity. But knowing that I may have unknowingly passed Lynch syndrome to my son has been the most challenging aspect of having the genetic condition. It has taken years to reconcile the toll this has taken. My son is still a teenager and has yet to see a genetic counselor and undergo genetic testing.

Over the years as a patient advocate, I have spoken with others with Lynch who were abandoned or abused by the parent from whom they inherited the syndrome. Living with Lynch is not easy under the best of circumstances, but it is even more challenging when it is inherited from an abusive parent.
Patients With Cancer Don’t Owe ‘Grief Tourists’ Anything

After going public with my cancer diagnosis, I was met with an onslaught of “grief tourists” who may not have been interested in the harsh realities of cancer. By CHELSEY GOMEZ

AS SOON AS I went public with my cancer diagnosis on Facebook in 2018, I was met with a flood of text messages, Facebook comments and phone calls.

People I had not heard from in years were suddenly in my inbox offering condolences and asking questions. Word of my cancer diagnosis spread like the latest TikTok dance trend. To say I was overwhelmed would be an understatement.

I did my best to respond to each and every person who wrote to me because I did not want anyone to feel like I wasn’t grateful for their support. I answered every painful question that popped up in my text messages. These questions ranged from what my life expectancy would be to when my hair would begin falling out. I felt compelled to share these intimate details with the world because I thought that’s what my role was.

People were offering their support, so I should offer information in exchange. The reality was I did not owe them anything, though I felt I did.

Soon a Facebook group was made to keep interested parties updated on my cancer. Facebook groups, CaringBridge pages and more have become a way for patients to cope with this onslaught of attention.

However, in my own experience, this group became like a group of reporters always seeking out the latest scoop. Even worse, I felt like these reporters didn’t want the true story. They wanted me to turn cancer into a fairy tale that they could more easily digest. They didn’t want to hear about me puking after chemo. They wanted to hear how I was “staying positive.” They didn’t want to see me breaking down over my own mortality. They wanted to see me in a wig, smiling despite it all.

The strange juxtaposition of utter pain, destruction and sadness in my private life and the brave, strong and positive patient in public was stifling. I didn’t want to hear how I was an inspiration simply for trying not to die. I didn’t want to hear how brave I was. I didn’t want to hear how upset my own cancer made Sally from fifth grade (who hadn’t spoken to me since).

I have come to understand that these people were “grief tourists,” those who do not really care but are there with buckets of popcorn watching the show. Some are there because they want to feel better about their own lives. Some are there because they want to feel connected to something “big.” Some are there because they want to portray a certain image.

No true grief tourist is there for the person in the middle of the tragedy.

If you were in the middle of an ocean, a grief tourist would ride by on a boat and snap a picture. A true friend would drag you out of the water and save you. I really wish I understood that my job was not to perform for grief tourists. It was to survive.

When I speak to newly diagnosed patients, I tell them to be selfish. Yes. Selfish. If you cannot be selfish while you’re fighting for your life, when can you? Don’t reply to every single person. They don’t deserve access to you just because they ask. You are in control. You decide. Focus on the people and things that matter. Focus on surviving. Focus on you!
In CURE®’s “Speaking Out” video series, on behalf of Living Beyond Breast Cancer, Dr. Nancy Lin discusses treatment planning for brain metastases in breast cancer and how patients can take part in driving their care. By KRISTIE L. KAHL

FOR TREATMENT SEQUENCING FOR brain metastases in breast cancer, a multidisciplinary team of medical oncologists, radiation oncologists, surgical oncologists and neuro-oncologists is necessary in driving one’s care along the way.

As part of its “Speaking Out” video series, CURE® spoke with Dr. Nancy Lin of Dana-Farber Cancer Institute in Boston about treatment sequencing for breast cancer brain metastases and how the multidisciplinary approach plays a role.

Q: How common are brain metastases in breast cancer?
A: If we look at people who have early-stage breast cancer, brain metastases are not a common site of initial recurrence. So among patients with early-stage breast cancer, less than 2% will develop brain metastases as their first metastatic location. It’s a little bit higher in patients who have stage 3 or inflammatory breast cancer, more like 8% or 10%. If we look at patients who have metastatic breast cancer, the risk over time is much higher in some groups of patients.

So in patients who have HER2-positive metastatic breast cancer, as their first location of metastasis, the brain is not very common. Over time, about half of patients will develop cancer in the brain. And similarly, if we look at patients with triple-negative breast cancer, over time between a quarter to 40% will develop cancer in the brain. For patients who have estrogen receptor-positive versus -negative breast cancers, it’s much less common; it’s about 10% to 15% over someone’s lifetime.

Q: What are the most common treatments for brain metastases, particularly in breast cancer?
A: For patients with brain metastases, there are three major types of treatments: surgery, radiation therapy and some sort of systemic treatment, whether it’s chemotherapy or targeted therapy. When
we look at patients who have a new diagnosis or recurrent diagnosis of brain metastases, we're trying to see whether each of those options is the right option at that one moment in time.

Q: How does the multidisciplinary approach play a role in treating brain metastases?

A: It's really critical. Taking the analogy from early-stage breast cancer, where you get optimal care, we have people see a breast surgeon, a radiation oncologist and a medical oncologist. For patients with brain metastases, we would very frequently involve the radiation oncologist and then sometimes would involve a neurosurgeon, if there's a potential for surgery to remove the cancer in the brain. (Neuro-oncologists) can be very helpful in things like managing seizures, understanding symptoms and where (metastases) might localize to. We also collaborate very carefully with neuro-oncology for patients with leptomeningeal disease. And then the medical oncologist provides the systemic therapy or recommendation. So all of these specialties are very important, and especially because sometimes we choose one over another. Sometimes we choose to combine different types of modalities of treatments. And so you really need everybody at the table to try to understand what's the best course.

Q: What is your advice on how patients can communicate with their multidisciplinary care team?

A: So a couple of key points. One is that it’s important as a patient to really feel like you know who is driving your care from a medical standpoint. Obviously, you as a patient should ultimately make the decisions about what you think makes sense and to go forward with. But you want to know, because if there are multiple people involved in your care, where the buck stops, and you want to know who's coordinating your care.

The other is, it's important to communicate your learning style, your communication style, your preferences. … People have very different styles. And it’s OK to have different styles. It’s important to communicate what your style is to your doctor. And the last thing is don't be afraid to ask questions. Don't be afraid to ask for a second opinion if you think that that might be helpful. My patients ask for second opinions. There's no ego here. We know patients want to have the best treatment options offered to them, and we want that for our patients, too.
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Stand Up To Cancer Ambassadors ERNIE JOHNSON & CHARLES BARKLEY

Photo By FRED SIEGEL

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