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HEALTH NEWS

A REVOLUTIONARY IN CANCER CARE

IT'S HABIT for Americans to declare war on problems. But Dr. Paul Schellhammer wants to change that – at least when it comes to prostate cancer. In his own 12-year struggle with it, he has declared "truce."

Story by ELIZABETH SIMPSON

The Virginian-Pilot

Photography by BILL TIERNAN The Virginian-Pilot

DR. PAUL SCHELLHAMMER is a world-renowned urologist, a cancer specialist, and one of the researchers behind the first vaccine treatment for cancer. During a career spanning nearly four decades, he has delivered the news of prostate cancer to hundreds of patients and guided them through the maze of options that include surgery, radiation treatment, and simple surveillance.

But one day in 2000 when he peered through a microscope at a tissue sample to discover an aggressive form of the cancer, his reaction was visceral:

Pounding head. Hollow feeling in the stomach. Sweat on the brow. Mouth as dry as a bone.

That's because the sample under the lens was his own.

Twelve years later, he doesn't call himself a cancer survivor but rather a "cancer participant."

He hasn't beaten prostate cancer, but it hasn't beaten him, either.

He prefers the term "truce."

Schellhammer, 72, has made plenty of headlines over the years – as a researcher, president of national urology organizations, a groundbreaker in the world of immunotherapy. The cellphone of the longtime professor at Eastern Virginia Medical School regularly rings with people in the field asking his opinion on various new treatments.

Now, in the twilight of his career, he's making another name for himself: as a prostate cancer patient.

In December, he spoke before a panel at the National Institutes of Health – not just as a researcher and doctor, but as someone who has endured treatment himself and lived with prostate cancer for more than a decade.

The main message that arose from the session: Do we really need to call it cancer?

It's been 40 years since then-President Richard Nixon declared "war on cancer," using the language that helped score millions in research dollars that led to screening tools, treatment and medical equipment, including precision radiation and robots and proton therapy.

It also introduced a warrior lexicon that some urologic oncologists, like Schellhammer, now question. Does that mindset work against making reasoned decisions, particularly when the cancer is a slow-growing form?

"When a patient hears the word 'cancer,' he feels the need to put on battle gear and go to war against the enemy," Schellhammer said.

During the past few years there has been fierce debate about screening, in particular concerning mammograms for women and prostate-specific antigen, or PSA, tests for men.

When the U.S. Preventive Services Task Force recommended in 2009 that women younger than 50 not get routine mammograms for early detection of breast cancer, howls of protest ensued. About 15 percent of women in their 40s detect breast cancer through mammography, but many other women experience false positives, anxiety and unnecessary biopsies as a result of the test.

The same task force late last year issued a draft recommendation saying healthy men should no longer receive a PSA blood test to screen for prostate cancer, because the test does not save lives overall and often leads to tests and

treatments that cause pain, impotence and incontinence.

That recommendation, too, was highly controversial.

For Schellhammer, the psychology surrounding the word “cancer” plays a role, one he hopes to illuminate by telling his own story.

“Even though I wish he didn’t have it, it’s made him more of a potent force,” said his son, Chris Schellhammer, who works in architectural design in Blacks-burg. “The fact that he is living with it for so long and so well puts him in a position to help redefine the public psyche about cancer.”

It comes in the arc of a career that’s gone from a time when the disease was discovered so late there were few options – “Treating advanced prostate cancer was like taking a man’s manhood away,” said Paul Schellhammer – to cancer being discovered far sooner, with so many treatment choices it can be dizzying for patients.

The prostate is a walnut-size gland that is part of the male reproductive system. Prostate cancer is the most common malignancy, with some 200,000 men diagnosed a year in the United States, partly due to advances in screening. But the majority of men have tumors growing so slowly that something else will kill them before the cancer becomes life-threatening. The challenge is distinguishing the fast-growing from the slow.

Schellhammer was 60 when a routine doctor’s check showed his PSA levels were climbing, a red flag of cancer.

He knew instinctively he had cancer, but he was assuming it was, like the majority of cases he reviewed, the non-aggressive type.

He underwent a biopsy, and his look through the microscope at his own tissue showed otherwise. Based on a scorecard called the Gleason Grading System, the tumor was classified as one that needed treatment.

More than a decade later, his reaction at that moment sticks with him. He testified about it before the NIH panel: the mix of anxiety and fear, and the desire to eradicate the cancer.

To put it in context, consider that two years earlier he’d had crushing chest pain that sent him to the hospital, where doctors discovered a blockage in the left side of his heart, a condition often known as “the widow maker.”

He had surgery to insert stents, changed his diet and stepped up his exercise. He recalls the treatment feeling more like a “partnership” with his heart. Contrast that to his reaction to cancer, which instead created a desire “to rid my body of the alien invader by whatever means.”

Schellhammer considered surgery and radiation. Being a surgeon himself, he selected the former route.

He turned to Dr. Paul Lange, a University of Washington surgeon who was involved in the development of the PSA. They had become friends when Schellhammer had treated Lange’s father-in-law for prostate cancer.

Coincidentally, Lange also was diagnosed with prostate cancer a year later and also sought surgical treatment. He’s had colleagues ask whether, had he known then what he knows now, he would have chosen the same course. Lange thinks so but concedes, “It’s become even more complicated and controversial since we had our surgeries.”

A year after surgery, Schellhammer experienced what he calls “the PSA creep.” His levels went up again.

He attacked again, this time with radiation. A year later, his PSAs went up again. Then came several medications. The cancer has not gone away, but hormone therapy has kept it at bay. “And I’m a much more pleasant person,” he joked. Schellhammer’s perspective on cancer has changed over the years. He describes his initial reaction to its presence as “disconcerting” – he’d make sure monitoring tests didn’t come before holidays so as not to ruin the spirit. Then, disappointment. And now? “That’s life,” he said with a wry smile.

The point of his story – his case study, as he calls it – is this:

He’s still here. He’s still working.

Schellhammer considers prostate cancer more of a chronic disease than a killer for most, and he’d like to be a player in showing other people that perspective at this stage of the game – to dispel the fear around the diagnosis, to urge reason and education in making decisions with a cancer in which less treatment sometimes can accomplish more.

He knows that’s a challenge: “As soon as you say ‘cancer,’ the mind shuts down.”

But to that end, after doing hundreds of research articles over the years with titles like “Transitional Cell Carcinoma of the Urethra,” he’s written a personal essay with Lange about prostate cancer. Using his own experience, he’s spoken

before panels, discussing the best way forward in cancer treatment.

His office manager, Susie Col-son, regularly gives out his writing to newly diagnosed patients.

Instead of fighting a war with the enemy, he has declared a truce and proposed a change in lexicon that uses words like “participant” and “care” instead of “survivor” and “cure.”

The group he spoke to in December was a “state of the science” panel examining protocols for what’s called “active surveillance,” which is monitoring low-risk cases of prostate cancer rather than treating them with surgery or radiation. An intriguing idea sprung from its conclusion: “Strong consideration should be given to removing the anxiety-provoking term ‘cancer’ for this condition.”

The challenge is distinguishing low-risk from high-risk – Lange calls them “turtles and birds” – and there are studies being done, some at EVMS, identifying markers that could better differentiate the tumors destined to kill from the ones that will grow so slowly that other diseases will lap them.

Schellhammer believes the screening and treatment developed over the years is why he is still here. After all, his cancer wasn’t low-grade. But the studies have made it clear since then that many cases fall into the category of not needing treatment.

He hails advances in treatment – there are many new medications on the horizon – but also concedes that the medical technology race, with ever-more-expensive equipment, has fueled unnecessary procedures to pay for the upfront cost of machinery.

But these are not easy decisions, as his own case reveals.

While he’s made peace with cancer, he’s also considered taking Provenge, the vaccine for which he helped oversee clinical trials. It won’t cure his cancer, but it could give him more time. The treatment, though, is covered by insurance only for men who are in the late stages of the disease, a point Schellhammer has not yet reached.

It extends life by about four or five months, but he believes it would help men in earlier stages, maybe even more. Because there have been no trials to prove that, however, insurance wouldn’t cover it. That means he’d have to pay nearly $100,000 for the treatment.

It’s a mental exercise – treatment or no? – that men across the country ponder as options multiply and studies unfold. As Schellhammer wrote in his “Views from the ‘Other Side’” essay, the ticking clock, regardless of how slow the tick, “still is an audible and repetitive reminder of the limitations of life.”

Schellhammer continues to practice two days a week with the group he has been affiliated with since 1974, Urology of Virginia . He used to practice in its Norfolk branch but now travels from his home in Virginia Beach to the Eastern Shore office in Nassawadox, which still uses paper instead of electronic records.

“I am able to go there and function as a dinosaur,” he said.

One day in January, he was talking with Donald Harmon-son, 54, whose elevated PSA levels first brought him in about three years ago. A repeat test showed the same high level, so a biopsy was done; it revealed no cancer. Now he’s monitored periodically.

Joseph Custis was diagnosed with prostate cancer a year ago, but it was a non-aggressive form, so no treatment was recommended.

“Is your weight still good?” Schellhammer asked. “Your appetite?”

Schellhammer said having cancer makes him a better doctor. He is better at relating to the fear that diagnosis brings, better at understanding the complexities of decision-making.

“He’s honest with them, and around here, honesty goes a long way,” said Colson, his office manager.

The pace and calmness of the Eastern Shore fit well with the course of action Schellhammer is much more likely to suggest now than a decade ago. People’s lives are not as hectic, so they’re more willing to opt for an “active surveillance” rather than “fix it immediately” approach.

His own patients over four decades also have taught him volumes about living with the disease he has spent his career treating. It’s the people who didn’t beat the cancer who taught him the most.

“They taught me about the resiliency of human nature in the face of adversity,” he said. “I’ve learned from them how to accept things and how to persevere.”

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a patient with perspective

Dr. Paul Schellhammer has been a researcher, a leader in the field of urology and a groundbreaker in immunotherapy. He discovered he had aggressive prostate cancer nearly 12 years ago and has had several treatments to hold it at bay.

a rebel with a cause

Schellhammer believes the ideology of a “war” may hurt more than help when dealing with prostate cancer. In his words, he has declared a “truce,” and he advocates terms like “participant” and “care” instead of “survivor” and “cure.”

ABOVE | Dr. Paul Schellhammer, 72, of Virginia Beach still practices two days a week. He said having cancer makes him a better doctor – better at relating to patients’ fears and the complexities of decision-making.

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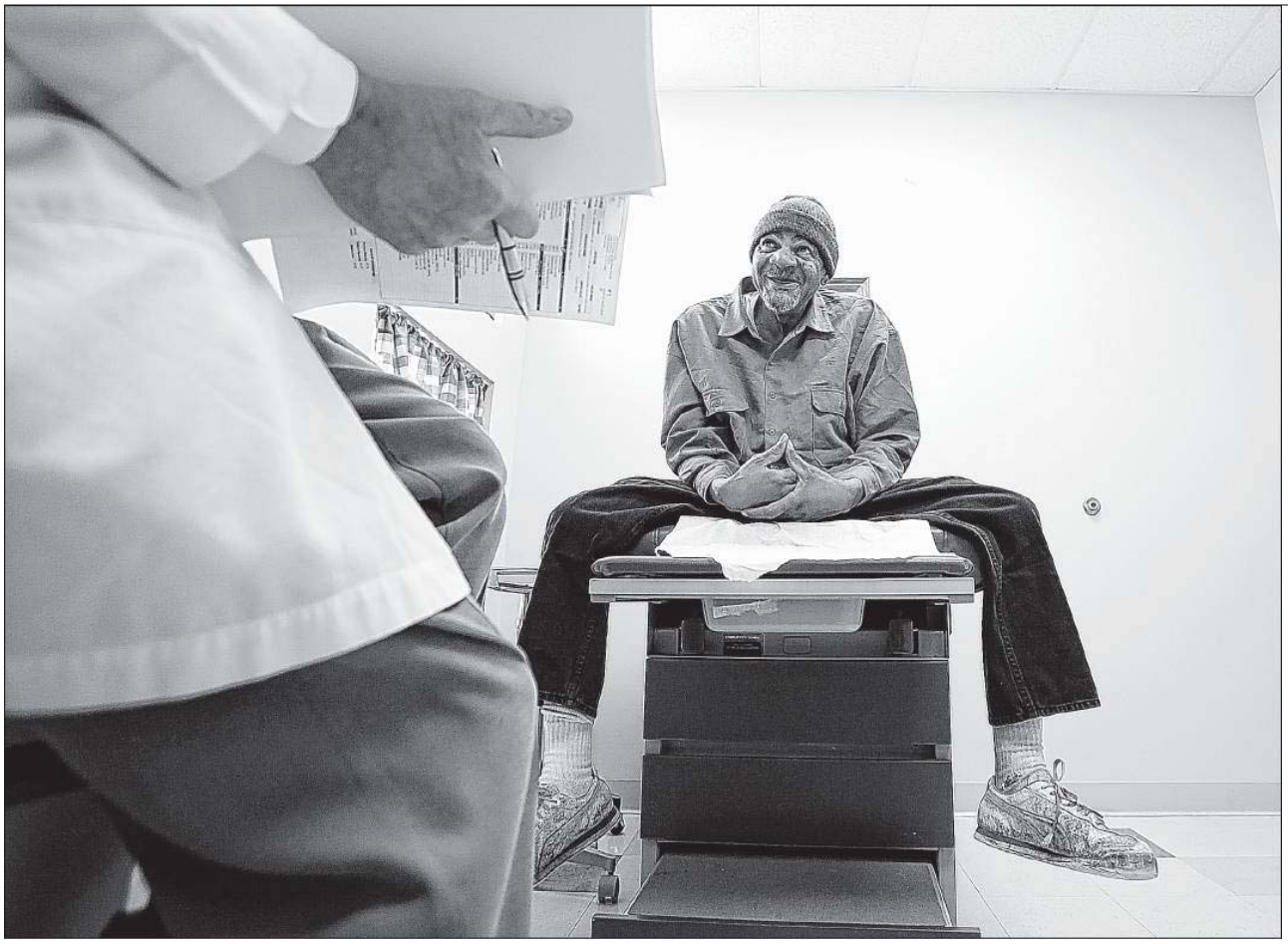
Dr. Paul Schellhammer has had stents implanted to deal with a blockage to his heart. Dealing with the heart problem felt like a “partnership,” whereas his reaction to cancer was to rid his body of the “alien invader.”



Schellhammer talks with patient Joseph Custis of Cape Charles. Recently, the doctor addressed specialists considering whether to recommend monitoring as the best approach to dealing with low-risk cases of prostate cancer rather than using surgery or radiation. He considers prostate cancer more of a chronic disease than a killer for most.

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