

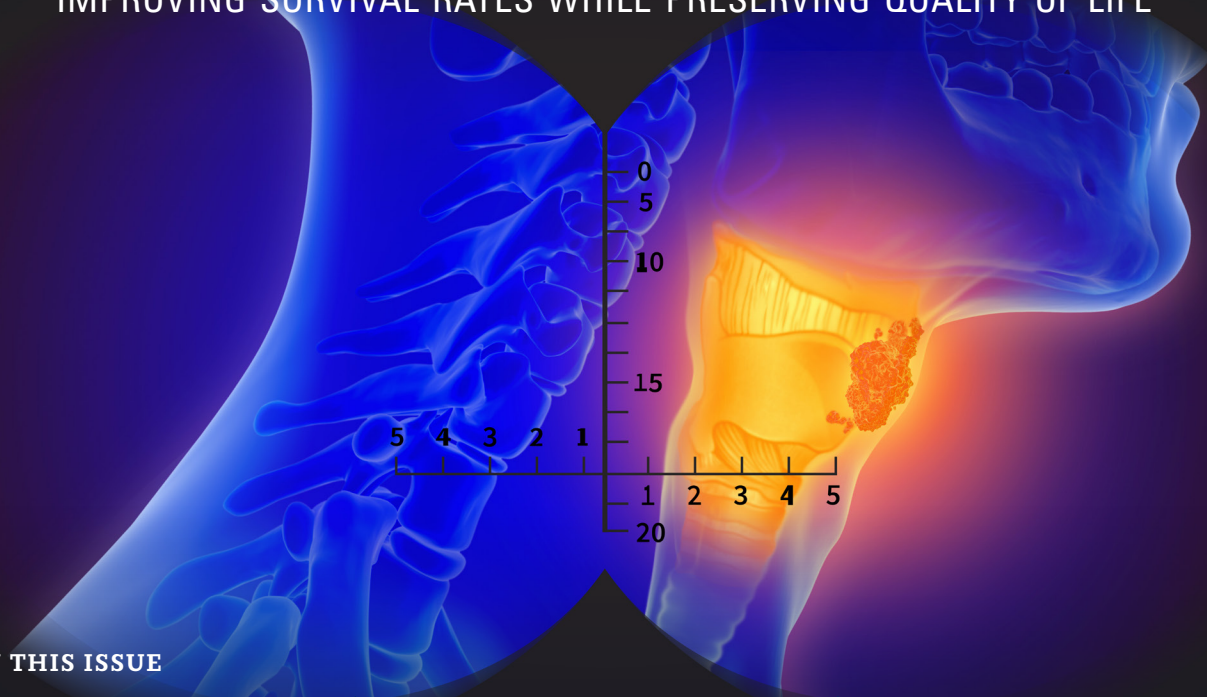
FALL 2022

# cure<sup>®</sup>20<sup>TH</sup> *anniversary*

Cancer Updates, Research & Education<sup>®</sup>

## A SHIFT IN FOCUS

YEARS AGO, THE GOAL OF HEAD AND NECK CANCER TREATMENT WAS STRICTLY FOCUSED ON A CURE. NOW, A NEW APPROACH FOCUSES ON IMPROVING SURVIVAL RATES WHILE PRESERVING QUALITY OF LIFE



### ALSO IN THIS ISSUE

#### BREAST CANCER

Expert urges patients to ask about sexual health concerns

#### MPNs

How a minor change led to major developments

#### KIDNEY CANCER

Guidelines recommend new treatment for pretreated disease

#### MYELOMA

Three hikers recall the climb that strengthened their bond

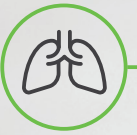
#### LUNG CANCER

Patients want more information on risk for a less talked-about side effect

#### SKIN CANCER

A surgeon is one of the first providers patients meet

# 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.

## FOR THE FUTURE



**Ongoing clinical trials** are exploring if KEYTRUDA can help treat more patients.

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.**

**KEYTRUDA is a prescription medicine used to treat a kind of lung cancer called non-small cell lung cancer (NSCLC).**

- **KEYTRUDA + CHEMOTHERAPY, NONSQUAMOUS**  
It may be used with the chemotherapy medicines pemetrexed and a platinum as your first treatment when your lung cancer has spread (advanced NSCLC) **and** is a type called “nonsquamous” **and** your tumor does not have an abnormal “EGFR” or “ALK” gene.
- **KEYTRUDA + CHEMOTHERAPY, SQUAMOUS**  
It may be used with the chemotherapy medicines carboplatin and either paclitaxel or paclitaxel protein-bound as your first treatment when your lung cancer has spread (advanced NSCLC), **and** is a type called “squamous.”
- **KEYTRUDA USED ALONE, PD-L1 POSITIVE**  
It may be used alone as your first treatment when your lung cancer has not spread outside your chest (stage III) and you cannot have surgery or chemotherapy with radiation, **or** your NSCLC has spread to other areas of your body (advanced NSCLC), **and** your tumor tests positive for “PD-L1” **and** does not have an abnormal “EGFR” or “ALK” gene.
- **KEYTRUDA AFTER CHEMOTHERAPY, PD-L1 POSITIVE**  
It may also be used alone for advanced NSCLC if you have tried chemotherapy that contains platinum and it did not work or is no longer working **and**, your tumor tests positive for “PD-L1” **and** if your tumor has an abnormal “EGFR” or “ALK” gene, you have also received an “EGFR” or “ALK” inhibitor medicine that did not work or is no longer working.

PD-L1 = programmed death ligand 1;  
EGFR = epidermal growth factor receptor;  
ALK = anaplastic lymphoma kinase.

## IMPORTANT SAFETY INFORMATION

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

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

- **Lung problems:** cough, shortness of breath, or chest pain.
- **Intestinal problems:** diarrhea (loose stools) or more frequent bowel movements than usual; stools that are black, tarry, sticky, or have blood or mucus; or severe stomach-area (abdomen) pain or tenderness.
- **Liver problems:** yellowing of your skin or the whites of your eyes; severe nausea or vomiting; pain on the right side of your stomach area (abdomen); dark urine (tea colored); or bleeding or bruising more easily than normal.
- **Hormone gland problems:** headaches that will not go away or unusual headaches; eye sensitivity to light; eye problems; rapid heartbeat; increased sweating; extreme tiredness; weight gain or weight loss; feeling more hungry or thirsty than usual; urinating more often than usual; hair loss; feeling cold; constipation; your voice gets deeper; dizziness or fainting; changes in mood or behavior, such as decreased sex drive, irritability, or forgetfulness.
- **Kidney problems:** decrease in the amount of your urine; blood in your urine; swelling of your ankles; loss of appetite.
- **Skin problems:** rash; itching; skin blistering or peeling; painful sores or ulcers in your mouth or in your nose, throat, or genital area; fever or flu-like symptoms; swollen lymph nodes.
- **Problems can also happen in other organs and tissues.** Signs and symptoms of these problems may include: chest pain; irregular heartbeat; shortness of breath; swelling of ankles; confusion;

*Important Safety Information is continued on the next page.*



**Teresa is a  
real patient**



**keytruda.com/lung**

### **IMPORTANT SAFETY INFORMATION (continued)**

sleepiness; memory problems; changes in mood or behavior; stiff neck; balance problems; tingling or numbness of the arms or legs; double vision; blurry vision; sensitivity to light; eye pain; changes in eyesight; persistent or severe muscle pain or weakness; muscle cramps; low red blood cells; bruising.

- **Infusion reactions that can sometimes be severe or life-threatening.** Signs and symptoms of infusion reactions may include chills or shaking, itching or rash, flushing, shortness of breath or wheezing, dizziness, feeling like passing out, fever, and back pain.
- **Rejection of a transplanted organ.** Your health care provider should tell you what signs and symptoms you should report and they will monitor you, depending on the type of organ transplant that you have had.
- **Complications, including graft-versus-host disease (GVHD), in people who have received a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic).** These complications can be serious and can lead to death. These complications may happen if you underwent transplantation either before or after being treated with KEYTRUDA. Your health care provider will monitor you for these complications.

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

**Before you receive KEYTRUDA, tell your health care provider if you** have immune system problems such as Crohn's disease, ulcerative colitis, or lupus; have had an organ transplant or have had or plan to have a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic); have had radiation treatment in your chest area; have a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome. If you are pregnant or plan to become pregnant, tell your health care provider. KEYTRUDA can harm your unborn baby. If you are able to become pregnant, you will be given a pregnancy test before you start treatment.

Use effective birth control during treatment and for at least 4 months after your final dose of KEYTRUDA. Tell them right away if you think you may be pregnant or you become pregnant during treatment with KEYTRUDA.

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

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

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

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

These are not all the possible side effects of KEYTRUDA. Talk to your health care provider for medical advice about side effects.

**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](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

Having trouble paying for your Merck medicine?

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**IT'S TRU. KEYTRUDA®**  
(pembrolizumab) Injection 100 mg

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

---

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

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

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

**Lung problems**

- cough
- shortness of breath
- chest pain

**Intestinal problems**

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

**Liver problems**

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

**Hormone gland problems**

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

**Kidney problems**

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

**Skin problems**

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

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

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

**Infusion reactions that can sometimes be severe or life-threatening.** Signs and symptoms of infusion reactions may include:

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

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

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

**Continued on next page.**

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

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

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

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

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

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

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

**How will I receive KEYTRUDA?**

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

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

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

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

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

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

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

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

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

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

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

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

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

These are not all the possible side effects of KEYTRUDA.

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

**General information about the safe and effective use of KEYTRUDA**

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

Based on Medication Guide usmg-mk3475-iv-2203r050 as revised March 2022.

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# cure<sup>20</sup><sup>TH</sup> anniversary Contents

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## Shining a Spotlight on What Lies in the Shadows

**A SPOTLIGHT DRAWS ATTENTION** to a particular area, person or thing. When something is illuminated by a spotlight, it often takes center stage. People talk about it endlessly, and news about that particular area, person or thing spreads until it reaches the masses.

In cancer, that spotlight regularly shines on diseases that are the most commonly diagnosed — colon, lung and breast cancer, for example. Moreover, side effects such as nausea, fatigue and hair loss are primarily discussed. There are, however, certain aspects of cancer that don't get enough recognition and are hidden in the shadows.

In this seasonal issue of *CURE*®, we shift the spotlight to a disease that is not frequently highlighted and a treatment side effect that, according to an expert, has been routinely ignored.

Dr. William Tseng, a sarcoma surgical oncologist at City of Hope National Medical Center in Duarte, California, writes that there must be a conscious effort to increase public awareness of sarcoma. A rare cancer of the soft tissues and bone, sarcoma is diagnosed in fewer than 20,000 people in the United States each year. Tseng explains that although this is at least twentyfold fewer than breast cancer diagnoses, the disease should no longer be in the public health shadows of the more common cancers.

"Sarcoma occurs in the rich and the poor, irrespective of access to health care and regardless of gender or race," he writes.

Also in this issue is an analysis of findings from the Sexual Health Assessment in Women With Lung Cancer (SHAWL) study. It demonstrated that three out of four women with the disease reported experiencing moderate to severe sexual dysfunction.

In an interview with *CURE*®, lead SHAWL study author Dr. Narjst Florez (Duma) explains that providers don't always perceive sexual health and dysfunction as priorities for their patients. However, she notes that many of the women included in the study reported wanting information to improve their sexual health. Additionally, she lets patients know that they are not alone.

"Sexual dysfunction is not a price that patients (with lung cancer) need to pay in order to be alive," she says. "I hear this over and over in my clinic, 'I thought that was the price I needed to pay.' And that's not true."

As always, we hope you find our stories inspirational and informative. Thank you for reading. 📖

**MIKE HENNESSY JR.**  
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## Moving the Needle

### SUCCESSFUL MANAGEMENT OF CANCER

requires treatment planning based on the best science available. Our growing knowledge of the biology of cancer has led to many refinements and innovations to surgery, radiation and medical treatments. Carefully designed, conducted and interpreted results from clinical trials testing each of the therapeutic components and modifications are needed to prove better outcomes — either a long-term cure, extension of survival or at least some control of the cancer and/or enhanced quality of life.

It is not uncommon to extend part of a patient's medical therapy to address the possibility of cancer that we cannot see or even test for — microscopic cancer cells that in some cases lay dormant for many years (even when the patient may live a full life free of recurrence). This approach is called “maintenance therapy” and is addressed in more detail in this issue of *CURE*, focusing on its application in ovarian cancer.

In many cases, maintenance therapy includes less-intense components of the initial treatment. For most malignancies, we currently do not have good ways to detect and measure microscopic cancer cells that could lead to recurrence and death. That is changing with newer technology, particularly the ability to assess and quantify tumor DNA circulating in the bloodstream.

Therefore, we still need to test types

and durations of maintenance therapy in controlled clinical trials that can take a long time to complete before a new therapy can be adopted. The notion of additional treatment after the patient is technically free of cancer can be daunting for some patients who may be sapped of energy and still have side effects from their long journey. There is particular interest in using biological therapies that home in on unique drivers of a patient's cancer, as is explained with the use of poly (ADP ribose) polymerase inhibitors, commonly known as PARP inhibitors, for ovarian cancer. This class of therapies is clearly active in ovarian and other cancers that carry an inherited BRCA1 or BRCA2 mutation or other characteristics seen with this aberration. It is critical that the side effects of maintenance treatments be such that patients can have some normalcy and move beyond the typical in-treatment phase.

We expect there will be more maintenance strategies adopted for a range of cancer types over time, particularly with more focused and less toxic protocols. It may become easier to conduct these notoriously difficult-to-complete clinical trials to prove and quantify their long-term effects. Not only are more targeted and immunologically-focused drugs becoming available, but imaging and blood-based technologies are advancing



### DEBU TRIPATHY, M.D.

EDITOR-IN-CHIEF

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ing to provide us “surrogate” measures that can complement, or even some day replace, the gold standard of following patients over the long term for recurrence and survival.

As the case with ovarian cancer proves, we can incrementally “move the needle” as maintenance therapy continues to evolve. ■

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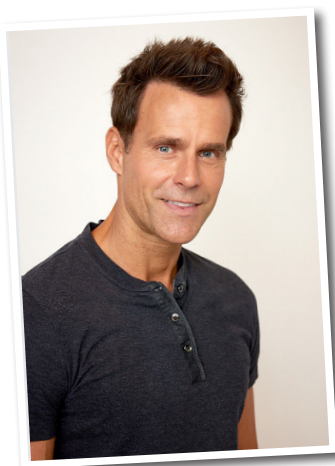
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## “General Hospital” Star Discusses Life After Cancer



**CAMERON MATHISON**

**CAMERON MATHISON, WHO** is known for his role as Drew Cain on the soap opera “General Hospital,” underwent surgery for kidney cancer in 2019. More recently, at the 49th annual Daytime Emmy Awards, the 52-year-old actor opened up about his cancer and what life has been like ever since.

“(Having cancer has) increased my desire and my willingness and my effort and motivation to help others and to spread the word and just to be a benefit,” he said in an interview. “I work with a health coach now — I thought I knew a lot about what I was doing in the right and the wrong ways or whatever, but in the last year, I’d say, maybe 14 months, I’ve

learned more about my own specific health challenges and growth than I have probably in decades before that.”

## Amazon, Fred Hutch Partner to Investigate Cancer Vaccine

**REPRESENTATIVES FROM FRED** Hutchinson Cancer Center in Seattle confirmed to *CURE*® that it recently partnered with Amazon for an ongoing early-phase clinical trial investigating the safety and efficacy of a cancer vaccine.

The plan is to enroll 20 patients in to the phase 1 clinical trial. Patients enrolled in the trial must have stage 3c to 4 melanoma or hormone-receptor-positive, HER2-negative breast cancer that has spread (or metastasized) to other parts of the body.

Patients will receive a personalized vaccine, along with a poly-ICLC. According to information from the National Cancer Institute, poly-ICLC is a substance being investigated in the treatment of cancer, and it has the ability to stimulate the immune system.

The goal of the early-phase cancer vaccine trial is to determine the number of side effects within one year of a patient’s first vaccination.



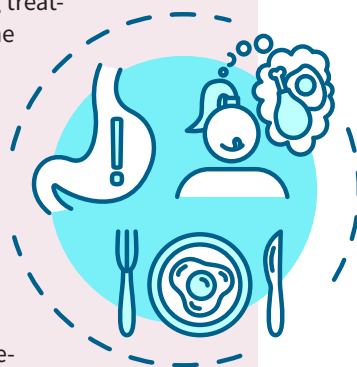
## Novel Drug to Curb Cancer Treatment-Related Anorexia Is Being Tested

**PATIENTS IN THE** CARES study are receiving treatment with the novel drug ART27.13 to investigate if its use increases appetite and food intake in patients who are experiencing anorexia (inability to eat) and weight loss due to cancer treatment.

Prior phase 1 trials of ART27.13 conducted by the pharmaceutical company AstraZeneca showed that the supportive therapy, which works by targeting cannabinoid receptors, led to a statistically significant increase in body weight in healthy individuals.

The plan for the CARES trial is to analyze the safety of increasing doses of ART27.13. The investigators then aim to take those data to determine the best dose for the phase 2a part of the study, which will then further analyze safety and how well the drug works.


So far research has shown that ART27.13 is well tolerated, with no dose reductions, dose interruptions or medical interventions needed from the drug’s side effects.



## Teenager With Blood Cancer Meets Country Music Singer Luke Combs

**ADDI CONELY**, a patient with acute myeloid leukemia, was living her dream when she met country singer Luke Combs. The 17-year-old who lives in California with her family said on social media that seeing the country singer perform live was high on her bucket list. The Grammy nominee eventually saw the post and flew her and her family to Ohio for a concert and spoke with her backstage.


During the show, Combs invited Conely on stage for her favorite song, "Better Together."

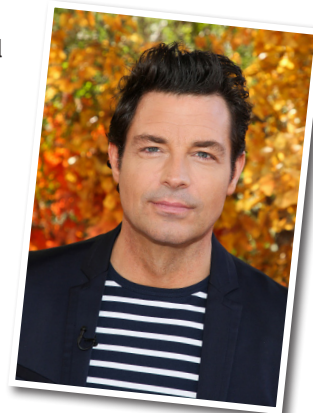
In a Facebook post, Conely's mother, Staci, said it was the best night of their lives. 

## Hallmark Channel Actor Reflects on Wife's Experience With Cancer

**ACTOR BRENNAN ELLIOTT**, who has starred in a "Christmas Encore" and "All of My Heart: Inn Love" on the Hallmark Channel, recently spoke out about his wife, Cami, and her experiences with stage 4 metastatic gastric cancer.

"She's hanging in there. She finished her last eighth round of chemo. She's done 16 (rounds) over the last two or three years," Elliott said in an interview. "Yeah, she's a warrior."

Elliott announced Cami's diagnosis in an Instagram post in April, stating that she was taking "one of the most aggressive types of chemotherapy and immunotherapy." 



 **BRENNAN ELLIOTT**

ELLIOTT: PAUL ARCHULETA/GETTY IMAGES ENTERTAINMENT VIA GETTY IMAGES

## Strength in Numbers

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Scan the QR code with your mobile device to visit [curetoday.com](https://curetoday.com) and check out our advocacy group partnerships.



## Strengthening the Foundation

Gynecologic cancer treatments may weaken a patient's pelvic floor region ultimately leading to pain and a poor quality of life, but physical therapy may help relieve symptoms. *By COLLEEN MORETTI AND*

LUCIA MILLER, PT, MPT, PRPC, WCS



**IN WOMEN WITH GYNECOLOGICAL** cancers, pelvic floor tissue may become scarred and friable (tears and bleeds more easily when touched) after treatments and surgery.

This may cause pain and can be quite disabling as far as quality of life, according to an expert. However, pelvic health physical therapy (PHPT) or pelvic floor PT (PFPT) may help ease the pain and improve quality of life.

Lucia Miller, a senior clinical specialist and founding pelvic health physical therapist at Stanford Pelvic Health Center in Redwood City, California, explained the benefits and importance of pelvic floor PT in an interview with *CURE*®.

“The pelvic floor muscle is the foundation of the spine, like the foundation of the house,” she said. “So if it’s functioning well, the whole house is functioning well.” Miller explained that the pelvic girdle (pelvis) is like a boney bowl or basin with a hole in the bottom of the bowl. The pelvic floor muscle fills in that hole to provide support for the pelvic and abdominal organs above, and teams up with the abdominal and deep back muscles to form a person’s “core,” which is essential for stability and movement.

The pelvic floor extends from the tailbone to the pubic bone and supports the uterus with fallopian tubes and ovaries, the bladder and urethra, the rectum, cervix and vagina. A well-functioning pelvic floor muscle should be strong and able to relax and lengthen fully. However, treatments and surgery for gynecological cancers may weaken the pelvic floor for some women. This may cause bowel and bladder problems, as well as sexual dysfunction, and affect overall quality

of life. But manual therapy and exercises for the pelvic floor muscle address those symptoms to restore normal function, including the strength and length of the pelvic floor, Miller explained.

A strong pelvic floor muscle supports the pelvic organs, ligaments and connective tissue of the pelvis. It maintains bladder and bowel continence, reduces the stress of impact from exercises such as running and jumping, is essential for sexual function and prevents pelvic organ prolapse. The pelvic organs sit directly on the pelvic floor muscle and above them are the abdominal organs and viscera. The weight of those organs is directly supported by the pelvic floor muscle, which also is affected by gravity.

### WHAT ARE THE BENEFITS OF PHYSICAL THERAPY?

Prior to surgery, PHPT may help patients learn to isolate, coordinate, lengthen and strengthen the pelvic floor muscle, making for an easier recovery after surgery. If a patient expects to receive chemotherapy or radiation, PHPT may address general conditioning and fitness and the therapist may establish an exercise regimen to improve resilience. PHPT also provides a patient with a vital educational component to understand how to improve pelvic floor function, as well as what to expect after surgery or chemoradiation treatment.

Evidence shows that prior to any surgery or medical treatment, PT can boost outcomes by educating the patient and setting expectations for upcoming procedures. It also strengthens weak muscles and improves muscle coordination and lengthening and general »



# How to Keep That Foundation STRONG

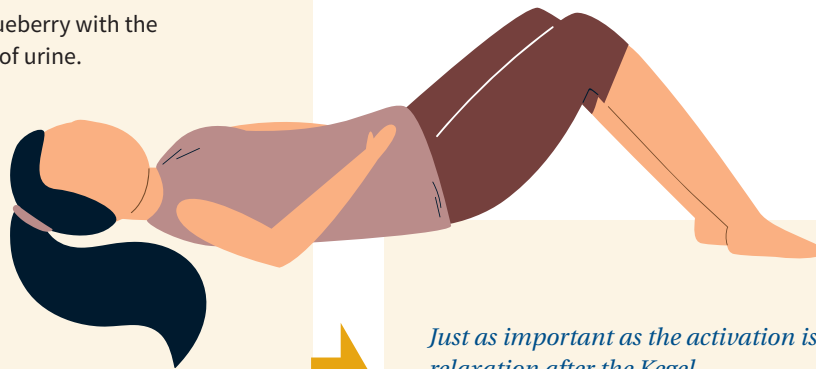
An expert provides two exercises to help strengthen the pelvic muscle.

By COLLEEN MORETTI AND LUCIA MILLER, PT, MPT, PRPC, WCS

**AFTER TREATMENT OR** surgery for a gynecologic cancer, patients may have symptoms or side effects that can affect their daily life. As part of its Heal at Home series, CURE® worked with physical therapist Lucia Miller, to provide a guide to exercises that patients can do at home that may help ease the pain and improve their quality of life.

## Pelvic Floor Activation and Relaxation (Kegel) Exercise

1. Start with the diaphragmatic breathing exercise above.
2. After slowly inhaling to expand the abdomen and pelvic floor muscle, gently squeeze and lift the vagina, rectum and abdominals at the same time as you slowly exhale.
  - a. Feel as if you are lifting a blueberry with the vagina or stopping the flow of urine.
  - b. Imagine you are tightening the rectum as if to stop the passage of gas.
  - c. Picture your lower abdominals pulling up and in as if zipping up tight jeans.
3. All this occurs as you exhale, squeeze and lift your pelvic floor muscle and abdominals at the same time, visualizing your pelvic floor rising like an elevator: one floor, two, three and back down to the ground floor.



## Diaphragmatic Breathing Exercise

1. Find a comfortable position lying down, in a recliner chair or seated upright.
2. Place one hand on your chest and one hand on your lower abdomen.
3. Take a slow deep breath in through your nose, imagining that you are filling your belly and pelvis like a balloon inflating.
4. Note that your belly expands and your pelvic floor lengthens and drops or “bulges” down.
5. Gently exhale, slowing your breath rate with each breath cycle.



*Just as important as the activation is the relaxation after the Kegel.*

1. Fully relax, release, drop and lengthen the pelvic floor muscle (PFM) with your slow diaphragmatic inhalation.
2. Picture the PFM as the base of a balloon with your abdomen as the front of the balloon. This balloon is inflating, expanding and lengthening with your inhalation.
3. Once the PFM is fully relaxed, try another Kegel with your slow gentle exhalation.

Lucia Miller, PT, MPT, PRPC, WCS, is the senior clinical specialist and founding pelvic health physical therapist at Stanford Pelvic Health Center in Redwood City, California. She also owns a private practice, Lucia Miller Pelvic Health Physical Therapy at Menlo Pilates and More, in Redwood City.

body awareness. In this way, a patient is better able to “bounce back” after treatment and surgery because their awareness and coordination of their pelvic floor muscle is improved by their “prehab” treatment.

Not only does PFPT benefit patients before surgery and chemoradiation, it is probably even more important after such procedures, Miller noted.

She explained that after surgery and treatment, patients may experience lymphedema (the build-up of fluid in soft body tissues when the lymphatic system is damaged or blocked), which may cause swelling in the pelvis, arm or leg accompanied by a sensation of heaviness and possible discomfort. Manual lymphatic drainage with a certified lymphedema specialist may help prevent and reduce lymphedema and the specialist can instruct the patient in appropriate exercise programs to reduce lymphedema.

Additionally, if a patient has any vulvar or vaginal scar tissue or sclerosis from chemotherapy and radiation, PHPT can help ease that. In patients who experience sensitivity to touch, or bladder, bowel or sexual dysfunction, desensitization techniques and manual therapy to the vulvar, vaginal and pelvic floor muscle soft tissues may reduce symptoms. Also, normal bladder and bowel function may be restored and sexual dysfunction relieved.

“For instance, if a patient is not tolerating vaginal intercourse, sexual intimacy may be reduced or avoided,” Miller said. “PHPT can help reduce pain and introduce techniques to restore sexual intimacy. ... This is one aspect of PHPT that can really improve quality of life in meeting the patient’s primary goal.”

Another evidence-based tool Miller uses in PHPT is biofeedback, which uses external or internal sensors at the level of the pelvic floor muscle that provide a patient with an objective measurement in real time of the activation and relaxation of their muscle. This improves muscle strength, length, relaxation, coordination and timing.

If a muscle is hypertonic and doesn’t relax and lengthen readily or if a muscle is weak with poor sensation, biofeedback is used to retrain muscle coordination and reduce dyssynergia or lack of coordination,” she explained. “If there is a loss of sensation due to nerve damage, a patient may not be able to isolate that muscle, so we use biofeedback to help them gain function and control of that muscle.”

## FROM PHYSICAL TO PSYCHOSOCIAL

Additionally, Miller said she focuses not only on the physical symptoms

but also on the psychosocial aspects with which the patient presents. It is important to integrate deep diaphragmatic breathing techniques to help calm the sympathetic nervous system or SNS (a person’s “fight or flight” response) and activate the parasympathetic nervous system (the “rest and digest” response), which can help reduce the patient’s stress and anxiety.

Laying bare hand to bare arms, chest or abdomen in combination with “belly breathing” evokes this parasympathetic response, according to Miller. Adding abdominal massage and colonic massage may provide additional benefits for circulation, bowel motility and “down-regulating” the SNS, Miller explained.

“This is something that’s minimally invasive, basically not invasive, and there is no downside,” she added. “A patient can perform diaphragmatic belly breathing anytime, anywhere to calm their SNS. Abdominal massage may be performed as often and for as long as a patient likes; it is always beneficial and never harmful and therefore a great tool for patients to learn for self-care.”

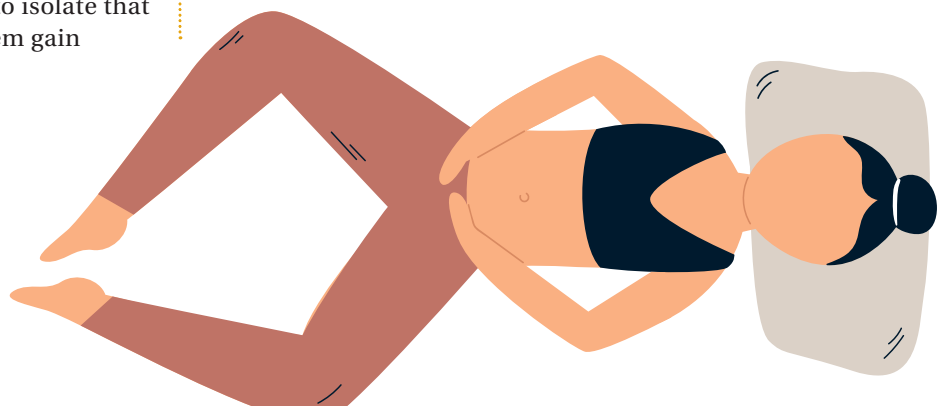
## RESTORING QUALITY OF LIFE

If a patient’s pelvic floor is not functioning well, this affects other bodily functions and quality of life.

“If (a patient) is having any issues as far as pelvic pain or bladder, bowel or sexual dysfunction, pelvic floor PT is vitally important to the function of the whole body,” she said.

If a patient is experiencing these symptoms, they may not want to go out and socialize because of discomfort or even embarrassment, she continued. Pelvic floor PT can help with that and improve patients’ quality of life, restoring the physical and social functions that are important to them.

“Much of what we do in PHPT may not be rocket science, but rather we teach basic behavioral modification for bladder, bowel and sexual function of which most patients are not aware until instructed,” Miller concluded. “Our approach is holistic — body, mind and spirit — following a biopsychosocial model of health care, with the goal of restoring function and quality of life to an optimal level.” ■





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# Diminished Sexual Health Should Not Be a Price Paid to Survive Lung Cancer

Three out of four women with the disease reported experiencing moderate to severe sexual dysfunction, a survey shows.

By RYAN MCDONALD



**FINDINGS FROM A RECENT** survey of more than 240 women with lung cancer highlight a universal issue that is worsened by ignoring underlying problems.

The survey, led by Dr. Narjust Florez (Duma), showed that 77% of the 239 respondents reported experiencing moderate to severe sexual dysfunction after diagnosis and treatment.

"I never expected that we were going to find 77% of patients have sexual dysfunction," Florez (Duma), a thoracic medical oncologist and associate director of the Cancer Care Equity Program at Dana-Farber Cancer Institute in Boston, said in an interview with *CURE*®. "Three out of four patients that walk into our thoracic medical oncology clinic (have) moderate to severe sexual dysfunction.

"(Oncologists) do a lot of clinical trials and studies, and to be honest with you, it is very hard to find anything where 77% of the patients have something in common."

## A GROWING ISSUE

Ten years ago, patients with metastatic lung cancer would survive only for approximately six to 12 months, according to Florez (Duma). But as new research has led to several Food and Drug Administration approvals of targeted and immunotherapy treatments, survival for many patients exceeds five years, she said, adding that, unfortunately, sexual health has been perceived as not a priority for patients with lung cancer.

Sexual dysfunction, however, has been linked to depression and is associated with higher symptom burden and a higher need for supportive medications like opiates and antidepressants, according to Florez (Duma), who noted that, traditionally, lung cancer providers have taken data and information from patients with breast cancer who experienced sexual dysfunction and used it to treat their patients.

"Many of these women (with breast cancer) become prematurely

menopausal due to the use of anti-hormonal medications," she explained. "We're using data from a (type of) cancer that is very different (in treating) patients with (lung) cancer."

To gather more accurate information for this patient population, Florez (Duma) and her colleagues set out to identify the rate of sexual dysfunction in women with lung cancer and reasons they reported a lack of sexual desire.

The responses showed that the most common symptoms of sexual dysfunction were vaginal dryness (34%), decreased sexual desire or interest (1%), and vaginal pain or discomfort with sexual activity (13%). The factors most frequently associated with affecting sexual satisfaction were fatigue (40%), feeling sad or unhappy (28%), partner issues (22%) and shortness of breath (15%).

"Shortness of breath is really on the bottom of reasons why patients with breast cancer report decreased desire, but for a patient with lung

## lung cancer

cancer who had a large lung surgery or high radiation to the chest, shortness of breath is in the top four reasons for sexual dysfunction,” she said. “And it can be easily addressed.

“People think addressing shortness of breath is super hard. I work with physical therapists that work with my patients to show them special sex positions (that) don’t require such a big lung capacity. So sometimes we think the problems are bigger than they are.”

### UNDERLYING ISSUES

Historically, the focus has been to develop new medications that target pain and help with depression, Florez (Duma) explained, but this approach ignores a patient’s underlying issues. For example, patients may be experiencing body image issues following surgery. This creates a trickle-down effect that may cause a

patient to become depressed, which may subsequently lead to issues with their sexual health.

She noted that precision medicine is necessary because it addresses the unique needs of a patient with lung cancer. The same is true, she said, for certain side effects such as sexual dysfunction, which should not be addressed in a cookie-cutter manner.

“I’m not a big proponent of just giving people pills without addressing the underlying problem,” she said.

She also wants patients who may be experiencing sexual dysfunction to know that they’re not alone.

“Sexual dysfunction is not a price that patients (with lung cancer) need to pay in order to be alive. ...” she said. “I hear this over and over in my clinic, ‘I thought that was the price I needed to pay.’ And that’s not true.”



OUT OF  
**239**  
SURVEY  
RESPONDENTS,  
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reported experiencing  
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*after*  
DIAGNOSIS  
& TREATMENT.

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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
- **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,**  
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**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.

## **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

- 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](https://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

**REGENERON | SANOFI GENZYME** 

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**Explore what could be possible with LIBTAYO**  
**Scan this QR code with your phone to learn more, or visit [LIBTAYO.com/NSCLC](https://LIBTAYO.com/NSCLC)**



## 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.

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

### Lung problems.

- cough
- chest pain
- 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
- severe stomach-area (abdomen) pain or tenderness

### Liver problems.

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

### Hormone gland problems.

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

### Kidney problems.

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

### Skin problems.

- rash
- painful sores or ulcers in mouth or nose, throat, or genital area
- itching
- skin blistering or peeling
- swollen lymph nodes
- 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
- dizziness
- chills or shaking
- feel like passing out
- itching or rash
- fever
- flushing
- back or neck pain
- shortness of breath or wheezing
- 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 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.

**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-Barre 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.

**REGENERON | SANOFI GENZYME** 

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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](http://www.LIBTAYO.com)





# Life-Altering Experience Changes Physician, Patient Perspectives



In 2018, 18 trekkers completed an awe-inspiring hike of the Himalayan highlands to the doorstep of the world's tallest mountain, Mount Everest. Three of the climbers discuss a bond that hasn't broken.

By RYAN MCDONALD

**AS THE HELICOPTER TOOK** off in the distance, 18 individuals watched and readied themselves to embark on a trek that would eventually take them to an altitude of 18,519 feet above sea level.

Four years after that daunting trek, three of the 18 hikers reminisced about their journey to the doorstep of the world's tallest mountain, Mount Everest. The friendship the trio has since built started outside a coffee stand after being dropped off by the helicopter, according to Dr. Saad Z. Usmani, a hematologic oncologist and chief of Myeloma Service at Memorial Sloan Kettering Cancer Center in New York City.

In 2018, Stan Wagner, who was diagnosed with multiple myeloma in 2013 and resides in Brooklyn, New York; Dr. Ben Marcus, who received a diagnosis of multiple myeloma in 2016 and is the director of facial plastic surgery at University of Wisconsin in Madison; and Usmani joined 15 other individuals on a hike that would forever alter their perspectives on life. During a recent CURE Educated Patient Multiple Myeloma Summit, the three discussed how participating in Moving

Mountains for Multiple Myeloma®, a joint initiative between the Multiple Myeloma Research Foundation and CURE Media Group with the mission of raising funds and awareness for multiple myeloma research, has helped them find a purpose.

**USMANI:** Those friendships from the trip changed my perspective on life. For the both of you, what can you say about the relationships that came from that trip?

**WAGNER:** It was kind of instantaneous. With the Kilimanjaro trek, we met the first time for our practice hikes and bonded immediately. And it was just like a big family. The same thing with the Everest trek.

Of the four years preparing, I spent almost two of those training. I looked at some of the other guys on the hike on the first trek: They were going to a gym. They're doing this, and I just thought, not me. So I had a plan: three days at the gym at lunch and long walks on the weekend, including hikes in upstate New York. And it got me through. But the family thing was the key.





**MARCUS:** One of the things that was so great about the trip is you got to see a whole bunch of people who were in the same spot as you, kind of with the same attitude. Anyone who decided to go climb Mount Kilimanjaro or Mount Everest probably has some zest for trying to live. But those people and the medical staff that were on that, and the people that work in advocacy, they get it. They know what it feels like to constantly have that little myeloma creature peeking over your shoulder. One of the people from our trip (recently) texted me about something with their medical condition, and we get each other in a way that's very hard to understand unless you've lived through that. I'm really grateful for those long-term friendships. I mean, it's four years ago, and we still all reach out every so often and stay in touch because that particular level of understanding and connection is hard to come by.

**WAGNER:** Having a doctor like Saad on the team is also a big plus. If I have a go-to question right away and I can't find my doctor, which is the case more than I'd like, he's just there for me, which I really appreciate.


**MARCUS:** Yeah, we also asked him about a thousand questions. I got a lot of free medical advice.

**USMANI:** In return, you changed my perspective on life. How precious life is and how important it is to have these relationships, to take on these challenges in life and do it for a cause.

That's the gift that you gave me. That trip also made me realize that I need to pay attention to my health. And it really changed my own perspective on getting on board with other endurance events and continuing to raise funds for the cause.

**USMANI:** What are your biggest takeaways from this whole experience so far?

**WAGNER:** How much money we've raised. Why we've done it. I mean, that's the biggest takeaway. Climbing mountains is one thing, but doing it for a real good cause and being somewhat successful, that, to me, is the biggest takeaway.

**MARCUS:** For me, the biggest takeaway is that the world's a huge place, and it's really nice to feel small sometimes. I'll never forget being in Nepal. When you're a patient, sometimes you tend to get in your own head a little bit. When you're sitting there and you're looking at these beautiful vistas, it just changes the world, right? Whether you're worried about your job, or you're worried about your family or you're worried about your health, when you're out there and you see how amazingly large this world is, it changes your perspective. And so I think that it's never bad for a change of perspective, but it's vitally important for patients with cancer to snap them out of sometimes this negativity and focus on all the beauty and wonder that's in the world. 

*This transcript has been edited for clarity and conciseness.*



## NCCN Now Recommends Fotivda for Pretreated Kidney Cancer

This medication elicited a higher overall response rate with fewer severe side effects versus another drug used in this setting during a phase 3 clinical trial. *By BRIELLE BENYON*

**THE NATIONAL COMPREHENSIVE CANCER** Network (NCCN) updated its kidney cancer treatment guidelines to include Fotivda (tivozanib) in its Category 1 status — which means the nonprofit alliance of more than 30 cancer centers strongly recommends the treatment — for patients with renal cell carcinoma who have received two or more prior therapies.

“Category 1 is the highest category recommendation offered by (the) NCCN, which is based on strong clinical evidence and perception of the product among the NCCN panel members,” Michael P. Bailey, president and CEO of AVEO, the pharmaceutical company that makes Fotivda, said in a press release. “The NCCN guidelines are recognized and followed by both academic and community oncologists when selecting appropriate therapeutic options for their patients.”


Fotivda is a tyrosine kinase inhibitor that is taken orally and works by inhibiting vascular endothelial growth factor receptor (VEGFR), which plays a pivotal role in the development of cancer cells.

The NCCN based its recommendation on findings from the phase 3 TIVO-3 clinical trial, which showed that Fotivda had similar efficacy to Nexavar (sorafenib),

another drug commonly used in this setting, with fewer severe side effects.

Long-term data from TIVO-3 showed that treatment with Fotivda elicited a higher overall response rate (percentage of patients whose disease shrinks as a result of treatment) than Nexavar, at 10% and 8%, respectively. Additionally, long-term progression-free survival (time from treatment until disease gets worse) rates were higher with Fotivda than Nexavar. At 36 months after treatment, 12.3% of patients receiving Fotivda did not experience disease progression compared with 2.4% of those treated with Nexavar. At 48 months, progression-free survival rates were 7.6% and 0% for the Fotivda and Nexavar groups, respectively.

In 2021, the Food and Drug Administration approved Fotivda for relapsed/refractory advanced, pretreated renal cell carcinoma based on earlier findings from the trial.

“This year we presented encouraging long-term, progression-free survival and overall survival follow-up data from the phase 3 TIVO-3 study,” Bailey said. “These new data demonstrate the durability of Fotivda’s anti-tumor activity.” 



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*Extraordinary*  
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Margaret Campbell, B.S.N., RN, Winner of 2022 Extraordinary Healer

CURE<sup>®</sup> is now accepting essay nominations for the 2023 Extraordinary Healer<sup>®</sup> award for oncology nursing! We invite you to describe the compassion, expertise and helpfulness a special oncology nurse has exhibited in caring for patients with cancer. Nominations are accepted from patients, caregivers, survivors, family members and peers.

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# Melanoma Care Spans From Surgery to Radiation and More

Patients with this skin cancer will meet with many health care providers, and one of the first will be a surgeon. By RYAN MCDONALD

**PATIENTS WITH MOST FORMS** of skin cancer should be prepared to see a variety of providers during their treatment journey, including surgical oncologists, according to a speaker during the CURE® Educated Patient® Skin Cancer Summit.

According to Dr. Erica B. Friedman, an assistant professor in the Department of Surgery at NYU Grossman School of Medicine in New York City, a surgical oncologist is often the first provider that

patients see after they receive a diagnosis of skin cancer from their dermatologist.

“(The care team) ranges from a dermatologist who likely is the one who made the diagnosis or treats earlier thin skin cancers to the surgical oncologist, which is where we’re treating early or regionally advanced or distant melanoma,” Friedman said. “And (it) spans to a medical oncologist who may treat a patient who’s not a candidate for surgery. Additionally, there’s a role for radiation oncology as well.”

## HOW TO PREPARE FOR AN APPOINTMENT WITH A SURGEON

When a patient arrives to meet with their surgical oncologist, it is important they bring their pathology report, Friedman said, adding that the report should have been reviewed by a dermatopathologist, a medical doctor who specializes in dermatology and pathology and looks at samples of skin, hair and nails under a microscope to diagnose disease.

This individual, she said, is instrumental in helping the surgeon determine the extent of surgery needed to treat the patient — specifically, the margins (the border of normal-appearing skin around the tumor that is removed).

“A well-done biopsy plus a well-read biopsy report really allows us to stage and treat melanoma appropriately,” she said.

## PRIMARY AND REGIONAL MANAGEMENT OF MELANOMA

The surgical management of local and regionalized melanoma has greatly evolved over the past three decades, according to Friedman. The primary advancement, she said, is that less is more.



➤ A health care provider assesses a mole on a patient's back.



“Oftentimes, (we) surgeons don’t like to hear this because we like to operate,” she said. “But the surgical treatment of melanoma has really evolved.”

The goal with surgery is to remove all the tumor cells from the initial melanoma, she explained.

“This means we don’t want any cells left behind, and we want the edges of what we remove to be clear,” Friedman said. “We would like to do this while minimizing morbidity, minimizing functional impairment and minimizing disfigurement.”

Which is the reason for a significant emphasis on less is more.

Friedman said this “less is more” approach is evidenced by findings from numerous clinical trials over the past few decades that have compared surgical margins across a variety of patients. As a result of these studies, the National Comprehensive Cancer Network (NCCN) — an alliance of more than 30 cancer centers in the United States — developed recommendations for the surgical management of melanoma. For instance, if a melanoma is 4 millimeters or thicker, the NCCN now


suggests surgeons no longer need to remove “extremely wide surgical margins.”

However, Friedman noted that controversy still exists as to what the true optimal surgical margin is for resecting melanoma.

#### **FIXING THE AFFECTED AREA**

Typically, Friedman said, the goal is to cut around the tumor in an elliptical shape to better facilitate a straight-line closure, which is described as it sounds — a horizontal or vertical scar that is not too disfiguring.

But this is not always possible. Sometimes, Friedman noted, the area the surgeon is operating on is in a sensitive area, so a plastic surgeon needs to perform the more complex closure of the area.

Occasionally, patients may need a full-thickness skin graft. Friedman presented a case of a patient who needed a significant portion of their nose removed. In cases like this, a plastic surgeon takes portions of a person’s skin — often from less visible areas — and surgically grafts them to the affected area. 

**new**

# Clinical Trial CORNER



Responding to the needs of our readers, we are proud to announce the launch of the new Clinical Trial Corner resource on curetoday.com. There you’ll find the latest news on clinical trial availability and enrollments.

Visit [curetoday.com](https://curetoday.com) to stay up-to-date on clinical trials.  
[curetoday.com/clinical-trial-corner](https://curetoday.com/clinical-trial-corner)







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%**  
**63 out of 137 patients**

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%**  
**23 out of 56 patients**

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.**

**LIBTAYO Surround® offers support and resources to patients prescribed LIBTAYO.  
If you think LIBTAYO may be right for you, talk to your doctor.**

## 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*

**Actual LIBTAYO patient.  
Individual responses may vary.**

To learn more about Dave and other patient stories, visit [MeaningfulStories.com](https://www.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.

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**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](https://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

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

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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.

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

### Lung problems.

- cough
- chest pain
- shortness of breath

### Intestinal problems.

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

### Liver problems.

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

### Hormone gland problems.

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

### Kidney problems.

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

### Skin problems.

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

**Infusion reactions that can sometimes be severe.** Signs and symptoms of infusion reactions may include:

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

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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](http://www.LIBTAYO.com)



# Few Patients With Breast Cancer Are Educated on How Treatment Affects Sexual Health

An expert urged patients to not be afraid to raise this topic with their oncology team because there are ways to mitigate symptoms and side effects. By MIRANDA LANKAS

**FEW PATIENTS WITH BREAST** cancer receive adequate information about the potential effects that treatment may have on their sexual health, according to newly released study results. The findings, published in *Annals of Surgical Oncology*, also showed that the education patients receive about the effects of breast cancer treatments is insignificant.

The study consisted of a questionnaire as well as interviews and focus groups. In total, 87 patients filled out the questionnaire and 16 patients were interviewed by the investigators.

Most patients were younger than 65 (85%), married (67%), White (83%) and heterosexual (98%), but the amount of time since their initial diagnosis varied from less than one year to more than four years. More than half of the survey respondents reported that they underwent surgery (86%) and received chemotherapy (71%) and/or endocrine therapy (66%).

Most respondents (93%) reported a symptom that negatively affected their sexual health. The most common symptoms included decreased sexual desire (69%), vaginal dryness (63%) or less energy for sexual activity (62%).

When asked when they would ideally like to receive education on the effects of breast cancer treatment on sexual health, most (73%) said they wanted to be informed of the risks early after their diagnosis. Most respondents also noted that their oncology team or health care providers failed to give them any information about possible sexual health side effects associated with breast cancer treatment.

For patients who received any information, it was more focused on fertility preservation and menopause and not on sexual health or pleasure.

“(Patients should) understand that these symptoms and side effects of treatment are incredibly common and that there are ways to mitigate and treat these symptoms,” study author Dr. Sarah Tevis, a breast surgical oncologist at the UCHHealth Diane O’Connor Thompson Breast Center in Aurora, Colorado, said in an interview with CURE®.

## The most common symptoms reported by survey respondents included

decreased  
sexual desire

**69%**

vaginal  
dryness

**63%**

less energy for  
sexual activity

**62%**

Tevis urged patients that they should not be afraid to raise the topic of sexual health with their oncology team.


## GIVE PATIENTS OPTIONS

The patients in the study suggested that many different educational resources be offered to patients, including the creation of support groups as well as videos, pamphlets and documents to be distributed at the doctor’s office and the implementation of routine sexual health questions during their appointments.

One respondent noted, “I feel that it would be best to have several avenues available. Then you could choose what you feel most comfortable with.”

As a result of the survey responses and subsequent interviews, Tevis noted that the University of Colorado is partnering with the nonprofit organization Catch It In Time to create sexual health videos for patients with cancer and health care professionals.

“The video series will cover what to expect with breast cancer surgery and how to actively prepare for surgery, (manage) sexual health symptoms related to breast cancer treatments and (navigate) relationships and dating,” Tevis explained. “We hope to have the videos completed by the end of (summer 2022) and plan to pilot test the videos in women with breast cancer this fall. If patients find the videos acceptable and appropriate, we plan to make them widely available online.”

She said there will be four videos in this series, with the potential to cover other cancer types and treatments in the future. 





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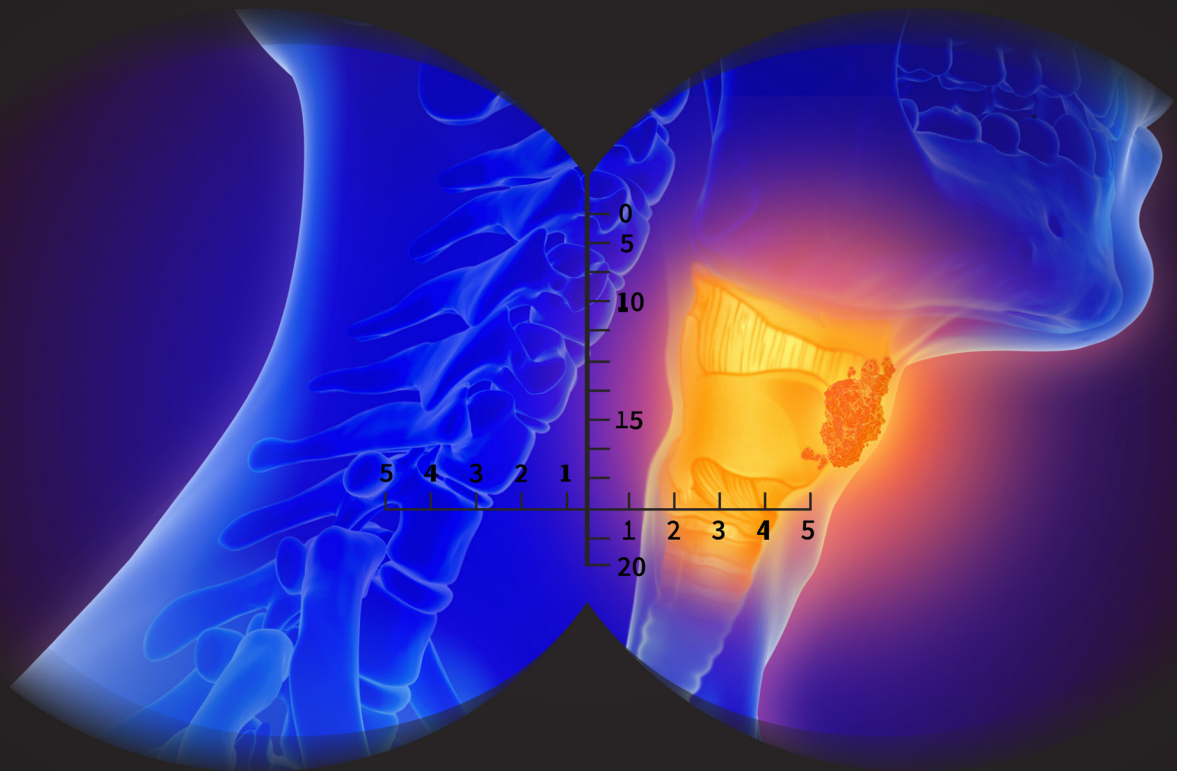
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# A SHIFT IN FOCUS





**KAREN HANNA**

enrolled onto a clinical trial investigating a maintenance therapy before it was approved by the Food and Drug Administration.



JORDAN BROWER



# ‘BIGGEST BREAKTHROUGH IN DECADES’

Although maintenance treatments have helped patients with ovarian cancer live longer, experts note there are still some unmet needs that must be addressed.

By KAREN BLUM

**K**aren Hanna was first diagnosed with ovarian cancer in April 2013. At the time, she underwent a debulking (tumor burden reduction) surgery and received chemotherapy. Then her oncologist asked if she would like to enter a clinical trial testing a new type of drug called a PARP inhibitor, which her doctor hoped would become maintenance treatment one day. Hanna gladly volunteered.

By the time Hanna's cancer recurred in November 2018, her oncologist had good news: the maintenance therapy was now approved by the Food and Drug Administration (FDA) and she would be eligible for it following another round of surgery and chemotherapy. She started the treatment, called Lynparza (olaparib), in February 2020. »





## KAREN HANNA

says it was interesting to be on a clinical trial testing a maintenance therapy she would later be prescribed.

She first heard about the potential for maintenance treatment in 2013. “I didn’t think much about it because I was just in survival mode,” says Hanna, now 50 years old, of Oklahoma City. “It’s kind of interesting that you’re in a clinical trial for a PARP inhibitor in hopes (it) will show that maybe it will be of benefit one day as maintenance therapy. And seven years later, you’re using it as maintenance therapy.”

### WHAT IS MAINTENANCE THERAPY?

Maintenance therapy is given after a patient completes chemotherapy to decrease the chance that the cancer will come back or to delay it from recurring, explains Dr. Kathryn P. Pennington, an assistant professor of obstetrics and gynecology at the University of Washington in Seattle.

“It’s given to continue or maintain the good results of a prior treatment,” Pennington says. “The idea behind it is that it is often better tolerated than traditional chemotherapy, so it’s something that someone could be on for a long time and feeling well, while hopefully delaying the cancer coming back.”

Maintenance therapy is an option for women with stage 2, 3 and 4 cancers that respond well or very well to

surgery and platinum-based chemotherapy, according to the National Comprehensive Cancer Network (NCCN). Options for therapy depend on whether a person has a germline (inherited) mutation in the BRCA1 or BRCA2 gene or if their tumor is considered homologous recombination deficiency (HRD) positive, meaning the tumor is unable to repair double-strand breaks in DNA and is determined by gene sequencing characteristics. Options also depend on whether a person’s primary chemotherapy regimen included Avastin (bevacizumab).

Two types of targeted therapies are used in this setting. Avastin works by inhibiting vascular endothelial growth factor (VEGF), a protein that helps cancer grow blood vessels for food and oxygen. And PARP inhibitors that stop cancer cell DNA from being repaired by a protein called PARP, so that damaged DNA stays at a level that causes cells to trigger their own death, constraining tumor growth. Three PARP inhibitors are approved by the FDA for ovarian cancer: Lynparza, Rubraca (rucaparib) and Zejula (niraparib).

Depending on the drug, patients should receive



JORDAN BROWER

maintenance therapy for 15 months to three years. The goal is to stop, says Dr. Kathleen Moore, the Virginia Kerley Cade Endowed Chair in Cancer Development and a professor of gynecologic oncology at the University of Oklahoma College of Medicine in Oklahoma City.

“Patients who have evidence of disease, and (for whom) you’re holding things stable, ... need to

could lead to a less robust response to subsequent chemotherapy if cancer recurs, Moore notes.

The rationale behind maintenance therapy is based on two principles, according to Dr. Robert L. Coleman, chief scientific officer at US Oncology Research, in Woodlands, Texas. One is that as many as 20% to 30% of patients will have a recurrence of their cancer in a short period of time following treatment, even if it doesn’t initially show up on biomarker tests or imaging studies, he notes.

“Many years ago, we used to assess the quality of the initial response by operating,” he says. The procedure is called second-look surgery. “When we looked for cancer in patients who didn’t have any other overt evidence of disease, we would ultimately find residual disease in about half the patients. So we knew this strategy probably wasn’t very sensitive or specific with respect to the disease being gone.”

A second principle is that maintenance therapy, when used to prevent cancer recurrence, also can shrink tumors if it’s active against cancer or has anti-cancer activity, Coleman adds. “Patients are getting even deeper responses while they’re taking the therapy, so in that context, maintenance is actually a form of additional treatment,” he says.

#### HOW IS IT WORKING?

Hanna says her experience on Lynparza since February 2020 has been positive, and she has tolerated the therapy well.

“I might have had a little fatigue up front,” she says, but she remembers telling her doctor at the four-month mark that it didn’t feel as though she was taking anything. “I try and take very good care of myself,” she adds. “I exercise six days a week, I eat very healthy (foods). I’m very mindful about living a healthy lifestyle.” She also has a busy career in pharmaceutical sales and serves on boards of directors for different

organizations. “I’m going and going and going all of the time. So if I am experiencing fatigue from this pill, I don’t know it.”

February 2022 marked her two-year check-in being on maintenance therapy. Her scans and blood markers looked good enough that her oncologist wanted her to remain on the treatment for one more year. If she continues to do well, she’ll then stop therapy.

Hanna is one of thousands of women who have done well on maintenance therapy. For such patients who have a mutation in either the BRCA1 or BRCA2 gene, maintenance therapy medications are “extremely effective,” says Pennington.

For example, investigators of a clinical trial called SOLO-1, which evaluated Lynparza after primary treatment for patients with BRCA1 and BRCA2 mutations, found that the drug delayed cancer recurrence by more than 40 months at the median. It also lowered the risk of cancer progression or death by 70% compared with a placebo, she says.

Other trials also have demonstrated benefits of the therapies. Results from the PRIMA study, which examined Zejula in patients who had responded to platinum-based chemotherapy, showed that the drug delayed disease progression for people with BRCA1 and BRCA2 mutations by 11 months compared with placebo. The drug delayed cancer progression by a similar length of time among patients who did not have a mutation but whose tumors had HRD. In contrast, the drug delayed cancer progression among people who had tumors without BRCA1/2 mutations or HRD by just three months.

Kim Bell, 58, of College Station, Texas, started maintenance therapy with Lynparza and Avastin in February 2022. Bell was treated for stage 3 ovarian cancer in 2021 and had surgery followed by six »



« HANNA notes that she maintains a healthy lifestyle and has tolerated her treatment well.

continue for as long as they’re receiving benefit,” she says. “But for patients who are in a complete response, I do think it’s important to stop, because some of those patients may not recur ever, or for many years.” Additionally, there is a sense that continuing on a PARP inhibitor





**KIM BELL** says that the severe fatigue caused by her maintenance therapy has forced her to cut back on her business.



chemotherapy treatments. She had an Avastin infusion in early February, with repeat infusions every three weeks, and takes Lynparza pills twice a day. At the time she spoke with *CURE*®, she was scheduled for imaging tests to see how well the treatment was working.

Her experience has been a little different from Hanna's.

Lynparza "causes severe fatigue for me since I'm taking 600 (milligrams) a day," says Bell, who has had to cut back a bit on her floral design business due to her lack of energy. "After periods of rest or sitting, it takes me a few steps to move normally since it is affecting my joints and muscles a great deal, as well as my back. My doctor and specialty pharmacist indicated that many patients see side effects subsiding after a couple of months, and I'm only two months in to taking the drug. I generally don't have any side effects from my (Avastin) infusions."

Although she says she doesn't want to quit the therapy because of the potential benefits, she notes she plans to ask her doctor about reducing the dose to see if that helps. That option had been presented to her during discussions before starting the therapy.

Fatigue, nausea, vomiting and low blood cell counts are among the most common symptoms with Lynparza,

according to the NCCN. Anemia or myelodysplastic syndrome, a cancer in which the bone marrow does not make enough healthy blood cells, are rarer.

Patients "feel like a wet noodle," Moore says. "They'll say over time they accommodate to it and they're able to do everything they want to do, but they do feel this level of fatigue that is real and needs to be acknowledged."

Despite that, "their quality of life, even though they may have more side effects, does not appear to be diminished," Coleman notes, "so it seems to be what we could call a tolerable regimen."

### WHAT'S NEXT?

As the science continues to evolve, oncologists are looking forward to additional or refined treatments including combination therapies. HR proficient tumors is one area ripe for improvement, Pennington says. "It would be ideal to find a maintenance therapy where we could do better than that three months' magnitude."

Another concern is what to do with patients whose cancer recurs even after treatment with PARP inhibitors, she adds. Should they be prescribed PARP inhibitors again? Are there ways to restore PARP resistance? Could





➤ **BELL** notes that her doctors' assurance that her body could adjust to the medications has given her hope.

the inhibitors be combined with another chemotherapy or medication to make it sensitive to PARP inhibition again? This is an area of active study, says Pennington, investigating combinations of PARP inhibitors with other drugs, such as agents that inhibit the ATR protein or those that block the growth of blood vessels that support tumor growth. Analysis of tumors that recur after PARP inhibition may be able to reveal specific alterations that could inform new therapies.

"Even in patients who are really good candidates for a therapy, we find some who still have recurrence and progression," Coleman says. "Better treatments are always going to be an unmet medical need for our patients."

There are potential opportunities for additional maintenance therapies using a newer class of drugs called antibody-drug conjugates, he notes, especially among patients that don't have BRCA 1/2 mutations. Some of these are in clinical trials launching now, Moore points out. "There's probably going to be a lot of development in this space moving forward."

For now, Hanna says she encourages patients to give maintenance therapy a try.

"This is the biggest breakthrough for ovarian cancer in decades, and one that is showing very promising outcomes ... and extending the lives of ovarian cancer patients, which is huge," she says. "Embrace it, don't be afraid of it. The odds of you being able to tolerate this are in your favor.

#### THE NATIONAL COMPREHENSIVE

Cancer Network has these recommendations for maintenance therapy for women with ovarian cancer whose disease has completely or partially responded to first-line therapy:

- Women who have a BRCA 1/2 mutation may benefit from a PARP inhibitor as maintenance therapy.
- Women who have a BRCA 1/2 mutation and had Avastin as part of their first-line treatment may benefit from a PARP inhibitor alone or Lynparza and Avastin as maintenance therapy.
- Women who do not have a BRCA 1/2 mutation and had Avastin as part of their first-line treatment may benefit from a PARP inhibitor alone or in combination with Avastin as maintenance therapy, depending on their homologous recombination deficiency status.
- Women who do not have a BRCA 1/2 mutation and did not have Avastin as part of their first-line treatment may benefit from a PARP inhibitor as maintenance therapy.

... Go into it knowing that this is something that can hopefully get you to the next best option that is coming in the future."

She also encourages patients to stay positive and to believe that "your mind is your greatest weapon." Staying in a positive and grateful framework makes a difference, she says, "I truly believe that."

Bell agrees. Hearing from her doctor that her body could adjust to the medications, making the side effects more tolerable, "gave me hope that at least there's a light there and I can work toward that light, push through, and get there." 📌

Years ago, the goal of head and neck cancer treatment was strictly focused on a cure. Now, there has been a slight change in approach to improve survival rates while preserving quality of life.

By MARIJKE VROOMEN DURNING

**W**hen Cindy Stemple of Westerville, Ohio, noticed a sore on her tongue, the last thing she imagined was that she may have head and neck cancer. After all, she was only 27 years old.

She finally went to see her dentist when the sore wouldn't heal. Since Stemple didn't have any known risk factors for head and neck cancer, the dentist didn't expect cancer either. After trying several treatments, they decided it was time for a biopsy. Stemple still wasn't concerned.

"It wasn't even in the realm of possible things," she says. "I didn't even take anybody to the appointment when I got the results and found out it was cancer because it was the furthest thing from my mind."

She received a diagnosis of stage 3 oral squamous cell carcinoma — which is a cancer that occurs in the mouth and/or throat. »



## FEATURE

# head and neck cancer

### TREMENDOUS CHANGE

Historically, head and neck cancer, the seventh most common cancer globally, was predominantly diagnosed in older individuals and was often linked to tobacco and alcohol use. As smoking rates began to decline, so did tobacco- and alcohol-related cases among older individuals.

But head and neck cancer rates began rising in another group — younger and middle-aged adults — driven by HPV infections, predominantly HPV type 16, which has been shown to be a clear risk factor for head and neck cancer as well as cervical cancer.

HPV-positive oropharyngeal cancers in the United States increased from 16.3% of head and neck cancers in the 1980s to more than 70% in the 2000s. Researchers, however, expect an eventual decrease as the effects of the HPV vaccine take hold, but it may take up to three decades to get to that point.

“I’ve been in the field for about 25 years, and it has changed tremendously,” says Adena Dacy, associate director of health care services in speech-language pathology at the American Speech-Language-Hearing Association in Rockville, Maryland. “Most of my patients tended to be older, usually with a long history of tobacco or alcohol use. Today we still see some of that, but we are seeing much younger patients, often (those who are) tobacco- or alcohol-free.”

### IMPROVING SURVIVAL WHILE INCREASING QUALITY OF LIFE

In most cases, different treatment approaches are used for the two groups. For instance, since many patients with tobacco- or alcohol-related head and neck cancer are often older and have other comorbidities, treatment options are limited.

On the other hand, patients who are younger and healthier are likely better able to tolerate side effects and extended treatment regimens, if deemed necessary. Additionally, HPV-related head and neck cancers are more likely to respond better to treatments, meaning less aggressive therapy may be used.

Initially, the primary treatment of head and neck cancer revolved around removing as much of the tumor as possible to extend life.

But surgeries often left patients disfigured, and high doses of radiation destroyed healthy tissues along with the tumors. These issues led to a significantly diminished quality of life for many patients, including not wanting to appear in public and being unable to enjoy a meal with friends and family.

In the early 1990s, researchers investigated a combination of chemotherapy and radiation aimed at better organ preservation. New drugs were also approved, such as Salagen (pilocarpine) to increase saliva production, which in turn reduced complications caused by dry mouth.

Survival rates also improved.

In 2016, the Food and Drug Administration approved Opdivo (nivolumab) after clinical trials showed that the



**CINDY  
STEMPLE**  
was only 27  
years old when  
she received her  
diagnosis.

drug doubled one-year survival (the percentage of patients who remained alive from diagnosis or start of treatment) for recurrent or advanced head and neck cancers and caused fewer severe side effects, compared with standard-of-care chemotherapy.

### SHIFTING THE FOCUS

The earlier the disease is detected, the better the survival rate. In fact, some estimates suggest that patients with locally advanced HPV-related head and neck cancer have up to an 80% long-term survival rate. These results, according to researchers, depict how harsh treatments can have a long-lasting effect on a patient's quality of life.

“Over the past 20 years, we’ve seen more of an emphasis on organ preservation and less aggressive surgical intervention,” Dacy says. “(For) 70% of the people who came in years ago





### CINDY STEMPLE

says she would have considered prehabilitation before treatment, but it was not presented as an option.



with cancer of the throat or larynx, the gold standard was that they would have a total laryngectomy.”

Now, surgical treatment is less invasive and more focused on improving quality of life, according to Dacy.

“Twenty or 30 years ago, the only focus was on a cure,” says Dr. Scott Roof, a head and neck oncologic and reconstructive surgeon at Mount Sinai Health System in New York. “Now it’s somewhat shifted to (asking), ‘Not only can we cure patients, but how are we going to leave them with the best functional outcomes?’ Speech and swallowing are integral to what we do in our everyday life and how we interact with people.”

### LOCATION, LOCATION, LOCATION

The location of the cancer also plays a role in long-term recovery, according to Roof.

“The head and neck involve everything from your lips all the way down to your esophagus,” he explains. “If you have cancer in your mouth, the side effects are different than if it’s in the larynx, or voice box.”

The location of the tumor also affects the type of long-term rehabilitation required after treatment.

Dr. Theodoros (Ted) Teknos, president and scientific director for the University Hospitals Seidman Cancer Center at University Hospitals Cleveland Medical Center and deputy director of the Case Comprehensive Cancer Center, explained that some head and neck cancers result in more extensive deficiencies than others because of tumor location.

Despite the widespread adoption of advanced reconstructive surgery, according to Teknos, cancers of the tongue base, jaw and throat often leave patients with both functional and cosmetic abnormalities, which require extensive rehabilitation.

In general, there are many possible side effects from head and neck cancer treatment. Surgery may lead to difficulties with chewing and swallowing, affecting not only nutritional status but socialization. Speech may be difficult or impossible for some patients. And if the surgery involves removing the larynx, cutting into nerves or removing lymph nodes, patients may be left with weakness in the shoulder and neck muscles.

Radiation alone or in combination with other treatments may also cause short-term sores and pain in the mouth, difficulty swallowing, changes in taste, nausea and even »



## FEATURE

### head and neck cancer

difficulty opening the mouth as wide as before treatment. But even if these side effects don't occur or resolve over time, radiation treatment may lead to the development of radiation fibrosis syndrome (injury to the skin, connective tissues, muscles and more) weeks or even years after treatment.

"Functional deficits can arise many years after the initial treatment," Teknos explains. "Patients (with HPV-related cancers) are typically treated with chemo and radiation therapy. And while those are highly effective treatments typically delivered to younger patients, as the patient ages, their ability to compensate for the damage caused by therapy decreases and they start developing swallowing and musculoskeletal deficits many years after their treatment."

Teknos also mentions that about a quarter of patients develop significant hearing loss, which may require hearing aids.

### LONG-TERM EFFECTS BECOME LESS COMMON

But as treatments improve, these long-term effects occur less frequently.

Dacy notes that she has seen a reduction in the effect of radiation fibrosis syndrome on patients' quality of life compared with when she started working with this patient group. The reason, she says, is because of lower dose regimens, newer delivery methods and preventive habilitation techniques.

Mike Jirousek, from Hamden, Ohio, received a diagnosis of head and neck squamous cell carcinoma four years ago at the age of 59. After noticing a rapidly growing lump in his throat, he went to a local urgent care clinic.



Although **MIKE JIROUSEK** remains on a feeding tube, he has maintained the ability to speak.







**MIKE JIROUSEK** underwent an extensive surgery followed by chemotherapy and radiation to treat his recurrence.

The attending physician was so concerned that Jirousek was immediately transported to the hospital by ambulance.

“They were afraid of (the lump) closing off my airway,” he says.

After a CT scan, Jirousek was rushed to the UH Seidman Cancer Center in Cleveland.

“I was admitted to the hospital that day, and things began to move very quickly,” he says.

The treatment plan was to remove the tumor and then start chemotherapy and radiation. But his treatment didn’t stop there, as Jirousek met with several other care professionals.

According to Teknos, a team approach is necessary for the recovery of patients with head and neck cancer. He notes that this multidisciplinary team includes speech pathologists, audiologists, physical medicine/ rehab experts, physical therapists and nutritionists, along with specialists in dentistry, prosthodontics and anaplas-tology (the use of removable facial and ocular prosthetics).

### INTRODUCING PREHABILITATION

Over time, there was a shift toward preparing patients for the aftereffects of surgery and other debilitating treatments.

“We used to get (other health care professionals) involved on the back end, once patients had gone through their treatments and were dealing with some of the functions afterward,” Roof recalls. “We’ve realized this is not as good, so there’s a big push to have patients work with people like speech and language pathologists pre-treatment, during treatment and then post-treatment.”

If scarring develops, Roof mentions, patients need to counteract the side effect by regularly using the muscles and structures to prevent stiffening of the area.

He likened it to the notion of if you don’t use it, you lose it.

Now, patients are also encouraged to swallow, eat, drink and speak during treatment. Actively participating in these activities may help retain some of those functions after treatment has stopped.

“We learned that if you can encourage patients to learn to swallow, eat, drink and speak throughout their treatment, they’re more likely to preserve (these functions) after treatment,” says Roof.

Jirousek says his first head and neck cancer diagnosis and treatment happened so fast that he was ineligible

for prehabilitation, but he notes he met with therapists when his treatment began.

“I met with the oncologists, radiation specialist, and then the nutritional experts and rehabilitation as well,” he recalls.

The therapists helped Jirousek prepare for potential difficulties with swallowing and limited nerve function in his neck and shoulder.

“During my first time, I was convinced that I would be able to keep eating and swallowing, and I was able to,” he says.

Unfortunately, Jirousek’s disease returned 18 months later, and his treatment was more invasive. He underwent a radical neck dissection — a notable surgery that consists of a significant removal of muscle, tissue and lymph nodes from the collarbone to the jaw — followed by chemotherapy and radiation.

As a result, Jirousek needed a feeding tube, and although he remains on the feeding tube, he is still able to speak.

Feeding tubes are not uncommon among patients treated for head and neck cancer. Data from a study published in 2017 in the journal *Cancer* demonstrated that more than 50% of patients with head and neck cancer required a feeding tube.

Of note, in many cases feeding tubes are temporarily placed during and after treatment. But they are often removed later as a patient’s swallowing function returns.

Stemple, whose disease returned five years ago, says that she didn’t see rehabilitation therapists before treatment for her primary diagnosis. She only recalls seeing them briefly during her radiation treatment.

It was after her treatment was completed that she received extensive therapy.

“I would definitely have been open to doing other therapies before treatment,” she says. “It wasn’t really presented to me as an option at the time.”





## SARCOMA NEEDS TO BE IN THE **SPOTLIGHT**



We must increase public awareness of this rare disease, restore hope and, with specialist care, ensure the best possible outcomes. *By DR. WILLIAM TSENG*

**SARCOMA IS A RARE** cancer of the soft tissues and bone that is not often in the public spotlight but certainly has quite an impact on those affected by it.

July was Sarcoma Awareness Month, but throughout the year, sarcoma deserves our attention.

The epidemiology of sarcoma is very different from the more common cancers. Every year, 17,000 people in the United States receive a diagnosis of sarcoma, a number that is at least twentyfold less than breast cancer. Although sarcoma is rare, anyone can get it.

Certain types of sarcoma are more common in children (e.g., rhabdomyosarcoma), but this cancer can affect individuals in any age group. Sarcoma occurs in the rich and the poor, irrespective of access to health care and regardless of gender or race.

Some hereditary cancer syndromes (e.g., Li-Fraumeni, neurofibromatosis) or prior history of radiation can predispose a person to developing specific sarcomas; however, common risk factors such as smoking,

obesity, diet or alcohol intake have no clear association with sarcoma. Although colonoscopy and blood levels of prostate-specific antigen are useful in screening for colon and prostate cancer, respectively, there are no validated tools for early detection of sarcoma.

Sarcoma often presents in subtle ways. It can be a painless lump that has been slowly growing over the last year, so the person thinks, “I’ll bring it up with my doctor at the next annual visit.” And then at that visit, it is not uncommon for the physician to inadvertently dismiss it: “We’ll watch it for a few more months.”

And when a work-up is initiated, the diagnosis is not always straightforward. The radiologist reading the MRI or CT scan reports that the mass is indeterminate — “likely a lipoma; however, liposarcoma cannot be ruled out.” A needle biopsy may be performed, but the pathologist may also be unclear about the diagnosis due to inadequate sampling or simply an unfamiliarity with sarcoma.

It is important to recognize that sarcoma encompasses almost 100 distinct types and subtypes based on the body tissue of origin (e.g., fat, muscle, blood vessel) and unique genetic features of the tumor cells. Therefore, it may be more appropriate to think of sarcoma as a group of cancers as opposed to a single entity.

Unfortunately, with all these potential obstacles to diagnosis, the net result for the patient with sarcoma is often delayed before any treatment is given.

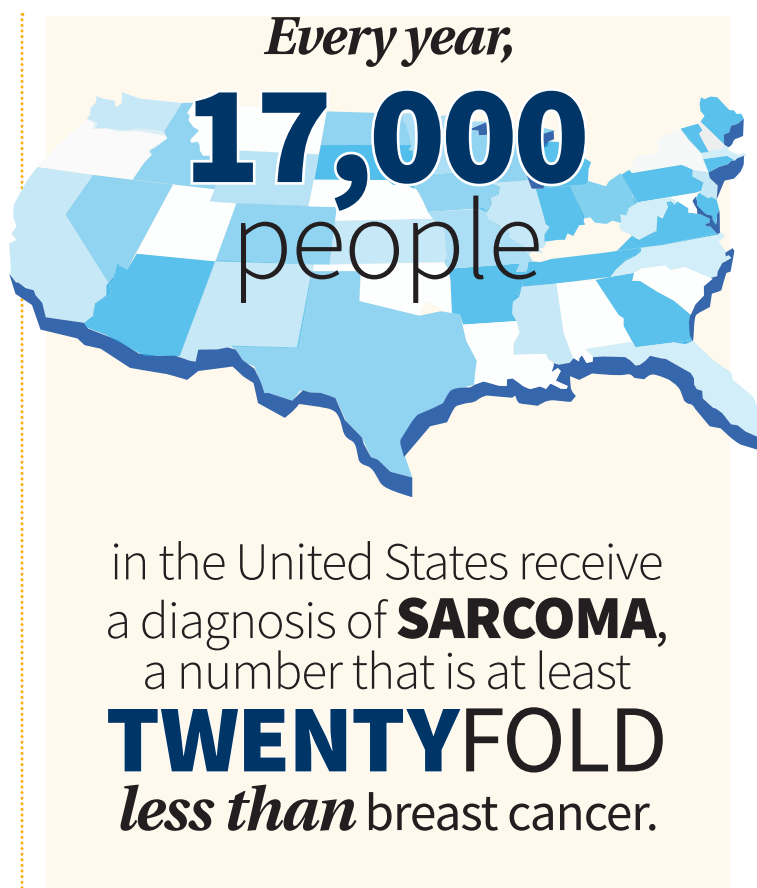
Treatment for sarcoma is incredibly complex, so referral to a specialist is critical. The treatment for sarcoma needs to be individualized for each patient. Ideally, a patient's case should be discussed at a multidisciplinary "tumor board" among specialists in this cancer from radiology and pathology to verify the diagnosis and sarcoma type and from surgical, medical and radiation oncology to mutually decide on the best course of treatment.

When sarcoma has not spread to other parts of the body, surgery is an option and often the main form of treatment. The surgical oncologist who specializes in sarcoma balances the technical aspects of performing a safe and complete tumor removal (or resection) with a deep understanding of the expected disease behavior that can, in fact, often nuance the surgical approach.

In some cases, there may also be a benefit to giving radiation or chemotherapy before or after surgery. For some sarcoma types, specific targeted drug therapies or immunotherapy may be more ideal than chemotherapy. A medical oncologist who specializes in sarcoma can discuss these options and provide guidance to a relevant clinical trial, when appropriate.

Because of the complexities in the diagnosis and treatment of sarcoma, the patient is encouraged to take a proactive role in their care. Getting to a sarcoma specialist or multidisciplinary sarcoma center is a very important first step. A multitude of studies have shown improved survival for patients with sarcoma when they are treated by a specialist, a concept that would seem intuitive for a rare, complex disease. Although high patient volume is often used as a benchmark to denote specialization, other factors such as dedication to sarcoma (versus other cancers) and active contribution to the field (with research and clinical trials) should also be considered. The patient can directly facilitate a more effective consultation by having relevant records available and organized.

For a new diagnosis, records may include radiology reports along with the actual images to view (e.g., on a CD), pathology reports and, in some cases, the actual tissue slides and paraffin blocks that may be used for re-review by a sarcoma pathologist. For patients who have had prior treatment, operative reports from the surgeon and treat-



ment summaries from the radiation oncologist and medical oncologist are useful. For patients with a particularly extensive history, a concise outline of treatments given can be helpful.

Overall, sarcoma is an aggressive cancer. Although there are exceptions, for most patients with sarcoma, the disease can indeed be lethal. A diagnosis of sarcoma can also be extremely anxiety provoking for the patient. The rarity of the disease, the relative lack of knowledge about sarcoma and, in some cases, inappropriate initial treatment by a nonspecialist further exacerbate the situation.

Sarcoma lies in the public health shadows of the more common cancers, but for the few patients with a diagnosis of sarcoma, we are obligated to spread awareness, restore hope and, with specialist care, ensure the best possible outcomes. 

**WILLIAM TSENG, M.D.**, is a sarcoma surgical oncologist at City of Hope National Medical Center in Duarte, California, and serves on the board of directors and medical advisory board for the Sarcoma Alliance.



# There Are 2 Sides to Every MPN Story

When you're living with a myeloproliferative neoplasm (MPN), a rare, chronic blood cancer, you may say that you're *fine*—even when physical and emotional symptoms are affecting your quality of life. But when you don't discuss how your MPN makes you feel, you miss the opportunity to get the care and support you may need from friends, family and *especially* your MPN Healthcare team.

***Fine is not enough for your MPN journey.***

MPNs are progressive diseases, which means they can change or get worse over time. That's why it's important to **speak up and spell out** how your MPN affects you. It's an effective way to take an active role in your ongoing care.



## Redefine your MPN communication

Watch real patient stories, plus explore helpful MPN communication tools and resources at [FinelsNotEnough.com/patientstories](https://FinelsNotEnough.com/patientstories)



## Take the *FINE* pledge

Empower your MPN journey by making a commitment to having more informed, meaningful conversations about your MPN.

**Louise**, real MPN patient



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**F**EELING  
TIRED EVERY  
SINGLE DAY

**I**TCHING AFTER  
HOT SHOWERS

**N**IGHT SWEATS  
KEEP ME UP

**E**EATING LESS  
BECAUSE I'M  
FEELING  
FULL





# LENDING A HELPFUL PAW

Pets may be like family to some individuals, but caring for them during illnesses such as cancer may force some to make a difficult decision. One nonprofit aims to help patients care for their four-legged companions. *By RYAN MCDONALD*

**FOR SOME INDIVIDUALS,** a pet may be more than just a three-letter word. In fact, a pet may be someone's only companion. However, in certain situations, some may find it extremely challenging to care for a pet while taking care of themselves.

At least that's what Patricia J. (Trish) Goldsmith said she realized eight years ago, when she was receiving treatment for cancer. Goldsmith, who has been the CEO of CancerCare for the past eight years, explained that she was diagnosed with cancer 10 days before starting her tenure as the leader of the Manhattan-based nonprofit.

It was a very stressful time, she said, as she was concerned about assuming the role of CEO while wondering what type of treatment she would need to undergo. Her reprieve during that chaotic time was her dog, Sully. "My dog was an absolute comfort to me; it was as though he sensed I was stressed, and I was worried," she said in an interview with CURE. "He was always at my side, and it made such a difference."

That's when Goldsmith said she understood that not everyone has the resources to be able to go through cancer treatment while

simultaneously trying to care for a pet. "Individuals might be struggling to care for their pet," she said. "(They may struggle)



to walk them because they may not have the physical energy, there may be issues with scooping a litter box if an individual is immunocompromised, and the expense of food, veterinary care, or even paying for the care of an animal (can be a challenge) if they're in the hospital."



Goldsmith said she looked to see whether any organizations provided both education

and support to patients with cancer who were also pet owners. Her search came up with no results, which eventually led to the birth of CancerCare's Pet Assistance and Wellness (PAW) Program.

## The Scoop Behind the Program

Financial assistance is provided to patients who qualify to receive aid from the PAW Program, according to Goldsmith. She explained that patients receive either a gift card or check for \$200 to help cover some of the costs associated with caring for a pet. Although she said it may not seem like a significant amount of money, it may help a patient buy necessary food or medication for their pet.

Additionally, the program offers educational resources to patients about caring for a pet while undergoing treatment. For instance, she said some patients undergoing radiation therapy have asked whether it is safe for them to be around their pet.

Since the program was launched in March 2020, it has helped 1,500 patients maintain ownership of their pets. Goldsmith said it was interesting to find out that 34% of those patients said their pet was the only form of support in their household.

## Future Plans

Goldsmith explained that CancerCare has plans to expand the offering of the program to build a repository of resources that span the entirety of the country. She said that if someone, for instance, lives in St. Louis, maybe there's a food pantry set up specifically for pets that the patient can utilize, or perhaps a volunteer dog walking service in a different city that patients can take advantage of.

They also hope to produce more educational content to address even further questions and concerns people may have. For example, Goldsmith said they recently received feedback from someone wondering what they should know about pet ownership while providing care to a child who has cancer. There are also plans to produce educational pamphlets to provide to physicians and cancer centers across the country that would pose the question of pet ownership up front.

"From my perspective, (I want there to be) very little for cancer patients to worry about, with only a few exceptions, in terms of pet ownership while undergoing treatment," she said. "Taking one less worry off their plate is a very important piece of this (program)." ■

**EDITOR'S NOTE:** The PAW Program is only for patients with cancer who own a dog or cat. Goldsmith said they haven't ruled out expanding the program to include other pets in the future.



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# SPEAKING OUT HEREDITARY CANCERS

## An Important Piece of the PUZZLE



An expert discusses genetic testing for gynecologic cancers and why patients should seek out genetic counselors to help them interpret their results. By RYAN McDONALD and KRISTIE L. KAHL



DR. NAVYA NAIR

**GENETIC TESTING FOR HEREDITARY** cancers has become more widely available over the past decade. Although more people now have access to genetic testing, not everyone is educated on the intricacies of the process.

As part of its “Speaking Out” video series, CURE® spoke with Dr. Navya Nair, a gynecologic oncologist at Louisiana State University Health Sciences Center in Metairie, about the importance of genetic counseling and why patients should avoid at-home screening tests.

**Q: How far have we come in understanding the role of genetics in gynecologic cancer?**

**A:** We’ve come miles and miles, and taking a moment to reflect back is important to understand how far we’ve come. If we think back, the BRCA gene was only discovered in the 1990s. And now, 20 to 30 years later, we’ve made significant strides in understanding the genetics of gynecologic cancers and also in developing targeted treatments that work for these cancers.

**Q: Where are the gaps in access to genetic testing?**

**A:** One of the biggest problems is that there’s just a limited number of genetic

counselors. To mitigate that, many oncologists are doing their own genetic counseling and testing so that the patient gets the care that they need. For some people, there are sometimes insurance barriers. But the companies that do genetic testing have gotten better and better, and testing has become much cheaper than it used to be even 10 years ago. So it’s much more accessible to all patients.

**Q: Can you discuss at-home testing and why you would advise people to make sure they see a genetic counselor?**

**A:** At-home testing is widely accessible. But just as important as testing is, so is the counseling. And that is not there when you do the at-home test. What’s important in genetic counseling is that you understand what test is actually being done, what your results may be and how that may affect your life moving forward. Like what if you got a diagnosis of a hereditary cancer syndrome? What does that mean for your risk of getting X, Y and Z cancer? And also, does this affect your ability to get life insurance, disability insurance in the future? These are all the things that go into genetic counseling that are really important to understand before

you get a test done, so I really caution people who get testing done without counseling because that's an important piece of the picture.

**Q: Why should patients consider genetic testing along with visiting a genetic counselor?**

**A:** Certain genetic mutations can lead to hereditary cancers. One of the most well-known ones and talked about ones is BRCA. But there are many other important ones. If someone gets diagnosed with one of these genetic mutations, they can be at risk for developing not just one, but multiple cancers in their lifetime, as well as having a risk of passing that on to their children.

In the world of gynecologic cancers, all patients with ovarian cancer — and when I say ovarian cancer, I mean, ovarian, fallopian tube

and primary peritoneal cancers — should undergo genetic counseling and testing because they have up to a quarter risk of having a hereditary cancer syndrome. Certain young patients, young meaning less than 50 years old, with endometrial cancer should get genetic counseling and testing. Some patients who've had more than one cancer or have had one cancer and have had a strong family history of cancer may also warrant genetic counseling and testing.

It's important to know that if you get diagnosed with one of these hereditary cancer syndromes, there's a lot that can be done to prevent you from ever getting a cancer. Heightened screening and risk-reducing surgery can prevent subsequent cancer diagnosis. And for oncologists, that's always the best kind of cancer — the one that never happens.

**Q: What advice do you have for patients who may be wondering if they should undergo genetic testing to screen for their risk?**

**A:** I encourage patients who are worried about that or think they may be at a heightened risk to speak to their doctor — whether that's their primary care doctor, their obstetrician-gynecologist, or if they're a patient with cancer, their oncologist — and have a real honest conversation. And if warranted, maybe even meet with a genetic counselor to talk about their risks and then actually get the testing if appropriate. ■

*This transcript has been edited for clarity and conciseness.*



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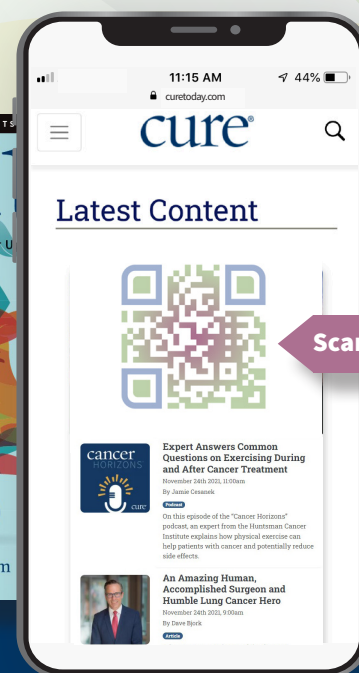


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# FROM 'GHOST TOWN' TO 'BONANZA'

How a decision to rename a disease led to a plethora of developments in a space where there was once little interest.

By LEAH LAWRENCE

**NAME RECOGNITION.** The term is often associated with Fortune 500 companies like Coca-Cola, famous celebrities and politicians running for office. But what about medicine and the subsequent treatment of diseases? What if a name — or rather, name change — could influence how the world views a particular disease and ultimately revolutionize the space?

To a greater extent, how would the evolution of the term myeloproliferative disorders (MPDs) — a group of diseases including polycythemia vera (PV), primary myelofibrosis (PMF) and essential thrombocythemia (ET) — to myeloproliferative neoplasms (MPNs) affect the lives of thousands upon thousands of people living with a rare disease?

As it turns out, that decision would transform the trajectory of a cancer space where there was once very little interest.

## WHAT'S IN A NAME?

In 2008, the World Health Organization (WHO) in collaboration with the United States-based Society for Hematopathology and the European Association for Haematopathology published a revised classification of the diseases that made up MPDs and officially classified them as neoplasms.

"They were considered a 'disorder' and then a 'neoplasm,'" says David Ricci, a long-time member of the MPN Research Foundation Board of Directors. "The diseases had not changed. There was nothing about these diseases that was different before the change versus after the change."

Instead, the change of name was made largely to be more accurate, Ricci explains.

The term MPDs dates back to a former president of the American Society of Hematology, Dr. Louis Wasserman, who coined the phrase to describe a range of diseases that had elevated blood counts, including chronic myeloid leukemia (CML), notes

Dr. Ruben Mesa, executive director of Mays Cancer Center at UT Health San Antonio MD Anderson Cancer Center.

In PV, patients experience an increase in all blood cells, particularly red blood cells, which supply oxygen. Patients with ET have bone marrow that produces too many platelets, which can cause abnormal bleeding or blood clots. And in PMF, patients build up scar tissue in the bone marrow that produces blood cells, impairing the body's ability to make normal blood cells.

"Over time we learned that all of these were neoplasms," Mesa says. "All of the abnormal cells are related to one another, and that is a defining characteristic of a neoplasm."

This characteristic is called clonality. Neoplasms are an abnormal growth of cells that can be either benign or malignant. MPNs start out as benign but may progress to being malignant.

"As science progressed and we learned this was a clonally driven disease, that sounded more like cancer," says Dr. Michael R. Savona, head of hematology, cellular therapy and stem cell transplantation at Vanderbilt University Medical Center in Nashville, Tennessee. "It would have been technically inaccurate to consider it otherwise."

## MOLECULAR DISCOVERIES

The impetus for the name change came in part after the 2005 discovery of the JAK2 mutation. A team of researchers in France announced the discovery of a single mutation in the JAK2 gene that appeared in 97% of patients with PV and about half of patients with ET (57%) and myelofibrosis (50%). These findings were confirmed by two additional research teams later the same month.

"In the end, there were four similar studies published in top-notch journals confirming the results, and



**DAVID RICCI** notes that until about 15 to 20 years ago, the incidence of MPNs was not well studied.



this took the field by storm,” Dr. Attilio Orazi, a professor and chair of the Department of Pathology at Texas Tech University Health Sciences Center El Paso, says. “Researchers started working and thinking about how we could use this information not only to create a drug to treat these patients, but how to integrate this information into a diagnostic algorithm.”

Shortly after the discovery of the JAK2 mutation, researchers discovered that mutations in another gene – MPL – are sometimes present in patients with ET (approximately 3% to 5%) and PMF (about 5% to 10%) who do not have JAK2 mutations.

Armed with this new knowledge, the International Working Group-Myeloproliferative Neoplasms Research and Treatment, a group of MPN experts, met to discuss how best to integrate these new molecular discoveries into the classification of these diseases. According to Orazi, the group knew that the WHO was considering an update of its classification of myeloid neoplasms, and they wanted to provide expert consensus on how to properly diagnose these conditions.

“The ability to integrate molecular knowledge into the diagnosis of these diseases went hand in hand with the change of name,” Orazi recalls. “At that point, it made no sense to call it ‘syndrome’ or ‘disorder’ when we knew it was a tumor.”

The discovery of these mutations led to the name

change and also increased attention from scientists and pharmaceutical companies, Orazi exclaims.

In the late 1990s/early 2000s, a blockbuster drug had been developed and approved by the Food and Drug Administration (FDA) to target BCR-ABL, an abnormal tyrosine kinase protein that causes cells to grow and reproduce out of control in patients with CML. Of note, many patients with CML in remission after two years of treatment with Gleevec (imatinib) have similar life expectancies as a person without cancer, although this is not the case for every patient.

“There was hope that we would get the same kind of results for a drug targeting JAK2 in MPNs,” Orazi says.

### INCREASED ATTENTION

“It kind of became a bonanza,” Ricci explains. “The reclassification to a neoplasm played a part in attracting new interest on the academic side, clinical side and pharmaceutical side.”

Ricci says that until about 15 to 20 years ago, the incidence of MPNs had not even been well studied. According to the National Cancer Institute, an estimated 20,000 new people in the United States are diagnosed with an MPN

each year and about 295,000 are living with the disease.

“These studies identified that it was bigger than most people thought and deserving of attention not only from the biotech industry, but also from the research and academic community,” Ricci recalls.

To put it in perspective, David Boule, treasurer of the board of directors for MPN Research Foundation, explains that before the discovery of the mutations and the subsequent name change, one of the biggest challenges for the MPN Research Foundation was finding researchers to give money to.

“Not a lot of people were concerned about MPNs. If anything, the research was focused more on reducing myelofibrosis symptoms and how to keep it from progressing,” Boule says. “Now pharmaceutical companies understand that (for) PV or ET, which someone can have for 25 to 30 years, it makes good economic sense to develop drugs to treat these diseases.”

In fact, Savona describes drug development for MPNs as a “ghost town” prior to the discovery of the driver mutations.

Mesa agreed that the reclassification has had a significant effect.

“There has been impact in terms of being a research focus for philanthropic organizations, and it has helped to augment scientific focus on MPNs that would not have occurred if they were not considered a blood cancer,” Mesa says. “It brings more people to the field (and) more investment from the pharmaceutical industry and increases support for research.”

Indeed, less than five years after the reclassification of MPDs to MPNs, the FDA approved the JAK inhibitor Jakafi (ruxolitinib) for myelofibrosis based on its ability to reduce spleen volume and ameliorate disease-related symptoms. Since then, Jakafi has also been approved for PV. »





## DAVID BOULE

recalls that not many people were concerned about the rare disease prior to the World Health Organization's decision to reclassify myeloproliferative disorders to myeloproliferative neoplasms.

In 2019, the JAK2 inhibitor Inrebic (fedratinib) was also approved for myelofibrosis after studies showed it reduced overproduction of damaged blood cells and increased control of disease-related symptoms. Then in November 2021, Besremi (ropeginterferon alfa-2b-njft) became the first interferon therapy approved for PV and the first PV therapy that patients can receive regardless of their treatment history. This interferon is long acting and should decrease the number of depressive episodes and flu-like symptoms seen with traditional interferon, Savona noted.

## CANCER ANXIETY

A shift from referring to something as a disorder to a cancer can be tough for some.

"It is not lost on me that the term cancer or leukemia creates a very negative connotation for patients. That is why, depending on the patient, discussing that these are cancers may not be the first thing I try to get across," notes Mesa. "When people hear cancer, they sometimes jump three steps ahead and assume (they) are going to die tomorrow. I don't want anyone led down a path of misunderstanding."

When the name change was announced, the MPN Research Foundation led an effort to educate people about the disease.

"Hearing it is cancer provokes anxiety," Ricci says. "We try to help people understand that many cancers can be managed or cured and that for the most part, many patients with MPNs live with the disease in a chronic format."

Savona adds that he often sees patients whose referring physicians avoided using the word cancer or even said the condition was not cancer.

"The word 'cancer' creates a lot of anxiety, but I think it is important to address it head on," Savona says. "I tell them, 'Technically, yes, it is cancer, but it is something we can manage, and often, not something that leads to earlier death or decreased quality of life.'"

Mesa emphasizes that he explains to his patients the term "cancer" does not refer to the severity of a disease, but rather, simply describes biology.

In addition, because of the name change to "neoplasm," Mesa notes that, "there are a whole range of supportive mechanisms that are available to patients that have cancer versus other medical problems." This includes copay assistance and other aid.

## BRIGHT FUTURE

All the scientific discoveries related to MPNs during the past two decades not only led to a change in name, but also brought about much greater diagnostic certainty, Mesa says.

"We have a much greater understanding of the natural history of

the disease," he explains. "This means we have a better ability to understand the biology and the prognostic implications."

In 2013, additional research filled another knowledge gap related to MPNs: Mutations in CALR, the gene that encodes the protein calreticulin, were discovered in most patients with ET or PMF who did not have mutations in the JAK2 or MPL gene.

Although most patients with MPNs have a single mutation in one of the three "driver" genes (JAK2, CALR or MPL), a small number of individuals may have concomitant additional "non-driver gene mutations," which can occur at the disease outset or during its progression and can affect its prognosis. These additional mutations provide clues as to the risk of disease progression, or rarely, transformation of the disease to acute leukemia.

"All of this knowledge helps us approach patients in a much more rational way using objective tools," Orazi says.

Information on CALR mutations and other diagnostic updates were included when the WHO again updated its classifications in 2016.

The future continues to look bright for the development of new treatments for patients with MPNs, according to Savona. In addition to the drugs already available, another drug that targets JAK2, Vonjo (pacritinib), received FDA approval in February for the treatment of patients with high-risk myelofibrosis with thrombocytopenia. The FDA is also expected to review the JAK1/JAK2/CRV1 inhibitor momelotinib for patients with myelofibrosis and anemia.

"All of this discovery in the laboratory builds upon itself and becomes, ultimately, translated to the clinic," Savona concludes. "In the end, it is our patients who we hope will see the benefit." ■



# Backtracking Is Allowed

If I make a wrong turn while hiking, I retrace my steps until I find my way again. I've decided it's OK to do the same thing when it comes to finding a cancer care team.

By BONNIE ANNIS

**I'VE ALWAYS BEEN** a person who liked to move forward, even when the path was difficult. As an avid hiker, I'd rarely waste time researching trails, even though trail guides provided a lot of information regarding difficulty levels. If I'd given a little time to studying those maps, I could've saved myself a lot of trouble. Sometimes a trail ended up being more strenuous than I expected, and my aging knees balked. Other times, I'd find myself on a very unfamiliar trail and have to backtrack when I got off course.

Nowadays, many hikers use portable GPS devices to pinpoint their location, but I can barely follow Google Maps. And heaven forbid if I find myself in a dead zone — I can get lost really fast.

Navigating isn't my strong suit, but since I like to hike, I must. Even though I don't use a GPS, I do try to be cautious and protect myself from injury. I wear sturdy shoes. I take along extra water, rain gear and a few snacks. I also notify family where I'm headed.

Serious hikers, like my cross-country trekking friend, Marie, use pacer poles. On a recent trip to Israel, she introduced me to them. Although we weren't hiking through the mountains the entire trip, we were hiking over rough and uneven terrain. Even in the city, traveling over 1,000-year-old bedrock, the stability those adjustable metal poles provided was so helpful. I felt safer and more secure using them to maintain balance.

Thinking about those poles today made me realize how much I wish I had pacer poles for navigating cancer.

When I was first diagnosed, I didn't know where to turn. We'd just moved to a new city and were barely established. I hadn't even had time to unpack all the boxes before my calendar began to fill with medical appointments. I used the internet to find an obstetrician-gynecologist. That doctor led me on the most treacherous path I'd ever taken. From her office, I was referred to a breast specialist and then, to an oncologist.



BONNIE ANNIS

As time went on, though I received good care with those doctors, I felt I needed more. When a new cancer treatment center was built 10 miles from our home, I decided to check it out. It was a new concept in cancer care and provided everything in one location: imaging, chemotherapy, radiation, infusion, also a gym, library, massage, chiropractic care, acupuncture, nutrition services and even a chapel.

Ditching the other doctors, I applied for health care with the new treatment facility and was happy to be accepted. At that time, only a certain percentage of city residents were accepted due to the center's policies. It was a regional facility and one of five locations across the United States, so it was important to keep some spots open for out-of-state residents too.

The cancer center was wonderful, and I loved receiving integrative care there, but when my oncologist, Dr. H, left, I felt abandoned. Of course, I was assigned another doctor shortly thereafter, Dr. M, but he didn't know me or my history. I felt uncomfortable and decided to go back to the original team. They asked for records from the treatment center and scheduled an appointment for me to become reestablished as a patient with their practice.

When I went in for that appointment, I felt like a fish out of water. Although everyone was nice, nothing was the same. Dr. F, my first oncologist, had moved on, and once again, I was assigned another doctor, Dr. P. At my scheduled appointment, I saw a nurse practitioner for about 20 minutes and Dr. P for five. It didn't feel right, and I didn't like it.

Six months have passed since that visit, and I've been ruminating. I really liked the care I received at the cancer treatment center. They focused on all of me, not just my physical well-being. The integrative health care approach was appealing, and I missed it, so I called the center and asked how to restart treatment there.

The scheduler hesitated when I explained my situation. She'd never had anyone leave and request to come back »



months later. She was cordial and promised to pass my information on to the patient care team. She gathered pertinent information, and after we finished our conversation, I felt flustered. I wondered if I was being unreasonable wanting to backtrack my cancer care or if it's my right to do so?

If I'd been hiking and missed a turn off, I'd have backtracked as soon as I realized I'd gotten off course. What was the big deal about doing the same with cancer care? Didn't I deserve to have the very best care available? Certainly, anyone would understand my plight, right? But I wondered if they might think I had a few screws loose.

Now I wait for the phone to ring. I'm hoping the cancer treatment center will reenlist me as a patient. If they want me to grovel, I'll do it. It feels a little like I'm



➤ Bonnie Annis wrote that her friend, Marie (pictured above), showed her the importance of pacer poles.

a spoiled-rotten kid. I want things my way, and I want them now!

But that's not exactly the way it is. All I want is a doctor who spends time

getting familiar with my case and doing whatever necessary to ensure I enjoy a long, healthy future. I'd like to remain with the same physician for a very long time and have a good doctor-patient relationship. The doctor — in essence, my human pacer poles — would help me stay on path with sure-footedness.

Navigating cancer care isn't always easy. At times it doesn't seem to make sense at all. When the path meanders into uncharted territory, patients can easily feel unsteady. But it's OK to go back a few steps if necessary and start over again when you must.

I may end up being the poster child for indecisiveness, but at least I'll be confident in my health care team's abilities. Being able to choose what's best for me matters, no matter what others think. ■

## Don't Treat Your Spouse Like a Therapist

My wife has been an amazing caregiver throughout my cancer experience, but I realized it's not fair for her to continually be on the receiving end of all my negative emotion. By RON COOPER

**I'M CONVINCED THAT** I have the best caregiver in the world. Since my prostate cancer diagnosis in 2014, my wife has been patient, loving and supremely understanding, without fail, 24/7.

I have tried to repay her kindnesses and soothing, supportive words with flowers, greeting cards and notes of thanks, taking her to dinner and even putting small snacks in her lunch bag overnight. She has been on the receiving end of hours, days and weeks of my angst, depression and frequent mood swings.

So I thought my outpouring of gratitude might balance the scales in our relationship.

*I was wrong.*

### INFORMATION OVERLOAD

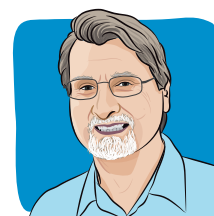
My mistake was in thinking that she needed to be the one to bear the brunt of my rantings and offer solutions to my

nagging concerns. Frankly, I had turned my wife into a mental health therapist, a role she was neither prepared nor trained for.

I knew that I needed to stop piling up on my wife. I knew that the therapist's office, not my home, should be the venue for airing some of my most deep-seated fears and overwhelming challenges that cancer brings to the table.

A counselor would need to become my safe haven, my listening post, my refuge.

With a therapist, I could safely speak about things too difficult to broach with my spouse. Things like the fear that my cancer might morph into stage 4, requiring the dreaded chemotherapy treatment. Or that I would become a burden to my wife, an invalid needing round-the-clock care. Or that I



➤ RON COOPER



might be hospitalized for weeks on end and emerge a shadow of my former self.

Or that cancer might kill me.

How does a patient with cancer talk to a spouse or significant other about such matters? These things might best be directed toward a professionally trained therapist — better yet, one familiar with the issues facing a patient with a life-threatening disease.

So, one day, I took the plunge into therapy land.

### COUNSELORS HELPED ME IMMENSELY

One of my counselors had an office at a cancer institute, where she specialized in advising patients in active treatment. She helped me immeasurably, bringing to bear on my issues the well-earned experience she had with this patient population.

Another counselor that I saw for a couple years was in private practice. She was of immense help to gauge my emotions and offered practical advice on how to convert chaos into calm. An important part of my therapy was reading aloud some of my writings about cancer. That brought me validation, connection and perspective.

When I returned from my therapy sessions, I did not want to recount chapter and verse what had been discussed. I did not want to return to my ranting ways. Most of all, I did not want to put an albatross around my wife's neck, constantly weighing her down with my emotional baggage.

So, instead, I doled out a few pertinent details and summarized the visit in five or 10 minutes, sparing her a blow-by-blow account. I could see in my wife's eyes relief that she would be spared the constant harpings of the past. She appeared, at long last, more accepting of the emotional roller-coaster that is cancer.

### SETTING BOUNDARIES

My wife will always be my confidant during my cancer journey. She will always be the devoted, loving partner whom I have come to cherish so deeply. But I know, too, that we need to set boundaries on how much information I should share and how much she can absorb.

The scales of our relationship have been recalibrated. Cancer still hangs over us at times like a dark shadow, but we are learning to walk out into the light. We are moving forward, hand in hand, to face the future, with our marriage stronger than ever before.

And my therapist is just one step behind! ■



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# There Shouldn't Be a First Class and Economy Class When It Comes to Life-Saving Treatments

In my naivety, I thought all patients with cancer had access to the same therapies that my daughter received. By DEBBIE LEGAULT

**I CAN'T IMAGINE** my daughter not getting important cancer treatments because we could not afford it or because insurance denied it. Unfortunately, that is the situation for many patients.

One of the things that triggers my Spidey-sense these days is all the new developments in cancer treatments and medications that help with side effects. When my daughter was diagnosed with breast cancer in 2019, the standard of care had changed for HER2-positive patients with the addition of Herceptin (trastuzumab), a medication that blocks the ability of the cancer cells to receive chemical signals that tell the cells to grow.

To help with chemotherapy-induced nausea, she was prescribed Emend (aprepitant). It has been approved for use for 20 years, but it was new to me.

These days, I scour articles that speak to advancements in treating metastatic breast cancer because although my daughter is currently NED, or no evidence of disease, I know that we are one scan away from that changing, and I want to be ready — list in hand — if we are ever in an oncologist's office again.

I recently listened to an audiobook by Cindy McCain, and in it, I learned that John McCain, an American hero, long-term senator and former presidential candidate, was initially denied his recommended chemotherapy drug by his insurance company. Mrs. McCain had to threaten to take her large family corporation's business away from the insurer to force the company to back down and authorize the prescribed regimen. The first thought that came to mind was if someone like John McCain could be denied, what hope does your average Joe or Jane have when the cost-benefit analysis suggests that saying yes will be more than the patient is worth?

In my naivety, I thought that all patients with cancer had access to the same medications that my child received, but



DEBBIE LEGAULT

I have learned in the past three years that this is far from the truth. What is also true is that breakthrough treatments available in one country are not necessarily available in another.

I can't imagine knowing that there was a drug out there that could help kill the beast or help my girl keep food down and that she could not get it because someone in an office somewhere decides she can't. I also can't imagine being

on the other end of a phone conversation having to listen to the tears and outrage when my job means I must tell someone with cancer or their loved one that although a medication might be the only chance at life, if they can't afford to pay for it on their own there is nothing I can do.

There shouldn't be a first class and economy class when it comes to life-saving treatments. Whether I have been lucky enough to accumulate wealth or power should not determine if I am able to travel down all the available paths to potential wellness when others are forced to take a different fork in the road.

There is something desperately wrong with a system that looks at dollar signs as a factor in determining the value of a human being and if they deserve every chance at seeing their children grow up.

I acknowledge that research and development of new medications are expensive. I understand the rationale behind a company needing to recoup its investment in the process. I am not sure what the answer is to solve this particular puzzle. What I am sure of is how it works right now is mind-numbingly unfair and terrifying for anyone who sits in a doctor's office and hears the words "It's cancer" if they don't have the means or coverage to say yes to the plan to save them.

All I know is that if the day ever comes that money comes between me and my child's life being saved, you may see a few organs on the black market all of a sudden. Just sayin'... 🍷





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## 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.

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