

Julie: 'I have a wonderful life.' p.12

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Kidney Cancer

Expert Q&A
on Dialysis
and Kidney
Cancer p.3



WELCOME to HealthCentral's guide to **Advanced Kidney Cancer**. Here, you'll learn about noteworthy research, the latest treatments, and how to navigate the challenges of living with metastatic cancer.

For additional info, go to [HealthCentral.com/KidneyCancerGuide](https://www.healthcentral.com/kidneycancerguide).



Why Stay Fit With Cancer?

AFTER a diagnosis of advanced kidney cancer, exercise may be the furthest thing from your mind, but research is showing that fitness activities may help people who have advanced cancers. For a review published in the *Archives of Physical Medicine and Rehabilitation* (December 2018), researchers analyzed data on possible benefits of exercise in people with a variety of advanced cancers. "Exercise appears to be an effective adjunct therapy," they reported, for improving quality of life, psychosocial functioning, and sleep, as well as lessening fatigue.

Another study, published in *Current Urology* (November 2017), found that people in various kidney cancer stages who reported any physical activity were 50 percent less likely to die of their cancer than non-exercisers. According to Michael Liss, MD, the lead author and a genitourinary oncologist at UT Health in San Antonio, Texas, "The fact that any exercise at all was helpful was definitely a surprise."

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Median age at kidney cancer diagnosis.

WHEN CANCER GOES TO YOUR BRAIN

Like most cancers, kidney cancer can spread, or metastasize, to other parts of the body, often to the brain. Not long ago, a diagnosis of brain metastasis meant a poorer prognosis with kidney cancer. Now, researchers have found that survival rates for kidney cancer that has spread to the brain are significantly better than before in people who develop the metastasis after their first treatment, according to a study published in *Clinical Genitourinary Cancer* (April 2019).

Out of 268 kidney cancer patients treated at the University of Texas Southwestern Medical Center in Dallas, 56 were also diagnosed with brain metastasis. Survival rates for those with brain cancer were remarkably better than expected—and not statistically different from those whose cancer hadn't spread to the brain.



I'll Have the Fruit Plate, Please!

Many fruits and vegetables get their vivid colors from phytochemicals produced by the plants. A review in *Oxidative Medicine and Cellular Longevity* (2019) suggests that, in the future, these chemicals might become part of therapy for certain cancers.

The researchers assessed cancer-fighting properties for several phytochemicals commonly found in produce (as well as spices), such as quercetin, curcumin, capsaicin, and resveratrol, and found that these compounds did indeed have anticancer powers.

Other research has supported this idea. For example, a study published in *Oncotarget* found that consumption of fruits and vegetables had protective effects against renal cell carcinoma, or kidney cancer.

How many servings of fruits and veggies do you need to reap anticancer benefits? That we don't know yet. But a diet rich in plant-based foods is known to have other positive health effects.

Q&A

Do all kidney cancer patients have dialysis?

Absolutely not.

A lot of people with kidney cancer have one or one-and-a-half kidneys because they had an entire kidney removed (total nephrectomy) or part of a kidney (partial nephrectomy). Most people do fine with just one kidney. Dialysis is not something we talk about right away with kidney cancer.

What exactly is kidney dialysis?

Dialysis, also called hemodialysis, is a process in which a machine filters waste products from your blood. It is *not* a treatment for kidney cancer; it's a treatment for kidney *failure*—when the kidneys are no longer able to clean the blood; keep safe levels of chemicals like potassium and sodium in your body; help control blood pressure; and remove waste, salt, and water.

Under what circumstances would someone with kidney cancer need dialysis?

If you have both kidneys removed, then you'd need dialysis. This could also happen if you have one kidney removed and the other one fails, or you have one kidney removed and the cancer comes back in the other kidney.

Do kidney cancer drugs increase the likelihood you'll need dialysis?

Some of the newer medications for treating kidney cancer—such as checkpoint inhibitors, which are immunotherapy drugs, and VEGF (vascular endothelial growth factor)



inhibitors, which are a type of targeted therapy—can harm your kidney function.

Checkpoint inhibitors stimulate the immune system to attack the cancer, but on occasion the immune system also attacks organs, including the kidneys. VEGF inhibitors can irritate the lining of the kidneys' blood vessels.

Sometimes, if you stop taking those medications, kidney function will level off. But in rare instances, dialysis might be needed.

These are tough cases because these medications can be effective cancer treatments but they're relatively new, so we're just learning how to handle these situations.

What are the pros and cons of dialysis for someone with kidney cancer, even in the situations you mentioned?

There are several, especially on the con side. If you have metastatic kidney cancer and cancer treatments aren't working, you may get sick or weaker after starting dialysis. If your kidney cancer was removed but

you develop kidney failure, you may do just fine on dialysis. With every patient, we weigh the benefits and risks of dialysis—but the pros and cons are very patient-specific.

Can having dialysis for kidney failure raise your risk of developing kidney cancer?

Some studies have suggested that people on long-term dialysis for kidney failure, which is caused mainly by diabetes and high blood pressure, may be at increased risk for kidney cancer.

But it's not dialysis that raises the risk: It occurs because the kidneys have gone so long without working. Why cancer risk increases as a result isn't clear, but it shouldn't affect the decision of whether or not to use dialysis. ■



JAMES SIMON, MD, is a staff nephrologist at the Cleveland Clinic's Glickman Urological & Kidney Institute in Cleveland, Ohio.



Kidney Cancer Essentials

Better therapies have more than doubled survival rates for some metastatic kidney cancers.

Kidney cancer is among the 10 most common cancers in the United States. While there are several types, **renal cell carcinoma** (RCC) is the most common, accounting for up to 90 percent of kidney cancers, according to the Urology Care Foundation. Subtypes include clear cell (80 percent of all RCC), papillary, chromophobe, and collecting duct.

Another type of kidney cancer, accounting for 10 to 15 percent of cases, is **urothelial carcinoma**, or transitional cell carcinoma. Other

kidney cancer types include sarcoma (rare), Wilms tumor (mostly diagnosed in children), and lymphoma.

RCC begins in the lining of the tiny tubes of the kidney. In its early stages, the cancer is confined to the kidney and surrounding tissues. When the cancer spreads, or metastasizes, beyond the kidney and nearby tissue, it is considered to be advanced, or stage IV; about 25 percent of people with kidney cancer are diagnosed at this stage. Common sites for it to spread to are the lungs, bones, and lymph

nodes. But even after kidney cancer has metastasized, there is a lot that doctors can do in order to control symptoms and slow the spread of the disease.

Exams, Labs, and Images

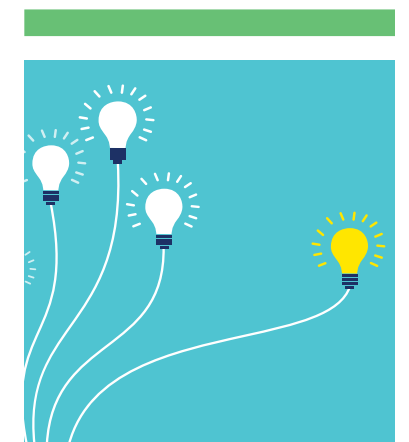
It used to be that abdominal pain or swelling, blood in the urine, or unexplained weight loss were the symptoms that brought people to the doctor when advanced kidney cancer was ultimately diagnosed. More recently, this cancer is often diagnosed when you're having imaging tests

for other reasons—an X-ray for a heart workup, say, or a sports injury. This is a good thing, explains Mollie deShazo, MD, associate professor of hematology and oncology and scientist at the O'Neal Comprehensive Cancer Center at the University of Alabama at Birmingham. "The prognosis is better if the cancer is found incidentally, before symptoms are obvious," she says.

No matter what your reason for making an appointment, if your doctor suspects you have kidney cancer, they will examine you, do a variety of tests, and take a detailed personal and family health history. They will feel for any masses (possible tumors), and you'll be asked to give blood and urine samples. A urine test may show if there are small amounts of blood in your urine that you were unable to see, while a blood count may show if you are anemic, among other possible indicators of kidney cancer.

Imaging tests also help diagnose kidney cancer. Computed tomography (CT) scans not only identify tumors in the kidney, but also can provide detailed information about the size, shape, and precise location of the tumors. Ultrasound is also useful in locating kidney tumors. Magnetic resonance imaging (MRI) is ordered if your doctor suspects your cancer has grown into your abdominal blood vessels. You may have a scan to see if the cancer has spread to your bones and a chest X-ray to see if it appears in your lungs. An MRI or CT scan could reveal whether the cancer has metastasized to your brain.

These tests help your doctor determine how advanced your cancer is—a process called "staging" the cancer (see the sidebar on page 9). Staging helps your team determine the best treatment. It can also predict how you may respond to certain treatments. The higher and more complex the stage, the more aggressive your treatment is likely to be. Sometimes staging can also



DOS & DON'TS

A diagnosis of advanced kidney cancer can be overwhelming—and it may leave you feeling helpless. But there is much you can do to improve your odds of responding well to treatment.

- **Be informed.** Learn all you can about your illness, because you're an invaluable part of your healthcare team. And don't be afraid to ask for explanations when you don't understand something.

- **Don't miss appointments, and do follow your doctor's advice to the letter.** If you have doubts or disagreements about your treatment, let your doctor know. But don't make key decisions about your care without conferring with your family and expert team.

- **Tell your team about other health problems.** They may seem unimportant compared to kidney cancer, but recovering from one disease requires managing all of your conditions together.

- **Keep your team informed of medication side effects or new symptoms.**

- **Reach out for emotional support.** It's normal to be depressed or anxious when you have a serious illness. Counseling won't cure your cancer, but it can help you live more comfortably with it.

(Continued on page 9)

(Continued from page 5)

be used to predict how long you may live. But survival predictions are imperfect because each person is unique and new treatments are quickly changing outcomes.

What happens next depends on the stage of your cancer. If you are diagnosed with advanced kidney cancer, your doctor will need more information to determine the best treatment for you. A complete blood count (CBC) will show your hemoglobin and neutrophil levels and your platelet count, which could indicate anemia or risk of infection or bleeding. Your doctor will also check for calcium in your blood, another possible indicator of cancer. And you'll be asked how active you are, which activities you're able to do, and which are difficult for you.

"Based on this information," says Dr. deShazo, "we'll assign a prognostic score." This is essentially a prediction that helps your doctor determine which treatment might be best for you. "Even with advanced kidney cancer, a small percentage of patients won't need any treatment right away," she says. "We just watch very carefully. This is called active observance. However, most people will get treated up front."

Treatment Combo Approach

Several newer therapies are now being used to treat advanced, or stage IV, kidney cancer.

Until about a decade ago, there were few effective treatments for metastatic kidney cancer. But since 2005, advances in immunotherapy and targeted therapies have changed the face of kidney cancer treatment.

"When the cancer has spread, we use systemic therapy. We call it this because we don't use traditional chemotherapy very often in kidney cancer. Chemo has not been effective in this type of cancer. Instead, we use targeted therapy or immunotherapy," says urologic oncologist John L. Gore, MD, a professor of urology at the University



STAGING & GRADING KIDNEY CANCER

- **STAGE I:** The tumor is small, no greater than 7 centimeters (cm)—about the size of a small peach—and is confined to the kidney.
- **STAGE II:** The tumor has grown to be larger than 7 cm across, but is still confined to the kidney.
- **STAGE III:** The tumor has moved beyond the kidney, but only to nearby tissues, such as lymph nodes or a major vein. This is sometimes called locally advanced cancer.
- **STAGE IV:** The tumor has spread to other organs outside the kidney, such as lymph nodes, bones, or lungs. This is called advanced, or metastatic, cancer.

Another part of staging is a system called TNM: T relates to a tumor's size and spread. N categorizes the degree of spread to nearby lymph nodes. M indicates whether the kidney cancer has metastasized. Within the TNM system are further, numerical, breakdowns, which you can see in detail on the American Cancer Society's website ([cancer.org/cancer/kidney-cancer/detection-diagnosis-staging/staging](https://www.cancer.org/cancer/kidney-cancer/detection-diagnosis-staging/staging)). So a mass classified as T1 (7 cm or smaller), N0 (not in lymph nodes), and M0 (no metastasis) would be stage I.



IMMUNE SYSTEM CONFUSION

UNLIKE CHEMOTHERAPY, which attempts to poison a cancer without doing too much harm to the person, immunotherapy enlists the immune system to kill cancer cells. While this is generally a gentler form of treatment, it can still have serious side effects. “Most people do wonderfully,” says Dr. deShazo, “but sometimes the immune system gets confused and attacks its own tissues.” You may get what doctors call the “itises”: arthritis, colitis, thyroiditis, or pneumonitis, which can be life-threatening. If this happens, you will be given steroid treatments, and immunotherapy will be stopped. You could still get a targeted therapy, however.

the cancer. The drug itself doesn’t attack the cancer; it just makes it possible for your immune system to do the work.

Immunotherapies used for kidney cancer include:

- **Avelumab (Bavencio)**
- **Ipilimumab (Yervoy)**
- **Nivolumab (Opdivo)**
- **Pembrolizumab (Keytruda)**

Cytokines, which boost the immune system generally, are sometimes still used, though not often. They include high-dose interleukin-2 (IL-2) and interferon-alfa. Interferon is sometimes still used in combination with bevacizumab (Avastin). Which drug or combination of drugs you’re given will depend on your prognostic score, says Dr. deShazo. The higher the score, the worse the prognosis.

While single systemic therapies are often effective, sometimes a combination is the most effective way to treat advanced kidney cancer. The targeted therapy denies the tumor the nutrients it needs to thrive, while the immunotherapy helps the immune system tackle the cancer cells.

“If you have risk factors such as high calcium in your blood or anemia, you start with the combo drugs,” Dr. deShazo explains. “For patients with a good (lower) prognostic score, I’ll flip it around, and may start with a single drug, such as pazopanib (Votrient), and go to the combo later. We can even use a new combination regimen with pembrolizumab (Keytruda) and axitinib (Inlyta) for good-prognosis patients now, so we have many options.”

Surgery: Not So Much

In most cases, doctors no longer remove tumors in people with advanced kidney cancer.

“If a patient has metastatic cancer, it’s best to concentrate on the cancer cells throughout the body and leave the original tumor in place,” says Dr. Gore. “It used to be that if we took out the main kidney tumor, patients would do better. But that was in the setting of less effective systemic therapies. As systemic treatments improve, there isn’t as much benefit to removing the kidney. Some patients will do better, but for most, it’s no longer a good idea to do the surgery as the first treatment. We prioritize starting systemic therapy, then consider surgery down the road.”

Once your treatment is done, your doctor will continue to follow you. How often will depend on your cancer stage and treatment. Thanks to treatment advances, your odds of longer survival are much greater now than they would have been just a few years ago.

“Not long ago, survival time with stage IV kidney cancer was about one year. Now, with targeted therapy, the mean survival rate is two-plus years,” says Dr. deShazo. And it might be even better with immunotherapy. “People [who have had this treatment] are still alive, and we don’t yet know how long they’ll live.”

Today’s therapies give people with advanced kidney cancer much reason for optimism. ■

For more info, go to [HealthCentral.com/KidneyCancerGuide](https://www.healthcentral.com/kidneycancerguide).

KNOW YOUR SCANS

■ **CT (computed tomography):** Uses X-rays to create a detailed cross-sectional image of the body.

■ **MRI (magnetic resonance imaging):** Uses a powerful magnetic field and rapid bursts of radio waves to scan the body.

■ **BONE SCAN:** Uses a small amount of radioactive material to highlight abnormal areas in the skeleton.

■ **ULTRASOUND:** Uses sound waves to create an image of an area of the body.

of Washington School of Medicine in Seattle. Targeted therapy basically starves the cancer. “Targeted therapy interferes with the cancer’s ability to grow new blood cells,” explains Dr. Gore. Targeted therapies for advanced kidney cancer include:

- **Axitinib (Inlyta)**
- **Bevacizumab (Avastin)**
- **Cabozantinib (Cabometyx)**
- **Everolimus (Afinitor)**
- **Lenvatinib (Lenvima)**
- **Pazopanib (Votrient)**
- **Sorafenib (Nexavar)**
- **Sunitinib (Sutent)**
- **Temsirolimus (Torisel)**

FROM TOP: GETTY IMAGES; ISTOCK

LIVE
BOLD
LIVE
NOW
STORIES THAT
INSPIRE



Julie (right) getting her PhD from Carine Feyten, president of Texas Woman's University.

One Day at a Time

A physical therapist in Texas was beyond shocked to learn she had advanced kidney cancer, but she says she's now living a wonderful life.

Julie Shill, 53, was diagnosed with stage IV clear cell renal cell carcinoma in December 2017. The Plano, Texas, physical therapist is being treated at the University of Texas Southwestern Medical Center in Dallas.

How did you first learn that you had kidney cancer?

In the fall of 2017, I was having night sweats and my blood pressure was a little high, like 142/91. I thought it was menopause, and my OB-GYN agreed. I went to an urgent care clinic, and they did blood and urine tests and said everything looked fine. But since I was still having symptoms, I decided to see my internist. She ordered a chest X-ray for tuberculosis. They discovered I had spots on my lungs, so I had a CT (computed tomography) scan, which showed a grapefruit-size tumor on my kidney that extended up through my inferior vena cava, a large vein that moves blood to the heart. I also had tumors in my lungs and some bones.

Were you in disbelief?

It was just shocking. It was hard to believe not only that I had kidney cancer, but that it was already stage IV and had spread throughout my body. I had

been a very active person, and I was in good shape. I'm a physical therapist and have worked in pediatrics and home healthcare, so it was very different for me to be the patient rather than the therapist.

You didn't have surgery right away. Can you tell us why?

I saw a urologist and an oncologist in Plano, and they were going to try to do the surgery the following week. But then a friend suggested I go to the University of Texas Southwestern (UTSW) for a second opinion, because they have an excellent kidney cancer clinic. I met with a urologist/oncologist there who specialized in renal cell carcinoma (RCC). It was the best decision I could have made.

The UTSW specialist told me that before I could have my kidney removed, I would need to meet with a cardiovascular surgeon and a liver specialist because surgery would require three doctors working as a team.

Because my cancer had invaded my inferior vena cava and blocked blood flow to my heart, the cardiovascular surgeon removed that section of the tumor. The liver surgeon removed part of my liver since my tumor was pressed against it. Then the urologist removed my kidney and the primary tumor. My surgery was complicated but went very well.

After that, things got more complicated, didn't they?

Yes, they did. I had started to limp a little bit on one leg and thought it was just sore or that I had pulled a muscle. But the doctor realized that I had a growing tumor in the top of my femur. An orthopedic surgeon told me that my femur was going to break any day, so three weeks after my first surgery, I had a hip replacement.

What came next? Did you have additional treatment after surgery?

I had radiation for my hip, three vertebrae, and my other femur.



Julie and her husband, Curt, enjoy a night out at a ball game.



Urologist Aditya Bagrodia, MD, oversaw Julie's complex surgery.



Oncologist Kevin Courtney, MD, was a key part of Julie's UTSW care team.

Immunotherapy got rid of a tumor in my liver and a few in my lungs, and shrank all of my other lung tumors.

While I was on immunotherapy, the cancer spread to my brain, and gamma knife radiation got rid of all seven of my brain tumors. It was like a miracle!

I now take a drug that targets a protein on the tumors. It's working well for me. My tumors are all stable. I will continue taking it until it stops working. Luckily for me, there are many more treatments available to choose from.

Have you had difficulty with side effects?

The biggest problem I have now is nerve damage in my legs. I have foot drop, because the nerves that tell my feet to lift up are damaged, so I have braces for that. I can use a walker in the house. Other than that, I'm in a power wheelchair. Because of my nerve damage, I'm unable to drive. Losing my independence has been the most devastating "side effect."

How do you feel now?

I feel pretty good, and everyone tells me I look great. Kidney cancer patients don't necessarily look sick. Because we don't get chemotherapy,

COURTESY OF JULIE SHILL

COURTESY OF JULIE SHILL (3)



Julie celebrated her son Ryan's wedding to Melissalyn Zentner with Curt, her daughter, Christie, and her new grandson, Melissalyn's son, Oliver.

we don't lose our hair. But my life is completely different now. I had to stop working, and that was hard. I left work for a few medical tests and basically never went back except to take down my physical therapist license and collect the things in my desk.

You have a great support network. Tell us about that.

I have a pain doctor who helps me manage the nerve pain in my legs, and my palliative care doctor helps me with every side effect, from nausea to depression.

Counseling has been invaluable. My UTSW counselor told me about cancersupportcommunity.org, and I go to a group every week at Texas Health Presbyterian Hospital in Plano. It's so helpful to talk to others who are going through what I am. They're helping me figure out how to live a productive life with cancer.

I also joined the Facebook group for the Kidney Cancer Research Alliance (KCCure; kccure.org). KCCure is a wonderful organization that's devoted to supporting patients and raising money to help researchers find a cure. Their renal cell carcinoma support group has thousands of members, and people share what

helps them deal with side effects and provide encouragement and support.

My adult daughter moved back home to help out, and I have friends who help, too. My husband, Curt, does so much for me, but he's still working so he's not around during the day.

I've learned that when someone asks, "How can I help?" they mean it. But you may be surprised that some people you thought you were close to don't know how to handle your cancer news. Others you didn't feel as close to suddenly step up and are there for you. I have one friend who takes me to my support group every week. Others take me to doctor and physical therapy appointments. I've learned that it's possible to find joy in my life, even as I fight this hideous disease.

You've accomplished a lot since your diagnosis. How did you manage that?

I'm getting fantastic care at UTSW, and I'm happy to be alive. The first oncologist I met with thought I had

JULIE'S BEST ADVICE

■ **Take It One Day at a Time.** Being hit with the news that you have stage IV cancer and hearing that you're having surgery and will be taking medicine for the rest of your life can almost paralyze you. But as someone said to me early on, you don't have to do it all at once. Just do the next thing. Don't look at the whole terrifying picture. Get through the next day. One day, one appointment, one surgery, one treatment at a time. You'll find you can eventually look out a little further.

■ **Definitely Get a Second Opinion.** You'll feel more confident with what you're doing. Choosing your medical team is the most important decision you'll make, and you make it when you're still in shock from the diagnosis and don't even know what questions to ask. But the more info you have, the better.

■ **Consider Counseling.** Whether it's in a group or individually, therapy can help you put your diagnosis in context and assist you with next steps.

six months to live, but it's already been two years. I finished my PhD in that time. I was here to see my son get married—and to become a grandmother!

I like to write, and I started a blog called *Julie's Not Dying Today* (juliesnotdyingtoday.com). Writing has helped me process all of this. I used to feel like cancer robbed me, but I no longer think I'm missing out. I have a wonderful life. My time on earth may be limited, but it's not stopping me from living my dreams. ■



For additional info, visit HealthCentral.com/KidneyCancerGuide.

1 Lean on Your Friends. How connected you are to family and friends during and after cancer treatment is a key predictor of mental and physical health. “Social support, particularly emotional support, is one of the most effective coping strategies when you’re diagnosed with cancer,” according to Kathrin Milbury, PhD, a cancer researcher at the University of Texas MD Anderson Cancer Center in Houston. “Knowing you are not alone is a profound human need, especially when you’re faced with a major health crisis. When a loved one says, ‘we are in this together,’ and really means it, it gives people courage and hope.”



 For more info, see [HealthCentral.com/KidneyCancerGuide](https://www.healthcentral.com/kidneycancerguide).

4 Kidney Cancer To-Dos



2 Get a Second Opinion. You need as much information as possible to help in your decision-making, and a second opinion can help you feel more certain about your diagnosis and treatment. Concerned that your oncologist might be offended? Don’t worry about it, advises Rick Wirtz, PsyD,

of Chester River Behavioral Health and Wellness in Chestertown, Maryland, who specializes in the psychosocial care of cancer patients and their families. “Your job is not to take care of your doctor’s feelings; it’s to get the information you need to make the very best decisions for your health. Your physician should prefer the best outcome for you.”

3 Let Your Oncologist Know Who You Are. Each person with kidney cancer has their own life story, responsibilities, and goals. To help you choose treatment that’s right for you, tell your doc about yourself and your life. Have you always been in great shape and love to work out? Do you have other medical conditions that

require ongoing treatment? The better your doctor knows you, the more likely you’ll be able to work together on a plan that’s a good match for your needs.

4 Try Not to Panic. If you’re one of the 44,000 men and 29,000 women diagnosed with advanced kidney cancer each year in the U.S., it’s understandable to feel afraid. But immunotherapy, targeted therapy, vaccines, and combination treatments have been game-changers for many people diagnosed at later stages. Not only are survival rates rising, there are many clinical trials under way ([clinicaltrials.gov](https://www.clinicaltrials.gov)), and there’s much optimism in the oncology world. Ask your doctor how you can take advantage of these breakthroughs.

MEDICAL REVIEWER: **Michael Hunter, MD**, radiation oncologist and medical director, EvergreenHealth Cancer Care, Kirkland, WA. HEALTHCENTRAL GUIDE MEDICAL EXPERTS: **Mollie deShazo, MD**, associate professor of hematology and oncology and scientist, O’Neal Comprehensive Cancer Center, University of Alabama at Birmingham; **John L. Gore, MD**, professor of urology, University of Washington School of Medicine, Seattle; **Michael Liss, MD**, genitourinary oncologist, Mays Cancer Center, UT Health, San Antonio, TX; **Kathrin Milbury, PhD**, cancer researcher, University of Texas MD Anderson Cancer Center, Houston; **James Simon, MD**, staff nephrologist, Glickman Urological & Kidney Institute, Cleveland Clinic, Cleveland, OH; **Rick Wirtz, PsyD**, Chester River Behavioral Health and Wellness, Chestertown, MD.

REMEDY HEALTH MEDIA: **Rose Pike**, executive vice president, editorial; **Rosemary Black, Stacey Colino, Tracy Davenport, Beth Howard**, writers; **Patricia Volin**, fact-checker; **Hallie Einhorn**, copy editor; **Douglas+Voss**, designers.

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