FINDINGS

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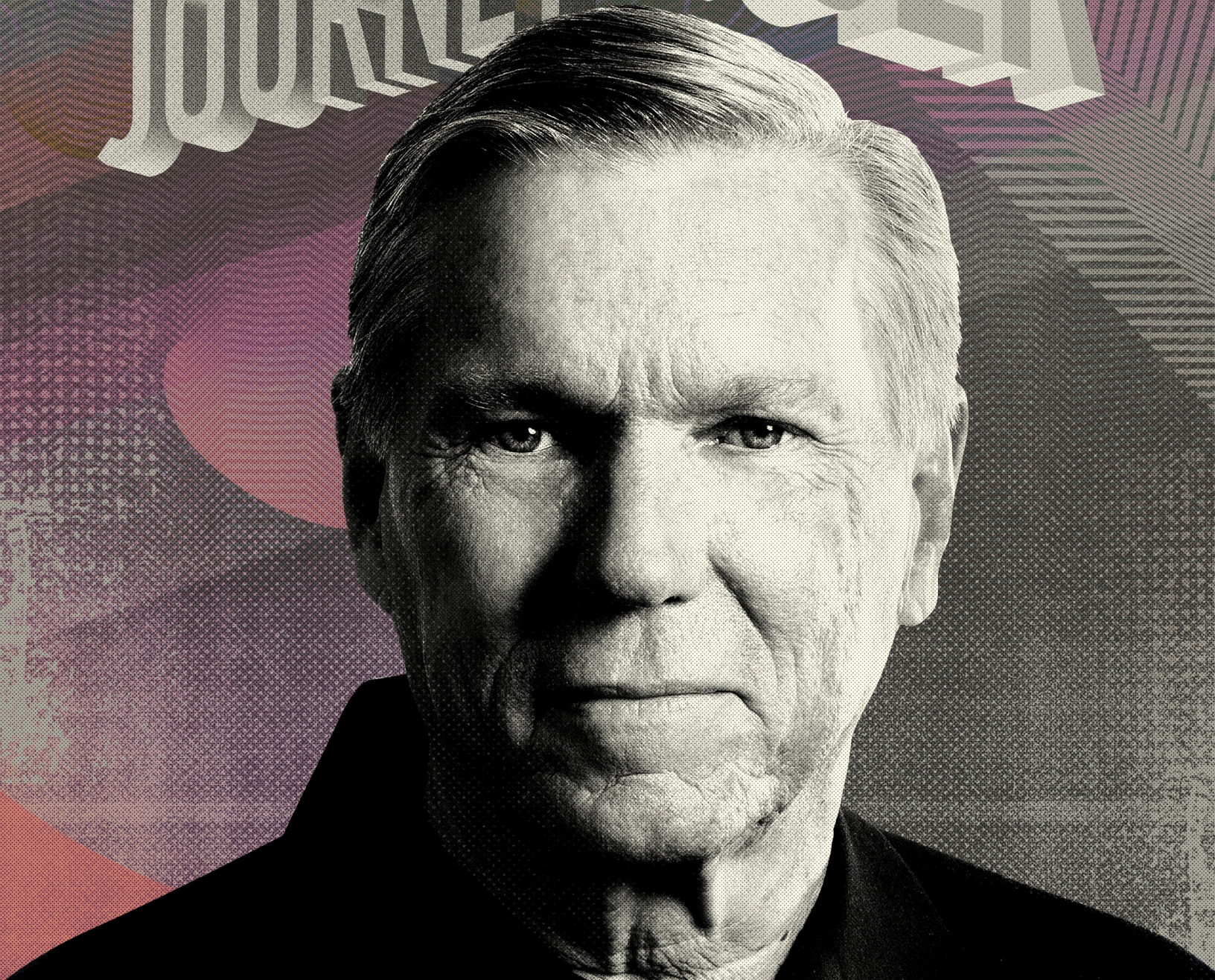
MY CANCER JOURNEY



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You helped make him possible

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MY CANCER JOURNEY

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He'd never heard of sarcoidosis. Then the rare disease struck David Key, stealing his health and replacing it with suffering and disability.

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Chartered in 1946, OMRF is an independent, nonprofit biomedical research institute dedicated to understanding and developing more effective treatments for human disease. Its scientists focus on such critical research areas as cancer, diseases of aging, lupus and cardiovascular disease.

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ON THE COVER: Steve Prescott. Illustration: Sean McCabe. Photo: Brett Deering.

A Breath of Fresh Air

Using 3D models to tackle respiratory illness

Respiratory syncytial virus is the leading cause of pneumonia worldwide. It takes a particularly heavy toll on children, infecting more than half in the first year of life and nearly 100 percent by age 2.

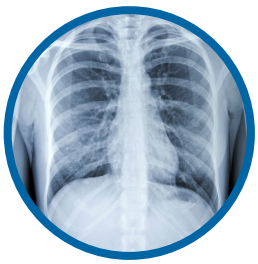
"RSV causes more frequent and more severe infections in infants, compared to adults, and it can be very serious in children, even requiring hospitalization in some cases," says Dr. Susan Kovats, who studies the virus in her lab at OMRF. "It's thought that the neonatal immune system is not very strong, so a lot of babies can be especially susceptible to RSV."

The virus is highly contagious and can run rampant through daycares and schools. While most children experience only cold-like symptoms, for those with weakened immune systems or conditions like asthma, the virus can be dangerous and even deadly.

Working with colleagues at Oklahoma State University and the University of Oklahoma Health Sciences Center, Kovats has been investigating why the disease strikes children more frequently than adults—and why it can hit some kids so hard.

To do so, the researchers are using a novel three-dimensional model developed by Dr. Heather Fahlenkamp, an OSU bioengineer. It's made up of human tissue, and it's designed to mimic how our lungs work.

"It's almost as if we have a functional artificial lung," says Kovats. "We can put all the correct cells of the human lung into a dish in the exact right organization. Then we can test how the cells respond to pathogens in something that functions like a real lung."



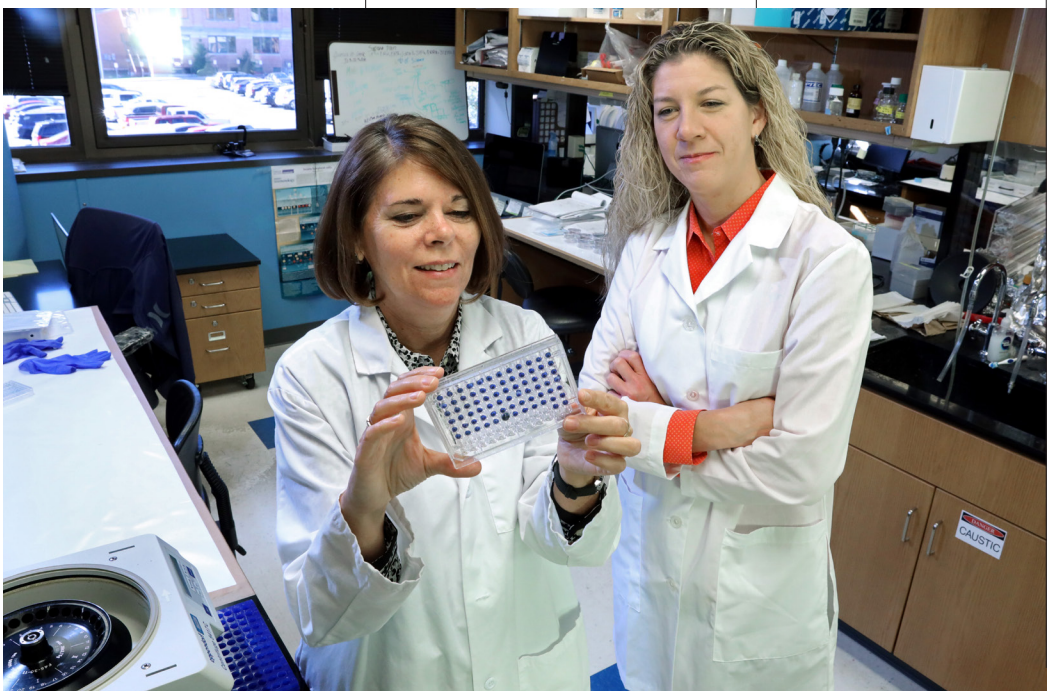
OMRF scientist Dr. Susan Kovats (left) and OSU bioengineer Dr. Heather Fahlenkamp have developed a 3D model to study RSV, a severe illness in infants.

By introducing immune cells from both infants and adults into the lung model, the scientists can study what differences occur at the point of infection. And they can do so without exposing human subjects to the virus.

In addition to its safety advantages, says Kovats, the 3D model is actually a better research tool than working with human subjects. "People show up sick, and doctors have no way to know when they were first infected. This gives us a lot more control to learn exactly what goes wrong and how to go about fixing it."

The researchers hope to reveal what predisposes infants to severe RSV infection and, ideally, to create a launching pad for potential therapies down the line. The "lung in a Petri dish" approach could also prove valuable for the study of other lung infections.

"RSV is where we are starting," says Kovats, "but this model also could be used to study the flu, allergies and other lung problems in ways we've never been able to before."



Arthritis Anxiety

Dear Dr. Prescott,
Over the past 10 years, arthritis has affected every joint in my body. I've seen my regular doctor, a rheumatologist and even other specialists. The diagnosis is always the same, and it almost seems they expect it to happen as we get older. Why is there not more research on this debilitating condition that affects the vast majority of people as they age?

Bob Coleman, Granbury, TX

Illustration: Matt Chinworth

Ask Dr. P

I can understand your frustration.

Arthritis is probably the most common disease among older adults. The Arthritis Foundation reports that almost half of people over the age of 65 have been diagnosed with arthritis. There are more than 100 forms of the disease, with the most prevalent being osteoarthritis, which results, at least in part, from the accumulated wear and tear on our joints. It sounds like that might be what's afflicting you.

From a patient's perspective, there can never be enough research. And scientists agree. Still, when it comes to arthritis, more research is occurring than you may know.

An entire portion of the National Institutes of Health—the National Institute of Musculoskeletal and Skin Diseases—is devoted to researching the causes, treatment and prevention of arthritis and related conditions. Each year, that federal institute spends more than $500 million toward that goal.

The vast majority of those funds go directly to research on arthritis. While those projects haven't yet found a cure, they certainly have yielded interesting insights that can help people with osteoarthritis.

First off, research indicates that one of the most important contributing factors to the disease may be fat. Extra pounds increase stress on joints, and OMRF's Dr. Tim Griffin has also found the fat molecules themselves may also cause osteoarthritis. The good news here is that even moderate weight loss of 10 pounds or so can significantly reduce the pain and disability associated with arthritis.

Research indicates that one of the most important contributing factors to the disease may be fat. Extra pounds increase stress on joints.

A multitude of studies have tied arthritis to inflammation. One way to try to reduce inflammation is to minimize or avoid foods believed to cause it, like sugar, saturated fats, alcohol and refined carbohydrates. Indeed, at OMRF, Griffin recently found that in laboratory mice, diets high in carbs or refined sugar—even if they didn't produce weight gain—increased the animals' rates of osteoarthritis.

Finally, research has shown it's important to stay active. You may have to shift from activities that are heavy on pounding (jogging, aerobics) to things that go easier on your joints (swimming, biking). Strength training is also key, because weak muscles can't support compromised joints.

Obviously, nothing here is a silver bullet. But you might try some of these approaches. In the meantime, we're going to keep working on finding new ones!

Saying Good-Bye to a Pioneer

Dr. Morris Reichlin developed a watershed test for lupus and reshaped research at OMRF

Autoimmune disease research was in its infancy in 1981. That was the year Dr. Morris "Moe" Reichlin packed his lab at the State University of New York at Buffalo to start a new scientific program at OMRF.

A rheumatologist, Reichlin gained prominence when he discovered antibodies associated with lupus, one of more than 80 diseases that cause the body's immune system to attack itself. The test he then created—the Reichlin profile—provided physicians with an important tool to assist them in diagnosing lupus and other autoimmune diseases. Its development marked a milestone in diagnostic medicine.

At OMRF, Reichlin built the foundation into a leading center for researching and treating lupus and other autoimmune illnesses. OMRF scientists have since played a role in identifying 65 of the 101 genes known to play a role in lupus. Thousands of patients have received treatment in OMRF's clinics to help them manage their conditions. The program Reichlin created now employs more than 150 staff members, and its clinical focus has expanded to include treatment for multiple sclerosis and rheumatoid arthritis.

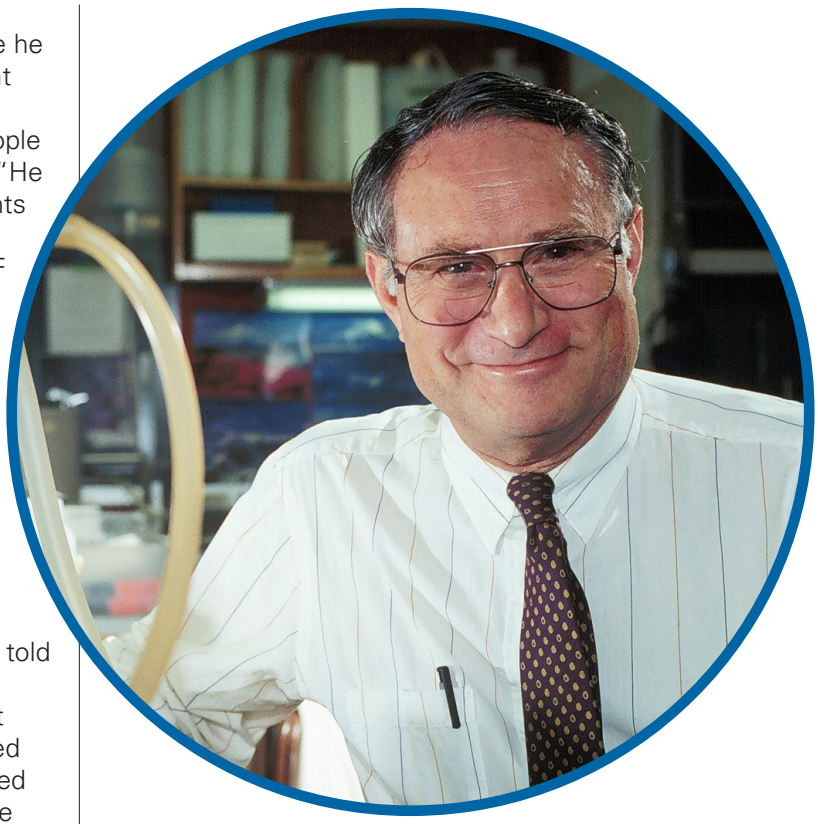
Throughout his 28 years at OMRF, where he became vice president of research, Reichlin continued to treat people suffering from lupus. "He cared about his patients as much as he cared for them," says OMRF Vice President of Clinical Affairs Dr. Judith James.

Indeed, it was the needs of the people suffering from lupus that guided Reichlin's scientific inquiries. "If it meant something to the patient, then it meant something to me," he told *The Rheumatologist*.

Upon his retirement in 2009, he was named an OMRF Distinguished Career Scientist. In the years that followed, he remained engaged and interested in science as long as he was able.

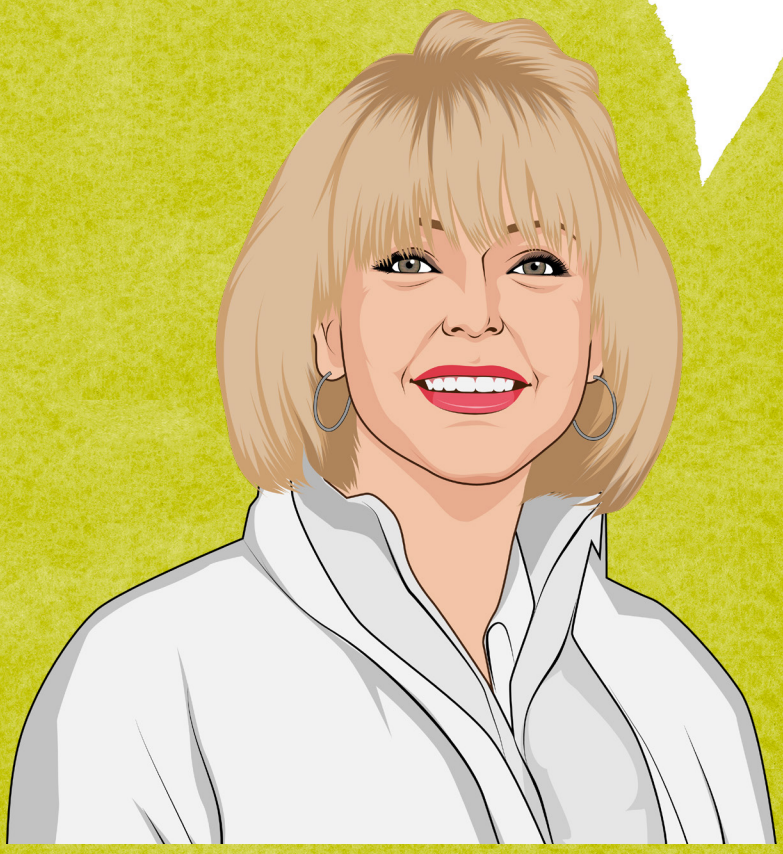
This past summer, Reichlin passed away at the age of 84. He is survived by his wife, Marianne, two children and a grandchild. His legacy includes nearly 500 scientific papers and more than 100 scientific and clinical trainees, a group that includes James.

"He was a master clinician, mentor and scientist," says James. "Many of us wouldn't be rheumatologists today without Dr. Reichlin's influence and the example he set for us all."



> "If it meant something to the patient, then it meant something to me."

When my husband suffered a fatal heart attack, one of his friends gave a donation in his memory. I looked up OMRF's website and appreciated knowing you're doing heart disease research. Bob would have appreciated it, too.



Debbie Craine

An interior designer in Tulsa, Craine has continued to donate to OMRF since her husband's death in 2014.

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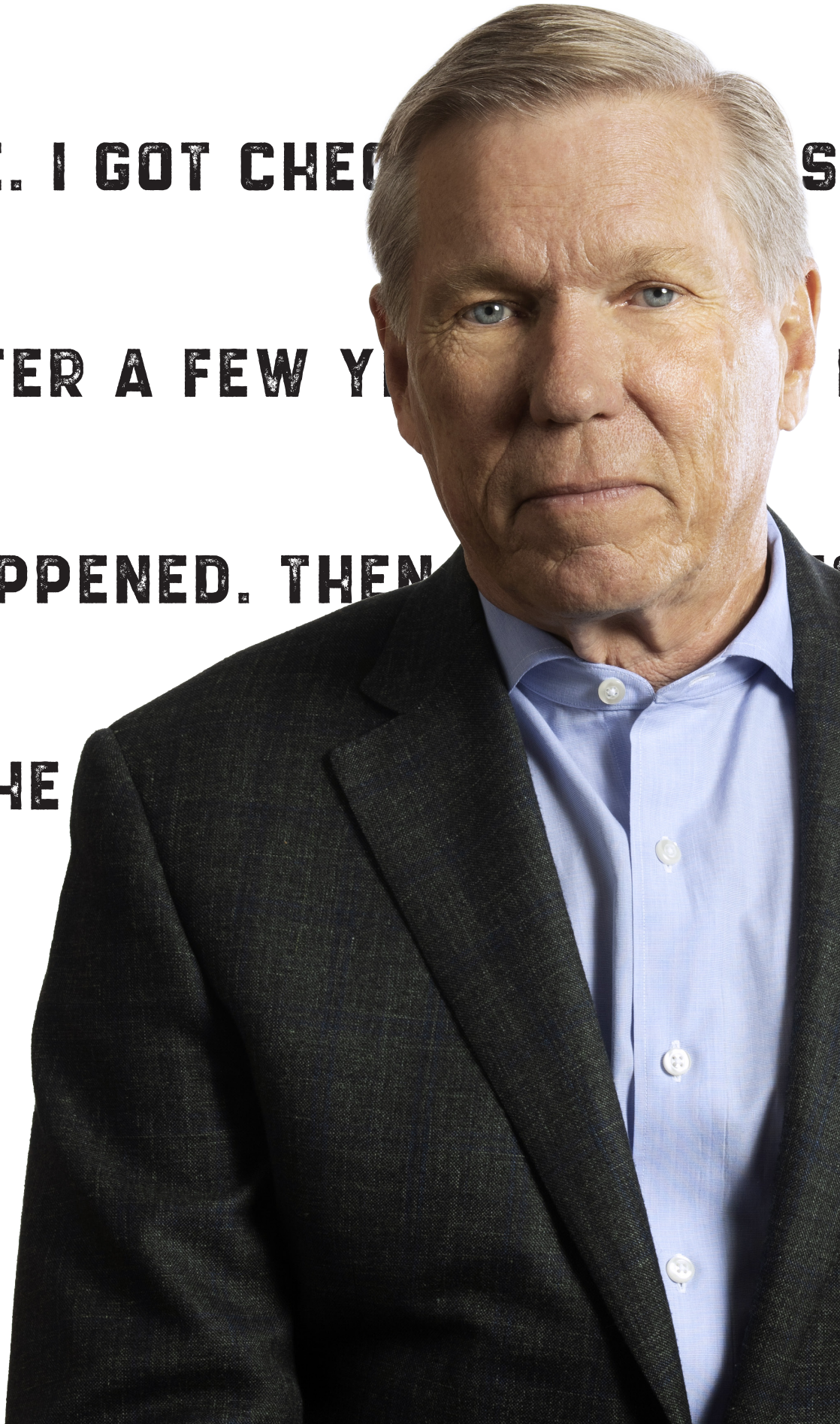

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REAL JOURNEY.

BY STEVE

PRESCOTT

Photo: Brett Deering

I DIDN'T EXPECT TO BE HERE TO WRITE THIS COLUMN.

WHEN I SAY "HERE," I DON'T MEAN OMRF OR OKLAHOMA. I MEAN HERE, AS IN, ON THIS EARTH.

You see, I've been diagnosed with cancer. Twice.

The first time was no big deal. I know it sounds like I'm being a tough guy, but that's not the case. I'm just being honest.

As a physician and someone who's spent decades of my life researching cancer, I like to think I have a pretty good handle on the disease. So, when my doctor told me in 2011 that I had prostate cancer, I didn't freak out. I knew it was completely curable.

Prostate cancer is a very common form of the disease—even more so if you have a family history, which I do. My dad was diagnosed two decades ago and received treatment. He's still alive today at the age of 97.

Of course, no one chooses to get cancer. Still, among all the possible forms of the disease, prostate cancer would be at the top of my list. Yes, you have to be treated. But the outcome is almost always positive. More than 90 percent of cases are completely cured.

I didn't tell anyone at work about my diagnosis. I barely spoke about it to anyone else, either. My wife, Susan, was puzzled by this, but I thought it best not to cause worry where it wasn't warranted.

For me, this approach made perfect sense. I'd processed the risk—minimal, I thought—and just moved on to picking a treatment. After talking to my doctor and mulling over my options, I opted for radiation.

The procedure I picked is called brachytherapy. A urologist and radiation oncologist implant radioactive "seeds" in your prostate. The idea is that over time, the radiation generated by the seeds wipes out your cancer.

It was an outpatient procedure, and I was under anesthesia for an hour or two. By that afternoon, I was up and walking around. In the ensuing weeks, I didn't experience any complications. Months passed, and my PSA level (a measure of prostate health; the lower, the better) dropped basically to zero.

I thought I was cured. So, I went back to the business of living my life. I got check-ups occasionally, and everything seemed fine. After a few years, it was pretty much as if none of this had ever happened.

That all changed in the summer of 2017.

If nothing else, my experience with cancer has shown me what a roller coaster this disease is. Up one moment, down the next. A jarring turn here, a rapid acceleration there. You think the ride's over, and right then, it hits you with a stomach-churning drop. The only thing you know is that you never know what's coming around the next bend.

During a business trip, I noticed that lymph nodes in my groin were swollen. When I returned home, I made an appointment with my urologist. He measured my PSA level, and I was relieved to learn it was still zero. When he did a CT scan, the only things it showed were those inflamed lymph nodes, along with a slightly enlarged one in my chest. Everything else was fine.

Lymph nodes serve as a sentinel system for the body. They filter out "bad" cells; when they're swollen, they're telling you that something in your body isn't right. Usually, it requires more detective work to discover the exact nature of the underlying problem.

With my history of cancer, I immediately suspected some sort of recurrence. Specifically, I worried the prostate cancer had come back, only this time I worried it had metastasized—spread—to my colon. The very

thought filled me with dread, and with shame.

I'd studied colon cancer in the lab. I knew how important it was to get regular colonoscopies after turning 50. I'd had one, but I was overdue for another. I grew obsessed with the possibility that I'd waited too long.

I guess there's a reason folks say that doctors make the worst sort of patients.

Still, when I had a colonoscopy, the results came back as normal. No cancer.

I then visited an oncologist, fully prepared for her to tell me I had metastatic prostate cancer (even though this would have been unusual given my low PSA). Much to my surprise, she didn't. Instead, she told me that a biopsy of my lymph nodes had revealed a cancer that looked like a form of the disease known as squamous cell carcinoma.

A few weeks later, further testing revealed the origin of the cancer. It stemmed from a tumor growing in my urinary tract, just outside the bladder.

The site of the tumor wasn't surprising: It was precisely where the radiation seeds had been most concentrated. That radiation had killed the prostate cancer. But, presumably, it had caused other cells to mutate—and induced this new variant.

What was so curious was the nature of this new cancer. It did not look at all like a typical male urological cancer. Instead, it had the characteristics of tumors that start elsewhere.

The cancer was anaplastic, which meant it was rapidly dividing and "jumbly." The cells were multiplying quickly, and they'd lost resemblance to normal, healthy cells. This was bad news.

When doctors sent a sample of the tumor out for genetic analysis, they found many mutations. These are changes in the DNA makeup of the cells. In cancer, the greater the number of mutations, the harder the disease can be to treat.

In other words, more bad news.

My urologist shared all this with me on the Friday before July 4. Susan and I had accepted an invitation to go to a wedding that weekend, and I figured we couldn't back out. Of course, I didn't want to tell anybody there. Instead, I just kept it bottled up inside me. By the end of the weekend, I was a wreck.

We'd been planning to take our granddaughter to the beach after the wedding, but I told Susan that I just couldn't do it. The thought of fireworks and picnics just didn't jibe with my reality any more. She agreed. We cancelled our plans for the next week and made new ones—at a cancer center.

The cancer I'd developed was so rare that doctors couldn't really compare my case to others. Still, one thing was abundantly clear: My circumstances were dire.

Despite what you may have seen on TV or the movies, doctors don't tell patients that they have a certain amount of time left to live.

WHEN I SHARED NEWS OF MY DIAGNOSIS, PEOPLE SHOWERED ME WITH MESSAGES OF HOPE. THEY PRAYED FOR ME. THEY SHOWED ME COUNTLESS ACTS OF KINDNESS.

CHEMOTHERAPY IS A BLUNT INSTRUMENT: IT FLOODS THE BODY WITH TOXIC CHEMICALS TO KILL THE CANCER CELLS.

But I, more than most, could read between the lines of what they were saying.

I looked at my calendar for the rest of the year. Every holiday or meaningful event on there, I realized, might well be my last. It was a bitter pill to swallow.

I put together a bucket list. It was pretty short. I wanted to see my family: the kids, grandkids, my father, my brother. And I wanted to live until Christmas.

In cancer, there's a certain sense of betrayal.

Your own cells have literally turned against you. It's as if there's an alien creature inside of you.

This idea of something "other" lurking within your body is terrifying. It's also, I believe, what's given birth to all the war metaphors that surround cancer. You have to do battle with cancer. Keep fighting. Never, ever give up.

But, for as long as I've studied cancer, I've disliked that language. Cancer is a disease. Like many other diseases, it can respond to certain treatments. The trick is to find the right one. And to be lucky enough to have a responsive form of cancer.

If your cancer doesn't respond—or stops responding—there's a point where continuing to seek out new therapies is fruitless. With certain forms of treatment, it can also be punishing.

In patients, I'd seen many forms of courage. One of the most poignant was the courage to stop treatment. To recognize that the best path was to move on to palliative care. To try to make the most of the time they had left.

This is how I wanted to handle my disease. I knew I wasn't yet at that point. But I probably wasn't that far away, either.

The tumor was deep in my urethra. As it grew, it caused me increasing pain and discomfort. When my physicians performed a PET scan, they saw that the tumor wasn't alone; my midsection lit up with metastases like a jack o' lantern. The scan also showed that the cancer had spread to my chest and lungs.

The best hope was not to try to dig out all the individual tumors. They were cropping up so fast that surgery would be no more effective than shoveling during a blizzard. Instead, my doctors recommended an aggressive course of chemotherapy.

Chemotherapy is a blunt instrument; it floods the body with toxic chemicals to kill the cancer cells. Still, like most poisons, those toxins harm more than their targets, wreaking havoc throughout the body. In particular, they destroy fast-growing cells. This is good when those cells are cancerous. But it's not so good when they're blood cells, which you must regenerate constantly to stay healthy and alive.

When doctors administer chemotherapy, they walk a fine line. Not enough chemo, and the cancer can kill the patient. Too much, and the chemo can devastate the body.

I had a few days to prepare for treatment. Doctors tested my hearing, as one of the potential side effects would be hearing loss. They also surgically implanted a port in my chest, which would allow for the most efficient I.V. delivery of the various medications I would receive. They urged me to clear my calendar and focus all of my energy on the 12-week regimen that was about to begin.

Up until that point, other than a small circle of family and friends, I'd kept my condition to myself. But with the long treatment road that awaited me, that would have to change.

I gathered key members of OMRF's leadership team and explained my situation. I didn't share every detail; who wants to hear about the agonizing night I spent in the ER because my primary tumor had blocked my ability to urinate? Still, I didn't mince words. I explained my diagnosis. I told them the long odds I faced.

I don't know how this will turn out, I said. And I have no idea the toll it's going to take on me. So, I need you guys to continue precisely what you're doing. Administrative staff, keep the foundation running in tip-top form. Scientists, keep pushing your research forward.

I sent emails about my cancer to all OMRF employees, board members and a broad group of friends. I wanted to be open. Most people aren't accustomed to dealing with someone facing a life-threatening illness. They feel awkward around that person, in part because they don't know what, exactly, they're supposed to know about his or her condition. By laying the facts on the table, I hoped to eliminate that barrier.

Sure, some would still feel uncomfortable around me. I mean,

how do you make small talk about last night's game with a guy who might not even be around come playoff time?

Plus, deep down—no matter how irrational we know it to be—there's a superstitious, frightened part of each of us. We're scared of catching what that person has. You look at me, and you're confronting your own mortality. You think, that could be me.

My treatment began on a Monday. I spent the morning getting pumped full of medications to prepare me for chemotherapy. There were steroids to prevent inflammation. Antihistamines to guard against any sort of allergic reaction. An extremely potent anti-nausea drug. Lots of fluids to ensure my kidneys were protected. Then drugs to drain excess fluids.

Even though I'm a physician, I didn't ask my doctor a lot of questions about my treatment regimen. That was by design. I didn't want to obsess over every little detail, I told myself. But if I'm being honest, there was a simpler explanation: I was scared.

A little after noon, I received my first chemo infusion. That took about an hour and a half to drip into my body. Following a brief interlude for more fluids, I got a second chemotherapy drug. Somewhere along the line, I received another dose of anti-nausea medication.

All told, I spent about eight hours in the infusion suite, watching as I.V. bags slowly drained their contents into me. When one emptied, a nurse came and switched it for another. Here and there, I'd drift off, drowsy from the antihistamines. But, happily—and surprisingly—I did not feel nauseated.

At around 4:30, my last I.V. bag emptied. I was ready to go home.

Just one more thing, my doctor said. She handed me a small backpack with a clear, rubber tube snaking out. She hooked the tube to the port in my chest. This was oncology's version of a to-go order. Inside was a pump that would push a third form of chemotherapy into me while I ate dinner with Susan, relaxed with a book and, finally, slept.

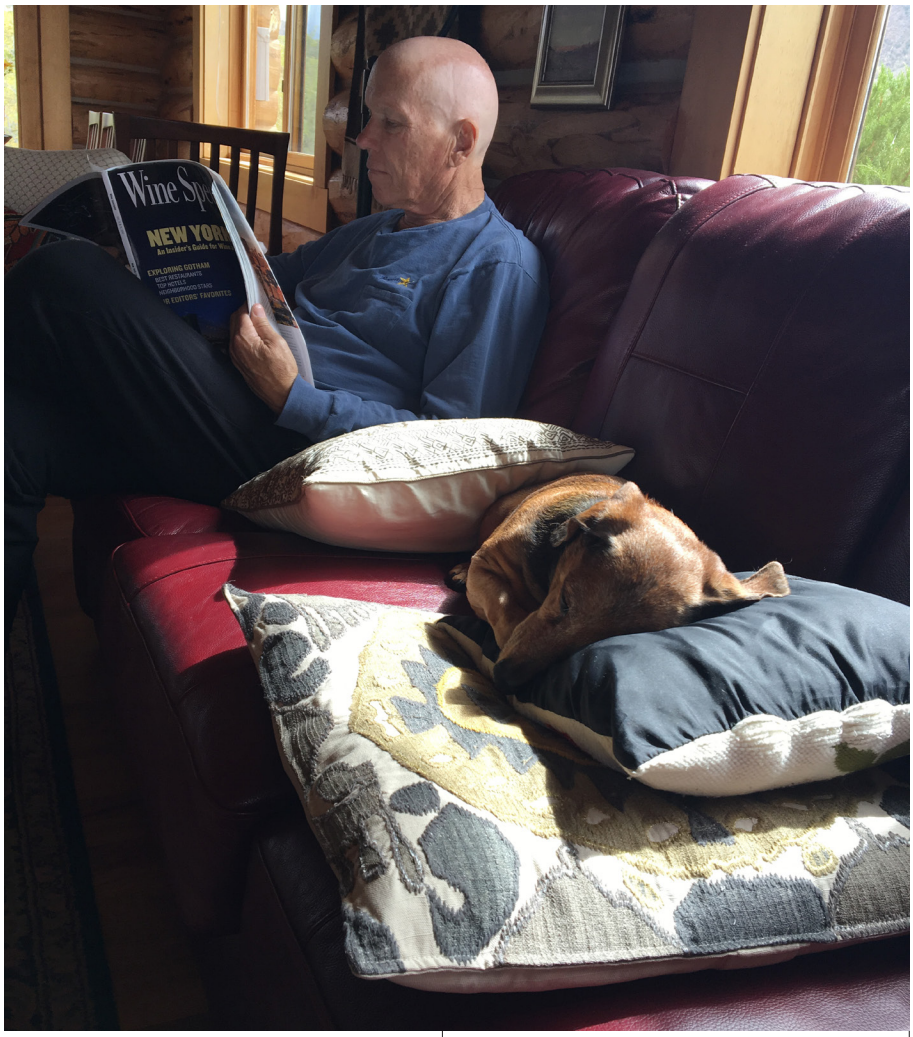
It was a long, exhausting day.

The rest of the week followed a similar path: I.V. medications at the doctor's office during the day, then pumped in through the backpack at night. On Friday, after I received a final injection of a drug to boost my white-blood-cell count, I let out a deep breath. I'd finished my first round of chemo.

Other than the port in my chest, which was a little weird, I didn't feel any different than normal. I had energy. No queasiness.

That continued for the next two weeks, during which I recovered from my treatment. Each day, I took a handful of pills. When my hair started to fall out, I decided to cut to the chase. I shaved it all off.

I would undergo three more rounds of chemotherapy like this: a week of treatment followed by two weeks of recovery. When my doctor examined me at the mid-point of this process, she voiced cautious optimism. The once-swollen lymph nodes in my groin had shrunk.



THESE PAST 18 MONTHS HAVE GIVEN ME A FRESH APPRECIATION FOR THOSE WHO KEEP SEARCHING OUT NEW APPROACHES FOR TREATING DISEASE.

That's a good sign, she said.

Still, we wouldn't know anything concrete until I had a full-body scan. For that, we'd wait until the end of the 12-week regimen. By that time, there'd be a clear picture of whether the drugs were working. Or not.

A dear friend of mine has lived with lymphoma for many years. So, he's no stranger to the periodic scans that cancer patients undergo.

It is, he says, like having someone lead you into a prison yard and hand you a cigarette. Then you're blindfolded and lined up against a wall. You stand there, just waiting for the bullet. But, instead, a voice says, "Not today."

At least I hoped that's what the voice would say.

The urinary pain and discomfort had vanished, and the swelling in my midsection seemed to have disappeared as well. Other than occasionally being caught off guard by a reflection in a mirror of a guy who looked like Mr. Clean, I could almost forget I had cancer.

Almost.

Because there were also times when I'd be overcome by intense sensations of dread. There wouldn't be any particular trigger I could identify. It happened at the most unpredictable moments.

I'd be having a routine conversation with someone, and—bam!—I'd be seized with a crushing sense that something terrible was about to happen. My heart thrummed. I could feel rivulets of sweat forming on my body. Breathe, I'd say to myself. Just breathe.

As the date of the scan neared, the frequency of these episodes picked up. It's not fair, I'd hear my inner voice say. Sometimes, it screamed, Why me?!

But, intellectually, I knew cancer was never fair. I mean, who deserves this disease?

You do your best to control the odds. But you don't get a free pass just because you don't smoke. Or because you exercise and eat well. Or even because you've devoted a big chunk of your career to trying to understand and find new treatments for cancer.

The nurse found the vein in my arm and inserted the I.V. needle. Moments later, a solution of glucose—sugar—laced with a radioactive isotope began to flow into my body.

Once we'd waited long enough for the radioactive sugar molecules to circulate throughout my tissues, I laid down on a sliding tray. For the better part of the next hour, that tray carried me, ever so slowly, through a doughnut-shaped hole into the belly of a massive machine known as a positron emission tomography (PET) scanner.

A PET scan detects cancerous tumors. It does so by measuring how cells deal with the sugar solution: Cancer cells retain it longer than normal ones. The radioactive particles linked to those sugars then create a visible map of that activity. The more spots light up, the more cancer.

As I lay motionless in the chilly room, I couldn't feel the scanner searching my every nook and cranny. My veins seemed no different than when they didn't have radioactive substances coursing through them.

Still, I knew that this moment was different.

Did life's journey have another leg or two remaining? Or had I reached the end of my travels?

Of course, nothing inside me would be altered by what the scan showed. But everything about my world would be transformed when the doctor announced those results. It's one thing to be dying. It's quite another to know it.

I can recall few times in my life more stressful than awaiting those test results. And few moments of greater joy than when I received them.

You're in remission, my doctor said. Complete remission.

I gulped, incredulous.

Complete remission?

My primary tumor had shrunk remarkably. The PET scan also showed that the tumor was essentially dormant, so my doctors saw no need to remove it. In the other parts of my body where the cancer had previously spread, diseased cells were no longer detectable.

I was done with chemotherapy, at least for now. Instead, my physicians recommended follow-up treatment with a drug called Lynparza. It's a therapy primarily used to treat ovarian cancer. However, genetic sequencing showed my cancer carried a mutation much more commonly found in ovarian tumors. So, my doctors hoped, a handful of these pills each day would keep my disease in check for the foreseeable future.

About a year has passed since that moment. Happily, my cancer has shown no signs of returning. Still, I don't consider myself cured.

One day, I expect the disease to come back. I'll feel a lump. A dull pain that doesn't seem to go away. Or, perhaps, at one of those periodic PET scans I still undergo, they'll tell me, "Well, Steve, the news isn't so great this time."

When that happens, I'll try a new therapy. Chances are, it won't be as effective as my previous treatments. It may not work at all.

At some reasonable point in the process, I'll say uncle. I won't throw any Hail Marys. Instead, I'll savor the time I have left.

But I hope that day is a long, long way off.

In the meantime, I've enjoyed having hair again. And celebrating Christmas—plus New Year's, my 70th birthday, Susan's birthday and my granddaughter's graduation. At this point, I'm deep into uncharted territory. I'm living days I never expected to see.

With each sunrise, my outlook has grown brighter. I've grown so bold as to start adding to the bucket list I put together when I was first diagnosed.

I'd like to float the Grand Canyon. See the Aurora Borealis. Clink a glass of bubbly with Susan on our 50th wedding anniversary in June.

That any of this is even possible is a tribute to medical research.

Each of the forms of therapy I've received came from laboratory discoveries like those that scientists at OMRF make every day. My doctors' ability to tailor my treatments to my particular form of the disease was a direct result of breakthroughs in DNA sequencing in the last decade. The drug I'm now taking to keep my disease at bay reached the market just four years ago.

I'm alive today because of the changed landscape of cancer research and treatment. Indeed, I shudder to think whether I'd be here had my cancer developed even a few years earlier.

Although I've spent most of my adult life in the lab, these past 18 months have given me a fresh appreciation for research. They've driven home why it's so important to keep searching out new approaches for treating disease. And they've instilled in me a profound gratitude for all those who show the foresight and generosity to support scientific investigations they know cannot benefit them—only, perhaps, those who come later.

Still, the most wonderful—yes, wonderful—part of having cancer has been the unexpected gifts it's brought me.

When I shared news of my diagnosis, people showered me with messages of hope. They prayed for me. They showed me countless acts of kindness.

That compassion helped give me strength in grim moments. And now, every day, it reminds me to do the same for others.

In our home, Susan and I recently hung a photo of the two of us dancing. It was taken last fall. In it, I'm bald as a cue ball. And I couldn't look happier.

That image perfectly captures my relationship with cancer. I know it's a part of me. But I'm not going to let it stop me from living my life.

A Name for his Pain

By Shari Hawkins

Just walk it off, David Key told himself.

He trudged along the roadside, hoping to outpace his pain. The gravel crunched under his feet, his steps kicking up faint clouds of dust in the moonlight.

Not much happens in the wee hours in Oil Center, a rural community in southeastern Oklahoma. And middle-of-the-night journeys weren't the norm for Key, then 41 and owner and operator of a construction and insulation business. But this was no ordinary evening.

Around 1 a.m., he'd awakened with stabbing pains in both his armpits. "It felt like someone had propped me up on a couple of broom handles," Key says. "The pain was excruciating." He stepped outside to clear his head and avoid waking his wife and two daughters. When a short walk failed to bring relief, he climbed in his pickup and drove to the E.R.

Key didn't know it then, but that night a dozen years ago would mark the end of an era. No longer would he be a healthy father, husband and business owner who raced motorcycles competitively. Instead, suffering and disability would come to rule his life.

"I have such pain in my chest," he says. Often, it goes on for days. "It takes me to my knees."

He cycled through hospitals and clinics. No matter what medications doctors prescribed, his condition worsened. He was wracked with uncontrollable tremors. Neurological problems. He could no longer run his business, so he changed jobs. Finally, after a pair of strokes, he was forced to go on disability.

Still, when Key arrived at the E.R. that night in 2006, physicians didn't know what was wrong. They gave him some pain pills and sent him home.

But within weeks, after shuttling to a number of different hospitals, Key learned a name for his pain. It was a word he'd never before heard. But in the coming years, he'd grow to know it well.

Doctors told him he suffered from a disease called sarcoidosis.

Researchers know little about what triggers sarcoidosis. It seems to start in the immune system, eliciting rampant inflammation. The disease also causes lumps of immune cells—called granulomas—to form in organs throughout the body. These tumor-like lumps can appear in the eyes, liver, heart, skin and brain and most often are found in the lungs. They also give the disease its name, as the growths were initially be believed to be a form of sarcoma, a type of cancerous tumor.

The lumps, though, are not cancerous. However, they cause Key intense bouts of pain. And while uncomfortable, the fact that they are not in his heart or lungs is fortunate. If too many of them form in a single organ, they can cause the organ to malfunction or even fail. This is the reason that one in 14 people with sarcoidosis eventually die from the illness.

Sarcoidosis can strike anyone, but it disproportionately affects African Americans: Disease incidence has been reported as high as 39 in 100,000 among African Americans, versus five in 100,000 for Caucasians. African Americans are also 10 times more likely to die from it than their European-American counterparts.

Mortality can result from respiratory, neurologic or liver failure. But the most common causes of death are cardiac conditions, which claimed the lives of the two best-known sarcoidosis sufferers: comedian Bernie Mac and NFL Hall of Fame defensive lineman Reggie White.

Most patients experience lung symptoms, including chest pain, dry cough or shortness of breath. Other symptoms can include fatigue, fever, joint pain, skin rashes and sores.

Because of the disease's rarity and wide range of effects, doctors often struggle to identify it. "Unless patients' first symptoms are in the lungs, they're usually misdiagnosed," says Dr. Courtney Montgomery, who studies the disease in her lab at OMRF.

Often, she says, patients like Key can ping-pong from physician to physician before one accurately identifies their condition. "It's a diagnostic odyssey. It can take six years, eight years, even longer. That's the story we hear most."

Even a definitive diagnosis brings little relief. There is no cure, and while the disease can go into remission on its own, no drug has been shown to definitively modify disease progression. While doctors are sometimes able to control symptoms with medications, the process of managing their condition can become a full-time job for those with sarcoidosis.

"Few specialists see sarcoidosis, so they aren't sure what to make of it. And there's no central place for these patients to go," Montgomery says. "Instead, they have a cardiologist. A pulmonologist. An eye doctor, a neurologist, a dermatologist. They see all of them."

This treatment landscape—confusing, lonely, bereft of promising paths forward—is what drew Montgomery to sarcoidosis. A geneticist by training, she'd spent more than a decade working to understand what predisposes certain people to diseases such as lupus and cancer. But while many other scientists around the world were focused on finding the roots of these conditions, only a handful were looking at sarcoidosis.

Montgomery had been peripherally involved in a research project on the disease in graduate school. She stayed connected to it when she joined the faculty at Case Western Reserve University in Cleveland and, subsequently, when she moved her laboratory to OMRF in 2008. Along the way, the project ran out of funding. Montgomery saw two choices: let it die, or go and get a new grant.

In 2009, she secured funding from the National Institutes of

sarcoidosis

David Key had never heard of sarcoidosis—until the rare disease stole his health.

Photo: Dan Morgan

Health. "With that grant, we were able to begin delving into the genetic roots of the disease," she says. She and her OMRF research team focused on African-American families, since they bore a disproportionate weight of sarcoidosis.

While the work was, to an extent, fruitful, she ultimately realized there was only so much she could learn from patient samples gathered more than a dozen years before. To make real headway, her team needed fresh samples. That meant connecting with patients.

Although any research Montgomery and her team did would not directly benefit the participants, Montgomery hoped they'd be willing to help. "By studying what's going on at a genetic level in patients with active disease, we hope to identify environmental triggers—pathogens, allergens, things like that—that initiate sarcoidosis onset," she says. Ultimately, that work might point scientists to an effective treatment. "Much like when researchers discovered insulin could control type 2 diabetes, we're hoping to find a protein we can either supplement or alter to treat sarcoidosis."

Of course, there's no guarantee the work will lead to new therapies. "But if we don't do this kind of research," she says, "we know things won't improve for these patients."

In early 2018, Montgomery opened the Sarcoidosis Research Unit at OMRF. "Within 48 hours, we had 20 people respond about participating," she says. "The disease strikes more Oklahomans than anyone imagined. We just had to go on faith that we'd find them, and we have."

Once enrolled in the study, participants undergo a screening process, complete questionnaires and donate a small blood sample to be used for research. Volunteers are also asked to provide consent to review medical records and request previous biopsies related to the disease.

No treatment is administered at OMRF, but the information gathered helps give researchers a clearer picture of the disease and how it progresses. The blood samples are examined in the laboratory to look at the genetic makeup of patients versus healthy controls—individuals without a sarcoidosis diagnosis—to help scientists identify triggers or biomarkers for the disease.

"Traditional thinking on sarcoidosis has always been broken into two camps: either it's an autoimmune disease or it's an infectious disease," Montgomery says. "Our preliminary findings are strengthening the argument that this disease has components of both. We've learned that just from our first round of recruitment."

For most participants, their visits culminate in face-to-face visits with Montgomery. In almost every case, she says, meetings end in tears, hugs or both.

"We understand them and what they've gone through to get here. We give them hope, because we're working hard for them. For many, it's refreshing to talk to someone, finally, who doesn't think they're crazy. They will drive for hours just for the chance to tell us about their personal experience with sarcoidosis."

That time with patients has also proven essential to steering Montgomery's studies in the lab.

"Their stories have guided the science from the start," she says. "Even as different as their conditions may seem, I find commonalities in their narratives. I like to take my time and get to know them, hear their experiences. At the end of the day, it lets me do what I do best: problem-solve."

Montgomery and her team are using sophisticated genetic techniques to analyze what's

Within 48 hours of opening OMRF's Sarcoidosis Research Unit, says Dr. Courtney Montgomery, "We had 20 people respond."

Photo: Steve Sisney

For more information or to take part in the study, call (405) 271-2504 or email sru@omrf.org.

going on in patients. "We're also trying to look at things chronologically to learn what tells the blood to migrate to a specific place and create a granuloma," she says. "We just now have the technology to do that."

She also aims to educate those on the front line of treating the disease. "We completely understand how challenging this is for some clinicians," she says. "There's no place for a general practitioner in a small town to get training on a rare disease like this one, so we want to bring the training to them."

Montgomery hopes to enroll 200 patients in the study. She knows that's a steep order for a rare disease, but having large numbers of research subjects is key to making new insights.

The ultimate goal of the work, she says, is simple. "All we do is pointed toward changing the treatment landscape for patients."

The night of David Key's midnight walk, emergency room staff had no answers for his agony. "I think they thought I was just after pain pills, you know, like an addict."

In the ensuing week, surgeons removed his gall bladder. When that did nothing to ease his suffering, another physician diagnosed him with pancreatitis. But, again, treatments failed to help. "I lost weight real fast. I looked horrible." Things got so bad that doctors suggested Key spend time with his family and get his affairs in order.

But then a physician thought he recognized Key's symptoms. A subsequent biopsy of lymph nodes removed from Key's chest proved the hunch: sarcoidosis.

"Boom. Everything changed," Key says. He started on a steroid that helped tamp down the inflammation that had run amok in his body. In time, though, he developed new symptoms.

First, it became hard to write. "I shook so hard, it was like I had Parkinson's. I couldn't eat with a spoon or eat chips and salsa, anything I had to hold," he says. "Then I got what I called 'needle pains,' where it felt like someone was poking me with ice picks all over my body, on my ears, legs, tongue, hundreds of times a day."

At his doctor's urging, he eventually sold his business and took a desk job. He enjoyed the work, but sometimes he'd get disoriented and couldn't find his way back to his office. Other times, he'd forget how to log into the computer system he'd used for years.

In the summer of 2017, Key suffered a stroke. A month later, he had a second one. With the increasing toll sarcoidosis was exacting on his body and mind, he could no longer meet the demands of the workplace. He took long-term disability.

"I got in a big depression over that," he says. "I had worked all my life and really enjoyed it. Then all of a sudden, I couldn't work anymore. It's really been rough."

Despite the physical challenges, Key still prides himself on keeping his yard in order. It might take two or three days to finish, but he keeps things mowed and tidy the best he can. He's also working on some projects around the house and in the garage.

Since the strokes, doctors have largely managed to control his symptoms. Steroids keep the inflammation in check, and he takes a laundry list of other medications for the tremors, pain, depression and neurological issues. Still, he continues to experience near-continuous pain in his chest and underarms. When his disease flares, he could swear he's having a heart attack.

For Key, a vital part of his ability to persevere has come from the online support he's received from other sarcoidosis patients. "It's really good to be able to share with somebody who knows what you're going through," he says. "We try to hold each other up and be there for each other. There's no cure and no perfect way to take care of us, so we talk about everything. Doctors, medications, depression, flares."

A Facebook group that started with a few hundred members has grown to almost 5,000. Through it, he's befriended patients as far away as Africa and Australia. "One just got a lung transplant. Others talk about getting infusions and other treatments." A young disease sufferer awaiting a lung transplant died recently, he says. "It can be hard, but it helps to have them for support, because everyone with this disease has a lot of questions."

It was through an online connection that Key found OMRF. Another member of the Facebook group is a sarcoidosis patient from Tulsa, and they began chatting on the phone from time to time. (They've never met.) One day, she mentioned OMRF and its Sarcoidosis Research Unit. She explained what it did.

As Key listened, something dawned on him. This disease had kept him powerless for so long. But here was an opportunity to do something. To make a difference.

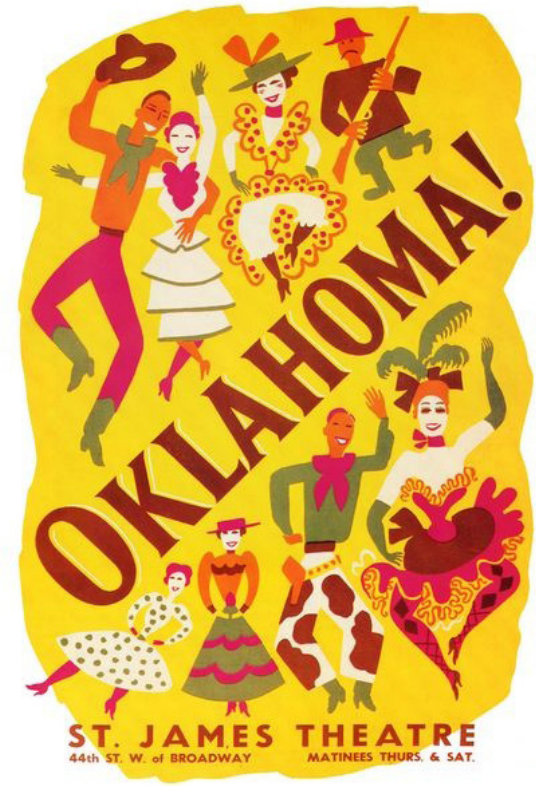
He drove to Oklahoma City. He filled out questionnaires detailing his history with the disease, his medications. He donated blood.

It's been almost a year since then. Key understands that researchers are working with the samples and information he—and others like him—provided. He also knows what he's given likely won't help him directly. If there are answers, they'll come slowly, and in little pieces.

Still, he says, "If it can help somebody down the road, it's worth it."

You're Doin' Fine, 'Oklahoma!'

How our state's namesake musical gives back to research at OMRF



The line at the St. James Theatre formed early on April 1, 1943. As it grew, the New York City police were called in to control the throng. Word had spread fast about the show that had opened the night before to a spotty—but enthusiastic—crowd. Patrons were eager to shell out $4.80 to enjoy Richard Rodgers and Oscar Hammerstein II's first collaboration.

"Oklahoma!" offered a whole new take on the musical genre. Instead of a string of random production numbers, it told in song the simple story of a young girl and her two suitors, a farmer and a cowboy, in the rough-and-tumble setting of Oklahoma territory.

Critics had expected the Western-themed show to be a flop, and many panned it even before it opened. But that April 1 performance would be the second in what would ultimately become a run of 2,212 nights on Broadway.

In 2007, Tony winner (and Oklahoma native) Kelli O'Hara helped celebrate the state's centennial with a Lyric Theatre production of "Oklahoma!"

In 2018, the show celebrated its 75th anniversary. The milestone met with much fanfare and, as usual, many new productions. Those included a stripped-down, off-Broadway version in Brooklyn and even an Oregon production where the central couple were women and the secondary romance was between two men.

All told, the landmark show is still performed about 700 times a year. And every time the curtain goes up on Curly, Laurey, Ado Annie and Aunt Eller, it helps OMRF.

Through an estate gift, OMRF receives one-quarter of 1 percent of box-office royalties for the musical. The gift traces its roots to Claremore native Lynn Riggs, who in 1931 penned "Green Grow the Lilacs," the play Rodgers and Hammerstein used as the basis for their musical. Hammerstein wrote that he "kept many of the lines of the original play without making any changes in them at all for the simple reason that they could not be improved on."

When Riggs died, he willed equal shares of his 1 percent royalty on the musical to his four siblings. Riggs' brother William Edgar lost his wife to heart disease and his daughter to cancer, so upon his death in 1977, he donated his portion to support research on those diseases at OMRF. The payments will continue as long as "Green Grow the Lilacs" remains under copyright.

Lynn Riggs

"Even though OMRF wasn't yet born when Lynn Riggs wrote his play," says OMRF Vice President of Development Penny Voss, "I hope he'd find it fitting that his work benefits Oklahoma's very own homegrown research institute."

Grassroots support from Oklahomans in all 77 counties helped make OMRF a reality. "They're the same kind of people portrayed in the musical: strong, caring, forward-looking," says Voss. "We still see that spirit in our donors today."

Royalties from performances of "Oklahoma!" have generated more than $700,000 for heart disease and cancer research at OMRF.

OMRF

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A Joyful Noise

On holidays, community volunteers pitched in to make the season bright for patients in OMRF's Research Hospital. In 1958, this accordion ensemble shared the Christmas spirit with a concert for hospital staff and patients.