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Advocating for You

Welcome to the premier issue of Cancer Health, the newest member of the Smart + Strong family of health publications and websites.

Smart + Strong started publishing POZ magazine in 1994, around the same time I started my career as a medical writer focusing on HIV. It was a dark era in the AIDS epidemic. Although a few early drugs were available, they came with grueling side effects and usually didn't work for very long before the virus developed resistance.

Yet within a couple of years, combination antiretroviral treatment gave millions of people a new lease on life, and today most people can keep HIV under control with a single, well-tolerated daily pill.

The cancer field is also on the brink of a breakthrough as researchers learn more about the biology of cancer and how to treat it.

I lost my dad to lung cancer in 2003. He underwent a couple of rounds of traditional chemotherapy but ultimately decided the side effects weren't worth it and declined further treatment.

Since that time, researchers have developed targeted therapies that are more effective and easier to take. Novel immunotherapies—like the groundbreaking CAR-T therapy described on page 22—offer tantalizing promise. But these treatments don't yet work for everyone or for all types of cancer.

As scientists unravel the medical mysteries, many people are still using radiation and chemotherapy. A key



part of cancer care is minimizing side effects and maximizing quality of life, as described in our profile of Deborah Cohan, MD, on page 16 and our interview with Lillie Shockney, RN, on page 28. We hope that sharing the stories of people living with and surviving cancer, like Charlie Christmann on page 14 and Catherine Guthrie on page 32, will offer support and help build community.

As noted HIV/AIDS advocate Tim Horn reminds us on page 12, advocacy doesn't end when science produces breakthrough therapies, but must continue to ensure that everyone can get the treatment they need.

Whether you are newly diagnosed, have advanced disease or are a long-term survivor, we hope you will consider Cancer Health part of your advocacy team.



Liz Highleyman

LIZ HIGHLEYMAN
Editor-in-Chief
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FDA APPROVES CAR-T GENE THERAPY

Cutting-edge approach creates customized therapy.

The Food and Drug Administration (FDA) recently approved a groundbreaking new kind of immunotherapy for people with hard-to-treat blood cancers. Chimeric antigen receptor T-cell (CAR-T) therapy takes a patient's T cells and reprograms them in a lab to recognize and attack cancer cells, creating a customized "living drug" for each patient.

Last August, the FDA gave the green light to Kymriah (tisagenlecleucel), from Novartis, for children and young adults with acute lymphoblastic leukemia. In October, the agency OK'd Yescarta (axicabtagene ciloleucel), from Kite Pharma. See page 22 to learn more about this cutting-edge treatment.



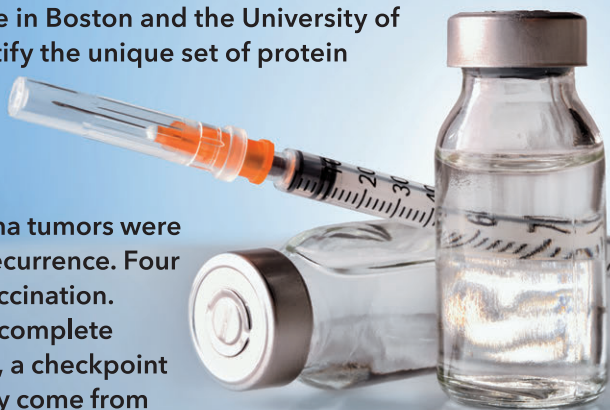
PERSONALIZED CANCER VACCINES

Individually tailored vaccines help T cells recognize tumors.

Some immune-based therapies take the brakes off T cells, but vaccines are more like stepping on the accelerator, boosting T cells' ability to recognize and kill cancer cells. Personalized vaccines designed to target each patient's particular tumor type have shown promising activity in people with melanoma in two small studies.

Researchers at the Dana-Farber Cancer Institute in Boston and the University of Mainz in Germany used gene sequencing to identify the unique set of protein markers expressed on a tumor to produce an individualized vaccine for each patient. These so-called neoantigens make good targets because they're not found on healthy cells.

One study enrolled six patients whose melanoma tumors were surgically removed but who were at high risk for recurrence. Four people were still free of cancer 25 months after vaccination. The other two had recurrent disease but achieved complete remission after adding Keytruda (pembrolizumab), a checkpoint inhibitor, suggesting that the greatest benefits may come from combining vaccines with other types of immunotherapy.



(CAR-T) COURTESY OF KITE PHARMA; (VACCINE) ISTOCK



Cannabis for Cancer

Marijuana is popular among people with cancer, but the FDA knocks cure claims.

Nearly a quarter of cancer patients treated through the Seattle Cancer Care Alliance used cannabis within the past year, according to a recent study. Survey participants said they used marijuana to relieve cancer symptoms and treatment side effects, including pain, nausea and loss of appetite, as well as to improve their mood and help them sleep.

The survey respondents, whose average age was 58, were several times more likely to use cannabis than their peers in the general population.

Washington is one of eight states that allow recreational marijuana use, and more than half of states permit medical use of cannabis or its non-psychoactive component cannabidiol. A majority of the respondents said legalization made them more likely to use cannabis.

Federal restrictions limit studies of medical marijuana, but a recent research review by the National Academies of Sciences, Engineering and Medicine concluded that cannabis and its chemical components can reduce chronic pain and help manage chemotherapy-induced nausea.

A quick web search reveals countless endorsements of cannabis as a cancer cure. But although some studies show that cannabis slows the growth of cancer cells in test tubes and in mice, it has not been proved as a cancer treatment in clinical trials.

In November, the Food and Drug Administration cracked down on overblown cancer cure claims. Four companies received warning letters for the online sale of cannabidiol oil, candies and other products that purport to prevent, treat or cure cancer. The agency fears such claims could steer patients away from conventional medical treatments backed by more research.

Can Daily Aspirin Prevent Cancer?

Taking a single aspirin a day—recommended to help prevent heart disease and colon cancer—may also lower the risk of other cancers, recent research shows.

A study from Taiwan, presented at the 2017 AASLD Liver Meeting, found that people with chronic hepatitis B who used aspirin therapy were nearly 40 percent less likely to develop liver cancer than those who didn't take daily aspirin. About 3 percent of people in the aspirin group developed hepatocellular carcinoma over five years, compared with about 6 percent in the untreated group.

Likewise, a study of more than 600,000 people in Hong Kong showed that long-term aspirin users had a 47 percent lower risk of liver cancer and esophageal cancer, a 38 percent reduction in stomach cancer, a 35 percent drop in lung cancer, 34 percent less pancreatic cancer, 24 percent less colon cancer and a 14 percent drop in prostate cancer.

Commonly prescribed as a pain reliever, aspirin also has anti-inflammatory effects, which may explain how it helps fight cancer.





NOW FOR NINE

New HPV vaccine protects against nine types of cancer-causing virus.

Among the more than 100 types of human papillomavirus (HPV), about a dozen cause cervical, anal, genital and mouth and throat cancers. Pap smears have dramatically lowered cervical cancer deaths by catching HPV-triggered precancerous cell changes before they turn into cancer. But vaccines can prevent young people from contracting the virus in the first place.

The first HPV vaccines, which have been around for about a decade, protect against only two cancer-causing HPV types (16 and 18). In 2014, the Food and Drug Administration approved Gardasil 9, which wards off five additional high-risk types (31, 33, 45, 52 and 58).

Long-term results from a study of more than 14,000 women, recently published in *The Lancet*, showed that those who used Gardasil 9 had lower rates of infection with these added HPV types, as well as fewer abnormal cervical cell changes, precancerous lesions and procedures to stop

disease progression. The researchers estimate that the vaccine could potentially prevent 90 percent of cervical cancer cases worldwide.

"There is no question that the vaccine works," said study author Warner Huh, MD, of the University of Alabama at Birmingham. "The challenge is to get the new vaccine into widespread use among young women."

But women are not the only ones who stand to benefit. As cervical cancer declines, rates of HPV-related anal and oral cancers are on the rise, with the number of non-cervical cancers now nearly matching that of cervical cancers, according to the National Cancer Institute. Most of these are occurring in men, who don't benefit from routine screening. The Centers for Disease Control and Prevention recommends HPV vaccination for both boys and girls at age 11 or 12, with eligibility extending through age 26. But nationwide, 40 percent of adolescents still have not received the vaccine.

Staying Cool During Chemo

Cooling caps, gloves and socks help lessen chemotherapy side effects.

Hair loss and peripheral neuropathy can be among the most distressing side effects of cancer treatment. But keeping things cool can reduce damage to the hair follicles and nerves in the hands and feet caused by

chemotherapy, researchers have found.

In July 2017, the Food and Drug Administration expanded approval of a cooling cap that helps prevent hair loss during chemotherapy. The DigniCap system was approved for women with breast cancer in 2015, but the expansion makes it an option for people with all types of solid tumors.

Available at more than 100 cancer facilities in the United States, the DigniCap system circulates a cooling liquid through a silicone cap. By lowering the scalp temperature to near freezing, it constricts blood vessels and reduces the amount of chemotherapy drugs reaching the hair follicles. A study showed that two thirds of

breast cancer patients who used the DigniCap system lost less than half their hair.

A Japanese study examined a simpler technology: gloves and socks containing a frozen gel. Peripheral neuropathy is a common drug side effect that can cause pain, tingling and numbness in the hands and feet; in severe cases, it can even interfere with walking. Women who wore Elasto-Gel gloves and socks on one hand and one foot during breast cancer chemotherapy reported fewer neuropathy symptoms on that side.

Strategies like these to reduce side effects can help people with cancer remain on treatment and have a better quality of life.

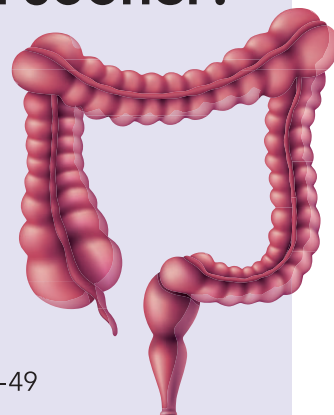


Should Colon Cancer Screening Start Sooner?

The American Cancer Society recommends that colon cancer screening should start at age 50, but this may be too late. Since the mid-1990s, experts have noticed a rising trend in colon and rectal cancer incidence and mortality among men and women under 55 in the United States. One study found that 30 percent of newly diagnosed people are younger than 55.

Based on an analysis of more than 6,000 colonoscopies, French researchers recently reported that the detection of precancerous growths jumped by 400 percent from the 40-to-44 age group to the 45-to-49 group. The average number of polyps in the colon and the proportion of people with adenomas (benign tumors) rose much more sharply from the 40-to-44 group to the 45-to-49 group than they did from the 45-to-49 group to the 50-to-54 group.

"The results of our research strongly indicate that screening for colorectal cancer should begin at the age of 45," said researcher David Karsenti, MD, of the French Society of Digestive Endoscopy.



Treating Cancer Anywhere

New therapies target similar tumors wherever they appear.

CANCER TREATMENTS ARE TRADITIONALLY tested and prescribed for tumors in specific parts of the body. Drugs for breast cancer, lung cancer and melanoma usually undergo separate clinical trials and are reviewed separately by the Food and Drug Administration (FDA).

But what if new therapies could be tested and approved based on shared tumor characteristics, regardless of where in the body the cancer appears? Today, this so-called tumor-

agnostic approach is starting to become a reality.

Last May, the FDA approved the first treatment that can be used for cancer with a specific type of genetic mutation anywhere in the body. The immune checkpoint inhibitor Keytruda (pembrolizumab) got the green light for the treatment of any solid tumor with mismatch repair deficiency or microsatellite instability.

Tumors with a broken mismatch repair system are unable to fix DNA damage that can shut down cancer growth. Mismatch repair mutations are seen in many types of cancer, including about 18 percent of advanced endometrial tumors and 6 percent of metastatic colon cancer.

This approval means that people with all cancer types—not just those whose cancer is common enough to have its own trial—may be eligible to try this effective new immunotherapy.

While Keytruda was initially tested in people with one type of cancer at a time, the promising experimental drug larotrectinib has been developed from scratch for patients with a specific tumor mutation anywhere in their body. Studies that collect people with specific cancer characteristics regardless of its location are known as basket trials.

Larotrectinib, one of the stars of the 2017 American Society of Clinical

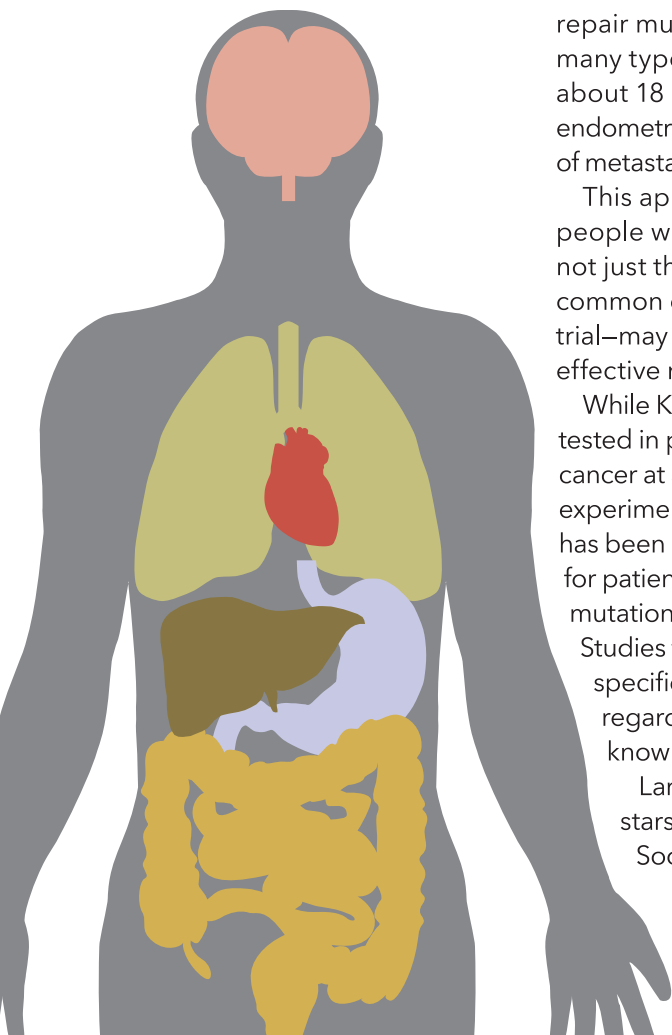
Oncology meeting, was tested in 43 adults and 12 children with 17 different types of advanced cancer. Some of the cancers were common, like melanoma and lung cancer, but others were so rare that patients traveled from around the world to join the studies.

What they all had in common was a tumor mutation known as a tropomyosin receptor kinase, or TRK fusion. When a TRK gene in a cancer cell fuses with another gene, it acts as an ignition switch to turn on cancer growth. By blocking TRK, larotrectinib halts cancer progression.

TRK fusion mutations occur in only around 1 percent of all cancers, but they're found in more than 90 percent of some rare cancers, says researcher David Hyman, MD, of Memorial Sloan Kettering Cancer Center in New York.

Overall, three out of four patients showed complete or partial tumor shrinkage in before-and-after scans, Hyman reported. At the time of the presentation, more than 90 percent of responders were still doing well on treatment, including two children who saw their tumors shrink enough that they could undergo curative surgery.

"This really brings us into a new era where treatment is truly based on mutation, not location," says Sumanta Kumar Pal, MD, from California's City of Hope Cancer Center. ■



Eating Well During Treatment

GOOD NUTRITION PROVIDES ENERGY, helps the body heal and supports the immune system. A healthy diet is more important than ever when you have cancer, but some symptoms and treatment side effects can make it hard to eat. Your care team may be able to adjust your treatment to reduce side effects or refer you to a dietitian who can help you stay well nourished as you face this challenge.



FATIGUE:

Treatment-related fatigue can make it harder to shop and

prepare meals. Stock up on groceries, and cook in large batches to freeze into meal-sized portions. When possible, ask family and friends for help. Easy foods like yogurt, granola bars and crackers with cheese or peanut butter provide lots of nutrients with little work.



LOSS OF APPETITE:

Many people don't feel like eating much during cancer treatment (known as anorexia). Try eating small meals or snacks every few hours rather than large meals. Keep nutrient-rich snacks on hand that can be eaten with little preparation. Mild exercise can stimulate the appetite, and some people swear by medicinal cannabis.

WEIGHT LOSS: Weight loss, especially muscle loss known as cachexia, is common among people with cancer. Try eating every few hours instead of waiting until you're hungry.

Focus on protein-rich foods, and add high-calorie extras like cream, butter and honey.



MOUTH AND THROAT PROBLEMS:

Radiation and chemotherapy can cause mouth sores and throat problems that can make it

painful to eat and difficult to swallow. Stick to soft foods and nutrient-rich drinks like shakes and smoothies. Puree food in a blender or moisten with sauces. Avoid spicy and acidic foods.

CHANGES IN TASTE OR

SMELL: Some medications can make foods taste different and leave a bitter or metallic taste in the mouth. Spices and other intense flavors can help mask bad tastes. If meat doesn't taste right, try vegetable protein sources like beans and tofu. Suck on sugar-free mints or candy, and brush your teeth often.



NAUSEA AND

VOMITING: Try eating small snacks throughout the day and sipping fluids to stay hydrated. Dry, bland and salty foods may lessen

nausea, as can peppermint, ginger and medicinal cannabis. But avoid greasy and spicy foods and those with strong odors. After eating, rest sitting up instead of lying down.

DIARRHEA AND CONSTIPATION:

Fiber from fruits, vegetables and whole grains helps move food through the digestive tract. Eat more fiber if you're constipated, but avoid it if you have diarrhea. Greasy or high-fat foods can worsen diarrhea. For constipation, drink more fluids and get more exercise.



AVOIDING INFECTIONS:

Cancer treatment can lower white blood cell counts and raise the risk of infection. Wash your hands before cooking, and clean fruits and vegetables thoroughly. Use separate utensils and cutting boards for produce and meat. Cook meat, seafood and eggs well. Avoid unpasteurized dairy products and foods from bulk bins, deli counters and salad bars.



New Light on Risk Factors

More than 40 percent of cancers are caused by factors we can control.

CANCER IS NOT ONE disease but many, and its causes range from unchangeable, like BRCA1 gene mutations, to fully preventable, like smoking. And in many cases, cancer is triggered by random mutations that accumulate as we age.

Modifiable risk factors are responsible for more than 40 percent of all cancers and cancer-related deaths, according to a recent study from the American Cancer Society (ACS). And while everyone knows that smoking causes cancer, other risk factors may come as a surprise.

The researchers calculated that more than 650,000 new invasive cancer cases (42 percent) and more than 265,000 deaths (45 percent) among people age 30 and older were attributable to about a dozen modifiable risk factors.

As expected, smoking was responsible for the most cancer cases (19 percent) and cancer deaths (29 percent).

Alcohol was blamed for nearly 6 percent of cancer cases and 4 percent of deaths. The American Society of Clinical Oncology recently warned that even light or moderate drinking raises the risk of several types of cancer, including mouth and throat cancers, colon cancer and breast cancer. Yet a survey by the group found that a majority of Americans don't recognize

alcohol as a cancer risk factor.

People who enjoy an occasional beer or glass of wine don't need to panic, according to Aaron Carroll, MD, of Indiana University School of Medicine. He calculated that if light drinking raises a 40-year-old woman's 10-year risk of breast cancer by 6 percent, that means one additional cancer case among 1,667 women.

About 8 percent of cancers were linked to being overweight, 3 percent to lack of physical activity and 2 percent to a shortage of fruits and vegetables. This is in line with a recent Centers for Disease Control and Prevention report showing that overweight people are at higher risk for at least 13 types of cancer.

Infections are another under-recognized risk factor. Nearly 2 percent of cancers were attributable to human papillomavirus (HPV), which causes cervical, anal and some oral cancers. However, these cancers can be prevented with a vaccine, which is now recommended for adolescents. Likewise, the hepatitis B vaccine and treatment that cures hepatitis C lower the risk of liver cancer.

Saying a risk factor is modifiable doesn't

mean it's easy to change—as those who have tried to quit smoking or lose weight can attest! It also doesn't suggest that people who get preventable cancers should be blamed or shamed. Most people have some less-than-healthy habits, and everyone living with cancer deserves care and compassion.

But knowing the risk factors can empower people to lower their odds of getting cancer.

"These findings underscore the vast potential for reducing cancer morbidity and mortality through broad and equitable implementation of known preventive measures," the ACS researchers conclude. ■



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Beyond the Ribbons

HIV/AIDS advocate Tim Horn highlights some golden rules for health activism.

HIV/AIDS ACTIVISM IS, perhaps, one of the most venerated movements in modern history—a groundswell of demonstrations and civil disobedience in the late 1980s and early 1990s that captivated the world and continues to bridge the chasm that has long separated the people from the scientists and policymakers. The lessons from HIV/AIDS activism are many—and not without controversy. But a couple of golden rules continue to shape today’s activist agendas, in both the fight against HIV/AIDS and the fight against cancer.

Know the science. While HIV/AIDS activism was best known for its “die-ins” and direct actions, something else was afoot in the early years of the epidemic: Men and women, many of them living with the virus, were teaching themselves and one another the science of HIV. Not just about medical care, to better advocate for themselves and their loved ones, but also about potential targets for drug development, clinical trial methodologies and biostatistics. The result? Activists became credible in the eyes of the “experts,” leading to a surge in funding, reform of Food and Drug Administration approval and early access processes and a

place at high-level decision-making tables.

Scientific literacy remains a cornerstone of effective health activism. As was the case with HIV, there is an urgent need for new cancer treatments, particularly for people who don’t benefit from or can’t tolerate existing options. We can’t push for changes in funding, health care delivery and access to treatment if we don’t know what science confirms is necessary for health and survival.

Understand the barriers. The past three decades have ushered in tremendous improvements in the diagnosis, prevention and treatment of HIV and many cancers, and activism has played a major role in hastening their availability.

But availability is not the same as access, and startling disparities persist with regard to who benefits from state-of-the-art care and who does not. Just like HIV, cancer can affect anyone, but it is more likely to be diagnosed and to cause death in some groups versus others. The reasons for the disparities are complex but are frequently rooted in unequal access to care.

Scientific advances are only a win if everyone benefits. Activists must push for the

research and political action needed to break down cultural and economic barriers in order to secure health care coverage for all, opportunities to participate in clinical trials of promising new therapies, access to experienced and culturally competent providers, and an array of social services that promote health and well-being.

Activism doesn’t end when science yields a breakthrough therapy, but rather then begins the hard work of ensuring the best possible care and treatment for all. The activist to-do list includes working in partnerships and coalitions, challenging the stigmas around disease that contribute to disparities in care, and pairing meeting-room diplomacy with brash protest. Drawing on what we’ve learned from HIV/AIDS activism can help us reach the remarkably similar goals shared by health activists in the fight against HIV, cancer and beyond. ■



All Hannah's parents should worry about is Hannah

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*"We're blessed to be here
because St. Jude makes it so
we really can just focus on her."*

—Chandra, Hannah's mom

A Prostate Cancer Diary

Charlie Christmann, 60, is an engineering consultant in Placitas, New Mexico.

December 2015

My doctor is a stickler for checking the PSA level in my blood, which can indicate prostate cancer. It had been slowly creeping up. After my annual exam, he said it had jumped over 4 and I should get checked for possible prostate cancer.

Cancer runs in my family. I lost my father to colon cancer. My mother had a double mastectomy and bladder cancer. When you hear the C word after that history, it kind of hits you in the gut.

January 2016

My PSA was tested again and jumped from 4 to over 10. The doctor recommended a biopsy to check for cancer. My wife and I decided that if this really was cancer, we were going to take a positive attitude and fight as hard as we could.

Waiting weeks to get the biopsy was gut-wrenching. I've had some friends pass on from prostate cancer, and I know several who currently have it. I was in limbo. I stopped a lot of my business activities while waiting to see what would happen.

March 2016

As the biopsy approached, I was very nervous. You hear all kinds of horror stories from people who've gone through it, and you read stuff on the internet.

We arrived in the morning, and I was out in a couple of hours. It wasn't pleasant. I was sore inside and had blood in my urine and stool, which the doctor had warned me about. The two-week wait for results was nerve-racking. You don't know what they're going to find.

They took 12 samples, and 11 had cancer in them. Most had a Gleason score of 7. The doctors said we should be aggressive with treatment

because I was only 59, but they gave me the option to do nothing, since it's usually a slow-growing cancer. I could do just radiation, but surgery's not possible afterward. If you do surgery first, you can do radiation later.

My wife and I went home and talked. Not doing anything was not an option. We've got lots of years ahead, things we want to do. I chose surgery, scheduled for June. Right before surgery, my insurance denied the planned less invasive robotic procedure. That was a down day. It took a month to get rescheduled for traditional surgery.

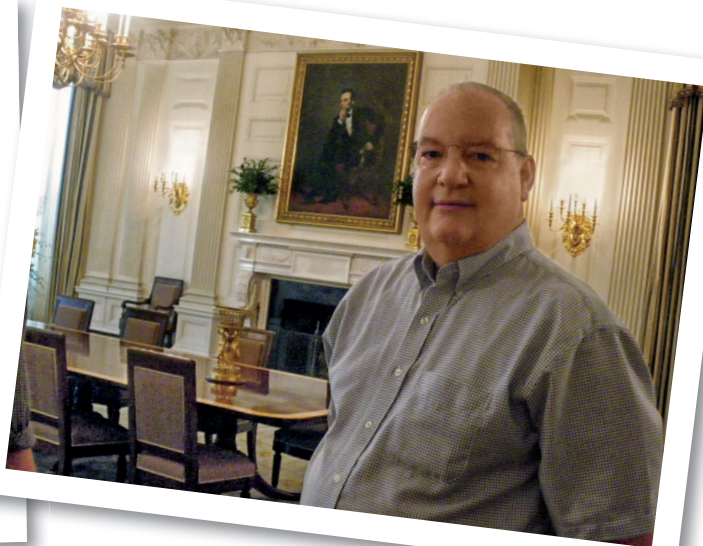
July 2016

Before my prostate was removed, my doctors talked about impotence and urination problems. They said surgery would probably take care of the cancer.

Two weeks later, we got the results. My wife and I went in upbeat. The surgeon said, "Well, your Gleason score went from 7 to 9. The cancer has breached the margins of the prostate, and it's in your seminal glands." He advised radiation. My wife and I looked at each other, and our faces just dropped.

I was in total shock. Nobody ever said there was a chance the cancer had gone past the prostate. I was expecting maybe 10, 15 years from now I might need radiation. Not in a million years did we





From left: Christmann on a cruise in April 2017; at the New Mexico governor's mansion in 2016 with Chuck Franco (left), Governor Susana Martinez and Dee Christmann; visiting the White House in October 2017

expect to hear that I needed additional treatment.

We wanted aggressive treatment, so the oncologist suggested hormone therapy plus radiation. That would start after I healed from surgery. The ride home was pretty quiet.

August 2016

While healing, we visited my mother in Texas on our way to Disney World. Before leaving, I had a CT scan. While we were in Texas, my oncologist called and told me to go to the emergency room immediately. The scan had caught a blood clot in my lung, a life-threatening pulmonary embolism that can be triggered by surgery.

I was hospitalized for three days and couldn't drive home for two weeks. We canceled our Disney trip. The medical costs were out of network. It got expensive real fast.

December 2016

I had hot flashes, night sweats and trouble sleeping from the hormone therapy. Then radiation began. They want your bladder full, so I drank 32 ounces of water before leaving home for the 45-minute drive. You get to the cancer center, put on a gown, sit, wait and suffer. I had 39 treatments.

There's a camaraderie with other guys in the waiting room. You start out being the newbie and everybody's telling you what to expect. Then you become old guard and trade stories. There was a rodeo guy in his 80s and he was still riding rodeo while getting his treatments.

April 2017

I finished hormone therapy, but the side effects are lingering, especially the hot flashes. Those continue for months.

September 2017

After not being able to go to Disney in 2016, we did make it in September 2017—during Hurricane Irma. We drank a toast to finishing all of my treatments.

November 2017

Just had my second checkup since radiation, and I'm feeling good. My numbers were great—PSA now at 0.01. We've been doing more traveling. I've got my business going again. I tell everybody who's going through this that it's not as bad as it could be, and I tell them they're doing great. My advice to others with cancer: First of all, be positive and upbeat—never let it get you down or defeat you. Second, find someone who has the same attitude to support you no matter what and keep your spirits up. ■

PSA: Prostate-specific antigen, a protein produced by the prostate gland; 4 ng/ml is the top of the normal range

Biopsy: Removal of prostate tissue samples for lab testing, usually using a needle inserted through the wall of the rectum

Gleason score: A score, ranging from 1 to 10, that indicates how abnormal a tissue sample looks and how likely the cancer is to spread

Hormone therapy: Also known as androgen deprivation therapy, drugs that block male hormones that stimulate prostate cancer growth



ECSTATIC HEALING

**Dancing through cancer with
Dr. Deborah Cohan**

BY CASEY HALTER | PHOTOGRAPHY BY WINNI WINTERMEYER

FOUR YEARS AGO, DEBORAH COHAN, MD, a physician and obstetrician-gynecologist at Zuckerberg San Francisco General Hospital, went viral on the internet in the midst of her battle with breast cancer. But her story isn't the typical tale of fear, reckoning and recovery that cancer patients are often primed for when they receive their diagnosis.



Deborah Cohan, MD,
made her cancer journey
a celebration of life.

Instead, Cohan made her journey a celebration of life, literally dancing her way into the operating room surrounded by a team of shimmying nurses and surgeons, smiling and gyrating her hips to Beyoncé's "Get Me Bodied" as she prepared to go under for a double mastectomy.

"I wanted to be my sole self. I didn't want fear to win. I didn't want to walk into the operating room afraid," Cohan says about that fateful day at the beginning of her battle. The video of her dance, which was later uploaded to YouTube by a friend, has been watched over 8 million times. Her video and advocacy have also sparked an online movement of cancer patients devoted to looking at things a little bit differently.

With Cohan's cancer finally in remission, Cancer Health caught up with "Dr. Deb the Dancing Doc" to map her journey, talk about her experiences with complementary therapies and discuss the ecstatic, holistic healing she embodies.

FACING HER FEARS

"I was a healthy yet overworked 44-year-old. I exercised, breast-fed my children for a total of four years, ate organic food. On the surface, I had no obvious risk factors for cancer," Cohan says, reflecting on her diagnosis in the fall of 2013.

After she discovered a tumor during a self-exam, Cohan's radiologist ultimately told her that she had invasive ductal carcinoma, in which malignant cells begin growing in the milk ducts and later invade the fatty tissue of the breast. The most common type of breast cancer in the United States, it accounts for about 80 percent of all breast cancers and affects more than 180,000 American women per year, according to the American Cancer Society.

Cohan, who has been studying movement in one form or another since she was 3 years old, didn't start out dancing about her diagnosis.

"I kind of went for it in terms of my initial exploration of fears—death, losing my kids who were 5 and 8 at the time, dying alone," she recalls. But as a doctor who's seen firsthand the effects of a surprise diagnosis on her patients, Cohan also knew that the first thing she needed to do was take some time to process and seek support.

That first day, she took a leave of absence from work, called her family and headed to her weekly Soul Motion dance class. Despite feeling overwhelmed and afraid,

Cohan says she decided to imagine death as her dance partner during the class.

"Somehow, I think addressing my fears directly and doing it in a place that was really safe emotionally for me, surrounded by friends and community, allowed me to pop through it. Near the end of the class, I actually felt joy in my body," Cohan remembers.

She wound up making dance an integral part of her cancer journey—and the rest is history.

On Cohan's cancer recovery page on Facebook today, one can still watch dozens of copycat videos featuring patients grooving in the face of their health crises. There's 16-year-old Amari Hall, dancing in celebration of a successful heart transplant. There's 32-year-old uterine cancer survivor Ana-Alecia Ayala cutting a rug through chemotherapy. And there's fellow breast cancer patient Doretta Noris getting down to "Gangnam Style" as she makes her way into surgery.

"It was a little surprising when I woke up to find that the video had gone viral," says Cohan. But the community that her brave action has since given rise to was worth the shock.

Cohan says she took immediate control of her cancer care after her diagnosis.

"I shopped around," she recalls, listing off the mastectomy surgeons, plastic surgeons, oncologists and radiation specialists she interviewed before undergoing any treatment. "I compiled my own team and came up with a plan," the dancing doc explains, and today she urges others facing cancer to do the same.

On the advice of her doctors, Cohan underwent a bilateral mastectomy, removing both of her breasts and nearby lymph nodes. She also underwent four rounds of chemotherapy using cyclophosphamide and Taxotere (docetaxel).

Cohan finished chemo and breast reconstruction in 2014 and now takes an aromatase inhibitor to halt the production of estrogen, which could cause her cancer to come back. In between work, online advocacy and taking care of her kids, Cohan still dances—and has begun spreading the wisdom of dance therapy throughout the cancer community.

DANCE AS MEDICINE

Today, if you visit Cohan's office at SF General, where she is an ob-gyn working with couples affected by HIV, you might notice a stack of "Movement Is Your Medicine" or "Hip Hop to Health" prescription notes lying on her desk.

A Quick Guide to Complementary Therapies

UP TO 60 PERCENT of American physicians have recommended that their patients use some sort of complementary therapy to help deal with an illness. Many types of therapy may be used to help manage cancer symptoms and treatment side effects. A growing number of cancer centers offer integrative therapy that combines proven medical treatment with complementary methods.

Below are several helpful and safe treatments that have been vetted by the American Cancer Society. Complementary therapies should be used only in addition to clinically proven medical care, not as replacements. Talk to your doctor or nurse before starting any type of complementary therapy.



ACUPUNCTURE: This traditional Chinese therapy involves inserting thin needles into the skin at specific points on the body. Studies show that acupuncture may help ease pain and swelling after surgery. It may also help control side effects like nausea and vomiting during chemotherapy.



AROMATHERAPY: Scented oils can be inhaled or rubbed on the body during a massage. Research has found that aromatherapy may relieve side effects like anxiety, depression and nausea in people with cancer.



ART THERAPY: Working with a trained art therapist to create pictures or objects with personal meaning can help people with cancer and their caregivers release bottled-up feelings. Studies show that art therapy can help people cope with an illness and improve their quality of life.



BIOFEEDBACK: This technique uses devices to train people to consciously regulate their body's autonomic processes, such as

respiration, blood pressure and heartbeat. Biofeedback may help people with cancer regain a sense of control over their bodies, and it can also reduce stress, pain and muscle tension.



LABYRINTH WALKING: This ancient meditative practice involves walking along a set pathway that weaves in a circle around a central point. More than 100 health care facilities in the United States have labyrinths to help patients relieve stress, improve coordination and build strength.



MASSAGE: Manipulating the muscles and rubbing the soft tissues of the body may help reduce cancer treatment side effects such as pain, fatigue, anxiety and depression. Massage can also help improve the health of scar tissue and increase range of motion after surgery.



MUSIC OR DANCE THERAPY: In a music therapy session, a person with cancer might listen to music, dance, sing, write lyrics, perform with simple instruments or use guided imagery along



SPIRITUALITY: Studies show that people who rely on their faith during cancer treatment tend to have increased hope and optimism and a higher satisfaction with life. Spiritual practices can also decrease anxiety and depression and better control nausea and discomfort.



TAI CHI: This martial art is often referred to as a "moving meditation." Practitioners perform a series of slow, graceful motions, concentrating on deep breathing and posture. Tai chi may help relieve pain, anxiety and stress for cancer patients and survivors.



YOGA: Moving through gentle yoga poses during cancer treatment can help increase blood and oxygen flow throughout the body while building and maintaining strength. Yoga can also help dissipate tension and anxiety, which studies show can suppress immune function.

"I give them out when a patient is stuck, when they have been trying something over and over again and it's not working for them," Cohan says.

On the notes, some people are directed to dance every morning, others, during their work breaks. Often, her patients are told to get down simply "as needed" while they work through illnesses like cancer, diabetes and depression. "It's a way of disrupting the script a little bit and allowing people to at least explore an invitation to do things differently," she adds.

Since overcoming cancer, Cohan has started the Foundation for Embodied Medicine, a nonprofit that hosts dance, meditation and mindfulness workshops for patients, caregivers and medical providers. Once a month or so, Cohan travels to hospitals, dance studios and offices across California to teach others to dance like she does and kick-start their own healing through holistic, complementary care.

"I didn't start teaching cancer patients until after my diagnosis," says Cohan, who specializes in a practice called conscious dance and has been sharing her secrets with fellow doctors for years. "It includes conscious movement and stillness for increasing one's awareness of their body and becoming more present." Conscious dancing ranges from ecstatic dance to somatic movement therapy and encompasses more than 100 different types of movement.

Dance and music therapy have started to gain a major following in many medical research and physician communities outside of Cohan's circle. Studies show that patients who listen to music during surgery may experience markedly lower blood pressure and stress levels and require less supplementary sedation than those who undergo an operation in a silent room. Research also suggests that people who listen to music posttreatment may have less inflammation and faster recovery times.

As for dance, besides the physical benefits and psychosocial support Cohan credits with aiding her along her journey, studies show that dance can also help people with cancer soothe symptoms of depression and anxiety, as well as cope with postsurgical challenges, such as fatigue, joint pain, weakness and balance problems.

Cohan says her love of dance and music makes her a better doctor.

"Being in your body can be really helpful in terms of interacting with patients," she explains. "Many of us physicians have been living in our heads for so long."



"IT'S NOT JUST A MATTER OF
CANCER, BUT ALSO
WELLNESS SO THAT
ANY RESIDUAL CANCER

Studies show that surgeons show fewer signs of stress and demonstrate improved job performance when they operate to the sounds of self-selected music. Taking cues from dance therapy—such as synchronizing breathing patterns with a patient and paying attention to where they hold tension in their bodies—can help doctors like Cohan reduce patient stress and provide a more personalized practice. "Obviously, it's incredibly helpful for pregnant women in preparation for labor," she explains.

Cohan compares her cancer diagnosis to a sort of "cosmic two-by-four—a message that I'm meant to do this work and be an ambassador for conscious dance in conventional medical settings."



Deborah Cohan, MD, teaches others to kick-start their own healing through holistic, complementary care—including her favorite method, dancing.

**BETTER OF KILLING THE
CULTIVATING TRUE
THE BODY CAN KEEP
CANCER CELLS IN CHECK."**

FINDING HER THERAPY

Dance and movement weren't the only techniques beyond traditional medical treatment that Cohan tried to help get her through her cancer. She also incorporated meditation, tai chi, qigong, acupuncture and energy practices such as Reiki and Tibetan healing into her regimen.

"I think what's been so important for me is finding my medicine and not just accepting what's been suggested to me," Cohan explains. "My diagnosis gave me an opportunity to explore all these different healing modalities that are not classically a part of conventional biomedicine. It was a very eye-opening and mind-opening part of my experience."

These therapies, Cohan says, are known in the medical world as complementary therapies, meaning they're used with a physician's permission and in conjunction with—rather than instead of—proven mainstream medical methods. They tend to be pleasant, do not involve substances with pharmacological effects, are relatively inexpensive and are intended to manage side effects and improve quality of life. Importantly, they're different from so-called alternative therapies, which are used in place of standard medical care and sometimes make false and dangerous promises of a cure.

Like music and dance, these complementary therapies have demonstrated positive effects on the body. Several lines of research suggest that our perceptions of the world inform our immune system responses in a way that make us better able to respond to current and future illness. Fear and stress can increase levels of hormones like cortisol and epinephrine, which over time may increase inflammation and lower natural immunity.

"It's not just a matter of killing the cancer, but also cultivating true wellness so that the body can keep any residual cancer cells in check," Cohan explains. Plus, she adds, "I haven't done any of it instead of. I've done it in addition to."

Cohan also participated in one of the first clinical trials of the DigniCap, a scalp-cooling silicone cap system that is designed to limit hair loss during cancer treatment. She says that in addition to dance, therapy and support, the cold cap—which saved as much as half of her hair—helped her stay positive and optimistic throughout her recovery and helped her tap into the healing power of positive thinking.

"People treated me as though I were a healthy person. Instead of receiving people's pity, I received their encouragement. I received people's surprise that someone going through chemo could actually be vibrant and look healthy," Cohan recalls.

Cohan's best advice to people seeking to find strength and positivity through their own cancer treatment? "Find what brings you joy," she says. "Even though cancer may be a big, scary roadblock in your life, don't let cancer become your life. Find your support. Be open to healing. And, most importantly, have compassion and love for your body." ■



**CAR-T therapy is produced
at the Kite Pharma
manufacturing facility.**





CAR-T THERAPY: LIFELINE TO A CURE?

Immunotherapy gives people with advanced lymphoma another treatment option.

BY ED SUSMAN

“I HAD BEEN TOLD THAT AFTER two years of being cancer-free, I had beaten the disease,” recalls Don Pender, 67, an autoworker from Spring Hill, Tennessee. He thought his struggle against non-Hodgkin lymphoma was in the rearview mirror.

Then, in early 2015, almost five years after showing no signs of the disease, he got some bad news.

“I was shaving, and I felt this lump in my neck. It was quite large. I went back to my doctor, and she checked it out and did a biopsy,” he says. “Then she told me, ‘I’m sorry to tell you this because it usually doesn’t come back.’”

But it had. Pender was told that his options at the regional center had been exhausted, and he was referred to Vanderbilt-Ingram Cancer Center in Nashville for a stem cell transplant using his own cells.

Lymphoma occurs when white blood cells, usually B cells, grow out of control. Although chemotherapy is effective for some people with aggressive non-Hodgkin lymphoma, the cancer often relapses and a stem cell transplant may be the next step. Cancerous immune cells are killed off

COURTESY OF KITE PHARMA

with radiation or strong chemotherapy and replaced either with a patient's own previously collected blood-forming stem cells or with those from a matched donor.

Pender underwent the grueling procedure that spring, but within a year, that treatment had also failed.

"I was told that the only thing that I could try was a transplant from my sister or brother, but I had already been told that the donor stuff doesn't really work all that well," he says. He was also told that he might have only six months left to live.

As Pender was leaving the office to consider his grim options, the doctor called out, "Wait a second, Don, come back in. Would you be willing to do a trial?"

In March 2016, Pender was offered a chance to join a trial of chimeric antigen receptor T-cell therapy, better known as CAR-T, a customized treatment that uses gene therapy to reprogram a patient's immune cells to fight cancer. T cells are collected from the blood and shipped to a manufacturing facility, where they are modified, multiplied and sent back to be reinfused into the patient. But in addition to killing cancer cells, the supercharged T cells can also harm healthy cells, leading to potentially life-threatening side effects.

Jamie Galucci, a 29-year-old paralegal from Stuart, Florida, was first diagnosed in January 2015 with primary mediastinal large B-cell lymphoma, a rare type of lymphoma in which abnormal B cells form a mass behind the breastbone. She received standard rituximab-based chemotherapy at a local hospital, but the treatment failed to completely eradicate the cancer.

Galucci did some research and sought a second opinion from Jason Westin, MD, head of the B-cell lymphoma research team at the University of Texas MD Anderson Cancer Center in Houston.

"After confirmation of cancer activity via a biopsy and a PET scan, my mass began to aggressively grow, and the plan was to get me into remission so I could ultimately undergo a stem cell transplant," Galucci recalls. "I went home to Florida and underwent two rounds of chemotherapy."

After returning to Texas for further testing, Galucci also received disappointing news: Her cancer was not responding to the treatment.

"We learned that my mediastinal mass was refractory to the chemotherapy regimen and had grown to approximately 7 centimeters," she says. "Due to time constraints and not being able to undergo the stem cell transplant,



**"THIS TECHNOLOGY
HAS MOVED
THE FIELD
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CANCER."**

I prepared for a concurrent radiation and chemotherapy regimen. There was a six-day waiting period before I would begin, so I decided to travel home to save money and spend time with family."

"On my way back to Houston for treatment, I received a call that would forever change my life: The FDA [Food and Drug Administration] had approved the Kite CAR-T immunotherapy trial, and I was moved to the top of the list," she recalls. "I was told I was a perfect candidate for the treatment. I was very nervous, to say the least, knowing that the side effects could ultimately result in my death, but I had no choice."

Today—almost two years later—both Pender and Galucci are feeling fine and their cancer is in remission. Pender is enjoying retirement. Galucci is back at work. They are among the first patients treated with Yescarta, the newly approved CAR-T therapy developed by Kite Pharma in Santa Monica, California, now part of Gilead Sciences.

On October 18, 2017, the FDA approved Yescarta (also known by the tongue-twisting generic name axicabtagene



ciloleucel) for adults with relapsed or refractory large B-cell lymphoma who have unsuccessfully undergone two or more types of treatment. The first CAR-T therapy, Kymriah (also known as tisagenlecleucel), from Novartis, was approved on August 31, 2017, for children and young adults with acute lymphoblastic leukemia.

With the current standard of care, people with aggressive B-cell lymphoma often have an expected survival of around six months. Now these patients have another option.

To understand the bewildering scientific aspects of the CAR-T therapy trial, Pender assembled his own expert team—his son and daughter-in-law, both trained as nurses. They accompanied him to meetings with the researchers to help him understand the process and its potential risks and benefits.

“But in my mind, I didn’t really see any other option that was good for me, so I had pretty much made my decision that I was going to do it,” he recalls.

After he agreed to be in the clinical trial, known as

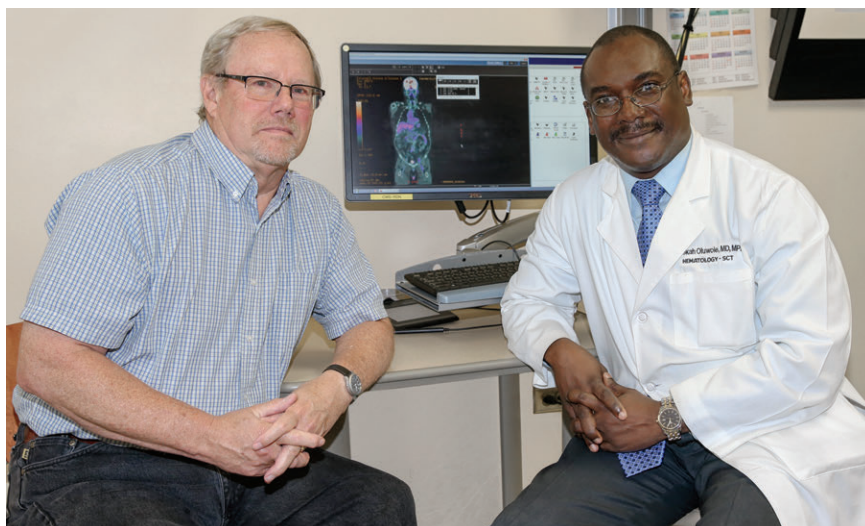
ZUMA-1, Pender had to undergo a battery of tests within a short two-week window of opportunity to determine whether he met the criteria for inclusion. “As luck would have it, the Good Lord was watching over me, and I qualified,” he says.

At Vanderbilt, Pender came under the care of Madan Jagasia, MBBS, MS, coleader of the Translational Research and Interventional Oncology Research Program, and Olalekan Oluwole, MBBS, MPH, the assistant professor of medicine who led the Yescarta trial at the center.

“The first day they put those cells back in me at Vanderbilt, I felt fine. I thought, Hey, this is no big deal,” says Pender. And then he went into a coma for four days and spent 10 days in intensive care.

While it has the potential to be lifesaving for people with limited options, CAR-T therapy is not a stroll in the park, as Pender and Galucci can attest. They both

T cells are genetically engineered to create a customized “living drug” for each patient.



developed cytokine release syndrome—also known as a “cytokine storm”—in which the ramped-up T cells unleash a flood of immune system chemicals, leading to severe side effects, such as high fever, low blood pressure and brain swelling.

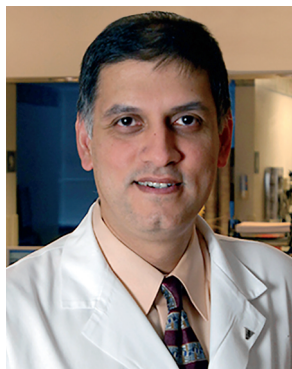
“As part of the national team testing this new CAR-T therapy, we have developed specific protocols to manage these patients,” Jagasia says. “Vanderbilt has a group of highly experienced physicians who work closely with subspecialty care teams, and we have immediate access to the intensive care unit.”

Galucci was reinfused with her modified CAR-T cells on November 30, 2015. Her treating doctor, Sattva Neelapu, MD, deputy chair of the Department of Lymphoma and Myeloma at MD Anderson Cancer Center, also had to manage a rough bout of cytokine release syndrome.

“I suffered from cytokine release syndrome, neurotoxicity and seizures, ultimately being forced to learn how to walk, talk and eat again,” Galucci recalls. “But if I had to do it all over again, I would, because, on December 29, 2015, I was informed that I was in remission, and I have stayed in remission since that date. I have also bounced back without any major residual side effects or issues.”

In her case, the comatose condition lasted for two days—the average time for the complication to run its course, according to Neelapu. Kite recommends that patients

**Clockwise from top left:
Lymphoma patient Don
Pender and Olalekan
Oluwole, MBBS, MPH;
Yescarta trial participant
Jamie Galucci; Sattva
Neelapu, MD; Madan
Jagasia, MBBS, MS**



undergoing treatment with Yescarta be monitored closely for seven days after the infusion. If they live some distance from the hospital, as was the case for both Pender and Galucci, they should prepare to stay nearby for at least four weeks in case life-threatening infections occur.

“The immune system is conditioned to fight viruses and bacteria, and when someone has a severe infection, it can cause fevers,” Oluwole explains. “A similar pattern occurs when the modified T cells encounter lymphoma or leukemia cells. There is an immune response that can cause fevers and other side effects.

“The more we use this technology, the better we get at detecting subtle signs earlier, and we can be more proactive in providing interventions to minimize the toxicities. The key is recognizing them early and intervening before the patient gets too sick,” Oluwole continues. “I think it is safe to say these new CAR-T therapies will become part of what we do on a day-to-day basis to treat lymphoma. Because of the way this

new immunotherapy works, this technology has actually moved the field further toward eradicating cancer.”

After working through the harrowing experience of the cytokine storm, patients come back for a radiological assessment about four weeks later; these evaluations occur regularly for around two years.

“I felt that the treatment had worked almost immediately,” Galucci recalls. Her feeling was backed up by the first of her tests a month after the initial infusion: “There was no more cancer.”

In Pender’s case, the first scan at 30 days showed that his cancer was reduced by at least half. At three months, the imaging tests showed just a few small spots of residual disease. By six months, his scans were clear—and they have remained that way.

“I knew something good was happening because you can feel your lymph nodes in your neck, and I couldn’t feel anything,” Pender says. After the scan was done, one of the technicians told him, “We are in awe of what we are seeing.”

“When I saw Dr. O, he said the cancer was at least 50 percent gone after just one month. He said the treatment was working and it would keep working for at least six months to a year,” Pender adds. “After six months, it was all gone. I was in remission. I just had another test in September, and it is still all gone.”

“I am Catholic, and I do practice my faith. A lot of my friends prayed for me, so I just believe a lot of that worked,” Pender says. “The people who developed this thing have given me a blessing. I feel good and I have my energy back, although it took a while to get there. I think this will save a lot of lives. I wouldn’t be here today if I hadn’t been in this trial.” ■

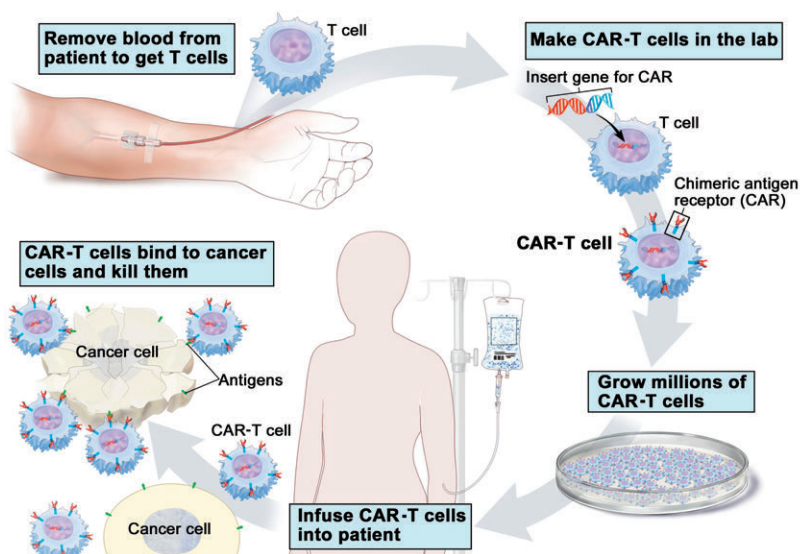
HOW CAR-T WORKS

Chimeric antigen receptor T-cell (CAR-T) therapy reprograms T cells to recognize and kill cancer cells. First, a sample of normal T cells is collected using a process called leukapheresis. Blood is removed from a vein in the arm, the T cells are separated out and the rest of the blood is returned to the body.

The T cells are frozen and sent to a manufacturing facility, where they are genetically engineered to create a customized “living drug” for each patient. Using an inactivated virus, lab scientists insert artificial receptors that bind to a specific type of cancer cell. The first two approved CAR-T therapies—Kite’s Yescarta and Novartis’s Kymriah—are designed to recognize the CD19 protein on B cells that grow out of control in lymphoma and leukemia. Researchers are now working on similar therapies that home in on other targets.

The engineered T cells are multiplied in an incubator and shipped back to the local hospital. Before receiving the modified cells, the patient undergoes strong chemotherapy to kill off existing immune cells and make room for the new ones. The whole process takes around two to three weeks.

Studies have shown that a single infusion of reprogrammed T cells can sometimes lead to complete remission that lasts for years. In the ZUMA-1 trial of Yescarta, 72 percent of lymphoma patients had at least a partial response, including 51 percent who achieved complete remission. The first child treated with Kymriah for leukemia remains in remission five years later. But researchers don’t yet know how to predict who will respond, and so far this type of treatment works better for blood cancers than for solid tumors.





**Lillie Shockney,
RN, MAS**

Overcoming Barriers

Lillie Shockney, RN, MAS, is an oncology nurse navigator, administrative director of the Johns Hopkins Breast Center, and the founder and program director for the Academy of Oncology Nurse & Patient Navigators.

What is an oncology nurse navigator?

An oncology nurse navigator is a specially trained registered nurse who works with patients to help them overcome barriers to care, as well as to educate and advocate for the patient. We provide patient education about the diagnosis and treatment of cancer, empowering the

patient to take a role in treatment decisions.

What are some of the ways you accomplish this?

The navigator looks for barriers and ways to overcome them. If patients can't get to their radiation appointments every day for six weeks, they may not get the care they need to treat

and prevent the return of cancer. Financial concerns are another barrier we can help address. There may also be cultural barriers—some patients may look at cancer, its treatment and the medical system differently.

Another component is ensuring the patient doesn't fall through the cracks. A patient

may have surgery at hospital A, radiation at center B and chemotherapy at clinic C, which may not belong to the same health care system or share medical records. The nurse navigator follows the patient throughout the continuum of care to prevent gaps.

What do you mean by empowering the patient?

We do this by explaining treatment options along with the risks and benefits. For example, one option may reduce the chances the cancer will return by 50 percent but have severe side effects impacting quality of life. Another lowers the risk by only 40 percent but has fewer debilitating side effects. Patients need this information to help them decide if less chance of cancer returning or better quality of life is most important to them.

Our work includes translating medical terminology. One study showed that most patients thought that a doctor using the word *respond* meant a cure. To the doctor, the meaning was that the cancer would temporarily shrink.

We also assist in helping preserve life milestones if possible. If a doctor tells a patient her surgery is scheduled in two weeks, the patient believes surgery is needed urgently. The navigator may find out that the patient's daughter is getting married in three weeks. If the surgery can be safely delayed, the navigator intervenes so that she can enjoy her

daughter's wedding and have surgery the following week.

When will you first meet the patient and how long will you work with them?

An oncology nurse navigator usually meets the patient within 24 to 48 hours following diagnosis, either in person or over the phone. The navigator is in the room when the physician discusses treatment and stays after the doctor leaves to assess the patient's understanding and look for barriers. The navigator

You are a breast cancer survivor yourself. How does your personal experience with cancer inform your work?

Getting diagnosed with breast cancer reframed my life and my purpose for surviving this disease. When I'm with newly diagnosed patients who are upset and I tell them that I am a survivor myself, the look of relief on their face is clear. No one knows how they will handle this situation until they are in it. I strive to get them through whatever lies ahead—including



Only give cancer the time it needs to get rid of it.

remains connected until the acute stage of treatment is completed and guides the transition to short-term and long-term survivorship. This can last a few months to one or two years.

How widely available are nurse navigator services?

All cancer centers are required to have nurse navigators in order to be a accredited, and 80 percent of these are small community cancer centers. They are also in private oncology practices. It's a rapidly growing nursing field. These services are billed as part of the overall care, not separately.

those with Stage 4 metastatic cancer who will die of this disease.

One of my philosophies as a result of being a patient is to only give cancer the time it needs to get rid of it—don't let it steal away any more personal, family, social or even work time, and don't let it rob patients of life goals they cherish.

What do you find most inspiring or hopeful about your work?

I enjoy advocating for patients and developing a personal relationship with them. It's a privilege to be part of these lives at this vulnerable time. ■



Talking With Your Doctor

DECISIONS ABOUT CANCER TREATMENT are rarely straightforward, but being direct with your doctor or nurse can make things easier.

Before suggesting a course of treatment, your doctor will consider the details of your individual case, the expected outcomes and the potential benefits and risks.

But your health care providers also need to understand what's important to you. For some people, the priority is simply to live as long as possible. Others put more emphasis on living well, with fewer symptoms or less pain. For some, being able to continue working or living independently are the primary concerns. Talking about your personal priorities will help your doctor or nurse provide better care.

When a treatment is suggested, ask questions to find out what it will involve. Basic information should include how long the treatment will last, how many hospital visits it will require, side effects, possible outcomes, how much it will cost and how it will affect your daily life.

Some of this information may be complex and confusing. Your doctor may use medical terms that don't make sense to you. If this happens, ask for the information to be explained in another way. If English is not your first language, a medical interpreter might be helpful.

Planning for your medical appointments can help you get the most out of them. Prepare a list of questions before you get there. When you arrive, tell your doctor or nurse the most important things you want to discuss that day.

It's easy to forget what you are told, so take notes during your appointment. Or ask if you can record the conversation on your phone. Having a friend or family member at the appointment is great for support—and he or she can also help you remember and interpret what the doctor said.

In many cases, a decision does not have to be made right away. If you are feeling overwhelmed, worried or upset, it can be difficult to take in new information and make decisions. You may simply need some extra time. ■

TOP 10 QUESTIONS TO ASK YOUR DOCTOR

- 1 What is this test for?
- 2 When will I have the results of the test?
- 3 What are the aims of this treatment?
- 4 Are there any alternatives to this treatment?
- 5 What will happen if I don't get any treatment?
- 6 What short-term and long-term side effects might I have?
- 7 Can anything be done to reduce side effects?
- 8 Given my insurance status, how much will treatment cost me?
- 9 Is there anything I can do to speed up my recovery?
- 10 Can you recommend websites or reading material?



Support Groups

NO MATTER YOUR DIAGNOSIS, cancer can leave you feeling isolated. The following support groups can help you find a community, either in person or online. Remember, whatever you're going through, someone else has already come out the other side.

CANCER AND CAREERS

cancerandcareers.org

646-929-8032

Cancer and Careers provides advice and educational events to help cancer patients and survivors navigate the workplace. Visit the site for regional events and resources.

CANCERCARE

cancercare.org

800-813-4673

CancerCare is a national organization that provides counseling, support groups, workshops, publications and financial assistance to anyone affected by cancer. Visit the site for more information.

CANCER SUPPORT COMMUNITY

cancersupportcommunity.com

888-793-9355

Cancer Support Community offers social and emotional assistance to cancer patients anywhere in the world. CSC's Cancer Policy Institute focuses on patient advocacy. Visit the site to find an affiliate group.

FRIEND FOR LIFE

friend4life.org

866-374-3634

Friend for Life is an international network of cancer survivors and caregivers who provide one-on-one emotional and psychosocial

support to people recently diagnosed with cancer, as well as their loved ones. Visit the site to be matched with a volunteer.

LATINAS CONTRA CANCER

latinascontracancer.org

888-522-8110

Latinas Contra Cancer's mission is to support Latinas who are living with or have survived cancer and to promote cancer awareness in the Latino community. Visit the site for international resources.

MALECARE

malecare.org

212-673-4920

Malecare is a leading support and advocacy organization for all men living with cancer, especially prostate cancer. Information is offered in multiple languages. Visit the site to find a support group near you.

NATIONAL LGBT CANCER NETWORK

cancer-network.org

212-675-2633

The National LGBT Cancer Network provides support to members of the LGBT community who are living with or have survived cancer and offers cancer education to the LGBT community. Visit the site to join its online support groups.

NUEVA VIDA

nueva-vida.org

Nueva Vida offers information, support and empowerment for Latino families, both cancer patients and those affected by cancer. Visit the site for services, locations and partners.

SHARSHERET

sharsheret.org

866-474-2774

Sharsheret serves Jewish women living with breast cancer or ovarian cancer or who are at increased genetic risk for breast cancer. Visit the site to find a chapter near you.

SISTERS NETWORK INC.

sistersnetworkinc.org

866-781-1808

Sisters Network offers support to breast cancer survivors, with a focus on African-American women, as well as community outreach and education. Visit the site to find a support group near you.

STUPID CANCER

stupidcancer.org

877-735-4673

Stupid Cancer offers guidance, support and empowerment to young adults (under age 40) affected by cancer. Visit the site to find online resources, meet-ups and a regional chapter near you.

Why I Went Flat

Health journalist Catherine Guthrie shares why she decided to skip reconstruction.

WHEN ASKED TO WRITE 500 words on why I went flat after breast cancer—that is, why I chose not to have reconstructive surgery after a double mastectomy—I assumed the task would take 15 minutes. I’d spun a 90,000-word yarn on the topic, to be published as a book in October. A few hundred words would be a throat clearing.

But my fingertips worried the *why* like a beach pebble in my palm. The word stirred the memory of a friend calling from London on the eve of my surgery to lament, “But why?” Those two words surged across the Atlantic and sucked sand from beneath my feet and air from my lungs. But in the eight years since, I’ve built a stalwart seawall upon which I can gut the question.

It started with the young plastic surgeon’s Brazilian accent, his eagerness to apply what he’d been taught about how to right breast cancer’s wrong.

I waited to hear the word *lumpectomy*. I remember how my feet dangled from the exam table like a child’s, the way my fingers curled around the table’s padded edge. But when the word came, he said a lumpectomy would *decimate* my breast.

At age 28, I’d had a tonsillectomy—a precise surgery to cut out diseased tissue. At age 38, faced with a cancerous lump, I’d naively envisioned something similar. A scalpel’s slice that would carve

the lump from my small breast as cleanly as my mother nicked eyes from Idaho potatoes.

But back in the sickly light of the exam room, *decimate* hung in the air, a word meant to convey total destruction. The surgeon explained that because of my body’s shape and size, my only option was a mastectomy and a reconstructive surgery that involved an implant and a back muscle.

He sketched out how he would carve apart the largest muscle in my back. With one end of the muscle connected to its blood supply, the harvested flesh would be pulled through the empty socket on my chest and placed over a silicone implant. I saw a steak laid over a tennis ball.

“But isn’t that muscle doing something?” I asked.

To which he answered, “You’ll look normal in clothes; that’s all most women want.”

My favorite yoga pose was handstand. Planting my palms on the earth, hugging my upper back muscles along my vertical axis and kicking my legs to the sky made me feel invincible in a world where everything told me the opposite. And there was nothing normal about me.

Not being a risk-taker, handstands had not come easily. Ten

years of practice is what it took to trust my body, my strength, my intuition. I was not about to throw that away for the chance to feel something I knew I wasn’t.

Breasts are beautiful, but for me, the price was too high. I loved my breasts, but I didn’t love them enough to sacrifice a back muscle on the altar of normative femininity. Eight years later, I mourn my breasts and savor my strength. ■

Catherine Guthrie



ADRIANNE MATHIOWETZ



It's estimated that around 1.6 million people in the United States will be diagnosed with cancer this year and about 40 percent of people will be diagnosed with cancer at some point in their life. Cancer Health wants to know how cancer affects you.

1 Have you ever been diagnosed with cancer?

- ☐ Yes ☐ No

2 Has anyone in your family been diagnosed with cancer?

- ☐ Yes ☐ No

3 If you have been diagnosed with cancer, what type was it? _____

4 How was your cancer discovered?

- ☐ I had a routine cancer screening.
☐ I felt an unusual lump.
☐ I had cancer-related symptoms.
☐ I went to my health care provider for something unrelated.
☐ Other (please specify): _____

5 Where are you in the diagnosis and treatment process?

- ☐ I have not yet started treatment.
☐ I am currently on treatment.
☐ I have finished treatment, and I have no evidence of cancer.
☐ I have finished treatment, but the cancer is still present or has come back.

6 What type of treatment have you received? (Check all that apply.)

- ☐ Surgery ☐ Chemotherapy
☐ Radiation therapy ☐ Targeted therapy
☐ Immunotherapy
☐ Other (please specify): _____

7 What side effects have you experienced from your treatment? (Check all that apply.)

- ☐ Anemia ☐ Change in mood
☐ Cognitive changes ☐ Constipation
☐ Diarrhea ☐ Fatigue
☐ Fertility problems ☐ Fever
☐ Hair loss ☐ Infections
☐ Loss of appetite ☐ Nausea/vomiting
☐ Pain ☐ Sleep problems
☐ Swelling (edema)
☐ Other (please specify): _____

8 Where do you get information about cancer treatment options? (Check all that apply.)

- ☐ Health care provider ☐ Family or friends
☐ Support groups ☐ Health publications
☐ Health websites ☐ Cancer websites

9 What types of support and services have you used? (Check all that apply.)

- ☐ Counseling/therapy ☐ Support groups
☐ Online forums ☐ Home health care
☐ Hospice services
☐ Financial assistance
☐ Transportation assistance
☐ Other (please specify): _____

10 What year were you born? _____

11 What is your gender?

- ☐ Male ☐ Female
☐ Transgender ☐ Other

12 What is your sexual orientation?

- ☐ Straight ☐ Gay/lesbian
☐ Bisexual ☐ Other

13 What is your ethnicity? (Check all that apply.)

- ☐ American Indian or Alaska Native
☐ Arab or Middle Eastern
☐ Asian
☐ Black or African American
☐ Hispanic or Latino
☐ Native Hawaiian or other Pacific Islander
☐ White

14 What is your ZIP code? _____

Please fill out this confidential survey at cancerhealth.com/survey or mail it to:

Smart + Strong, ATTN: Cancer Health Survey #1, 212 West 35th Street, 8th Floor, New York, NY 10001

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