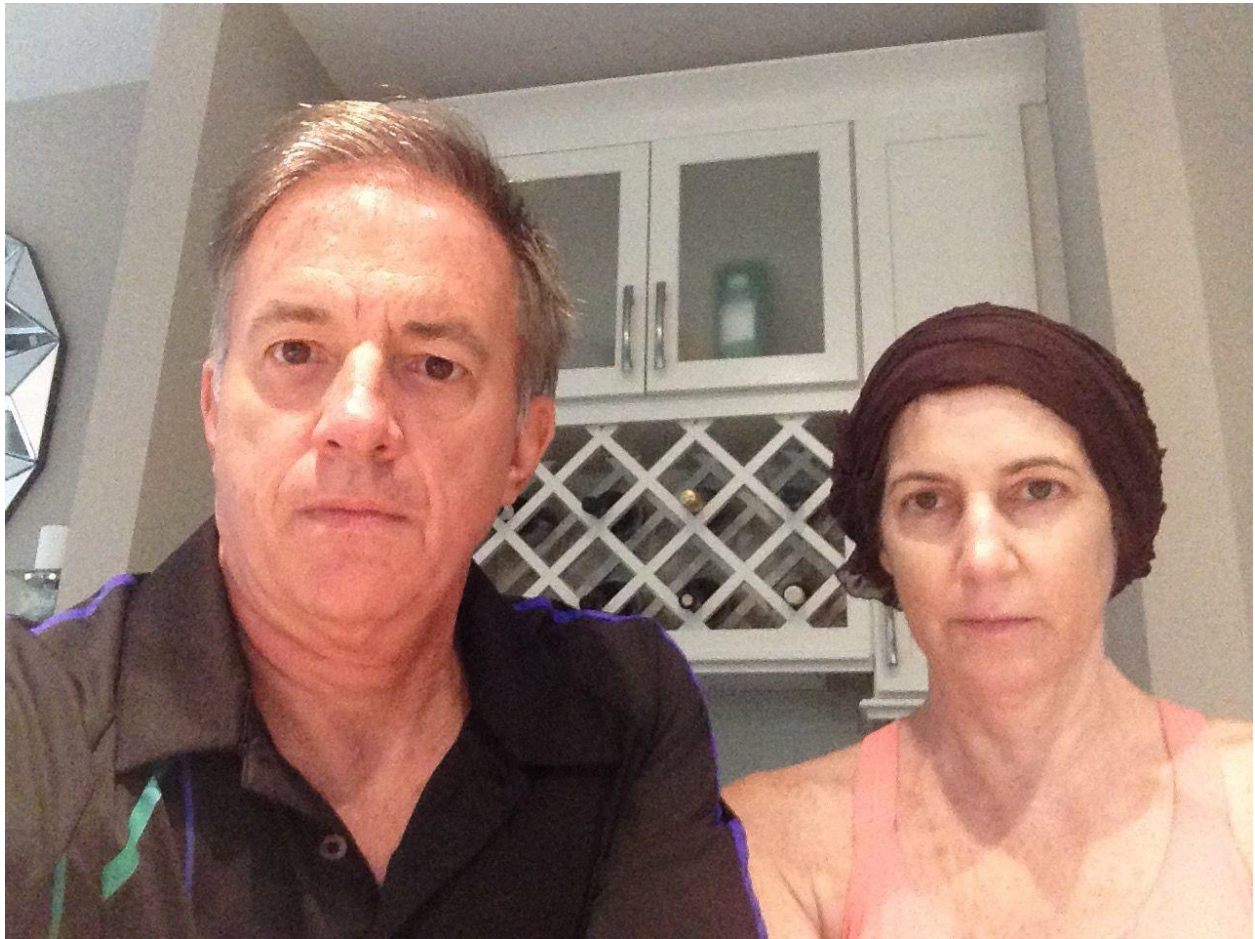


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With clock ticking, Virginia couple fights Anthem to get wife's cancer treatment



By KATIE O'CONNOR Richmond Times-Dispatch Aug 29, 2017

In every human body, the aortic bifurcation marks the point where the aorta — the largest artery — splits and descends into each leg. In Dianne Weber's body, a tumor sits directly in that fork.

It is a life-threatening disease, but it doesn't have to take her life.

The tumor is a remnant of the anal cancer she was treated for — and beat — five years ago. Her doctors are recommending a precise form of radiation likely to rid her of this last vestige of cancer, but her insurance provider, Anthem Blue Cross Blue Shield in Virginia, won't cover it.

Weber's request for proton beam radiation therapy was denied Aug. 16. Since then, her husband, Jack Weber, has been fighting tooth and nail against Anthem. And her providers at MD Anderson — one of the premier cancer institutes in the country — have worked alongside him, writing a thorough appeal letter that details all the ways that Anthem was wrong for denying her claim.

On Friday, though, Anthem denied the Webers' appeal despite legislation passed this year aimed at increasing access to the procedure. Anthem claims that proton radiation therapy has not been deemed effective in treating anal cancer.

It could cost \$70,000 to \$80,000 out of pocket for Dianne Weber to get proton beam radiation.

"We'll have to borrow money; we'll have to do something," Jack Weber said. "I can't let my wife die because the insurance company won't pay for it."

But so far, nothing has worked.

The Webers pointed out that, in the denial letter, Anthem was relying on an outdated policy — the reviewer had cited a professional organization's policy from 2014, but a more recent policy had been released this year. On Monday Anthem sent them another denial, upholding the original decision even with the additional information.

Now the Webers are hoping Virginia's Bureau of Insurance will step in and rectify the situation through an external review process.

Meanwhile, Dianne Weber lives with near-constant anxiety. She can't sleep, she suffers from panic attacks, and the tumor presses against the joint connecting her pelvis and lower back, making it painful to sit. Her doctor told her she needs to get the radiation therapy within two weeks, or she risks losing all the benefits of the chemotherapy she endured over the past few months and her cancer could start growing again.

"Somebody should get upset with these insurance companies that they treat cancer patients like this," said Dianne Weber, who lives in Sterling with her family. "Where is the humanity in all of this? At some point, it's got to go beyond just profit taking. Somebody has to say, is this right?"

"I might die because of what they're doing, and they don't even care."

Radiation is especially tricky for Dianne Weber because she already went through it in 2012. Her small bowel received the maximum dose of traditional radiation then. Doing that again could compromise the organs immediately adjacent to the tumor, including her bowel, soft tissue, skin, bladder and bone marrow.

But she needs radiation. The chemotherapy was successful in getting rid of some of the cancer, and while the tumor did not grow larger during chemo, it didn't shrink, either.

Radiating again, though, could result in an abscess or blockage in her colon or, in the worst case scenario, could mean she has to use a bag to use the restroom for the rest of her life.

"From a business perspective, I'd say to Anthem, 'It's going to cost you so much more money if I had to have surgery or had to live with a bag than if you would to just approve the proton radiation therapy,'" she said.

Traditional radiation therapy uses X-rays to radiate a cancer patient's tumor, which are made up of photons that cannot be prevented from damaging healthy tissue before reaching the cancer site.

But with proton beam radiation therapy, the physician has more control over where the protons release the energy that fights the cancer, according to MD Anderson's website.

If Weber were to be treated with conventional radiation, her physician argues in the letter of appeal sent to Anthem, she would have "significantly increased risk for subacute complications: chronic diarrhea, and radiation enteritis, strictures, abscess and fistula."

In its first denial letter, Anthem wrote that, "Medical studies have not shown that this treatment (proton radiation therapy) is as good as other treatments for this condition."

The denial letter from AIM Specialty Health, which is owned by Anthem, referenced the American Society for Radiation Oncology's policy for proton beam radiation therapy from 2014.

Jack Weber pointed out to Anthem that that policy is outdated — the organization released another policy in 2017 that appears to support the Webers' claim.

The updated policy states that proton beam radiation therapy is medically necessary when the same or an immediately adjacent area has been previously radiated, and there is concern about other areas exceeding the cumulative tolerance dose that normal tissue can undergo.

But Anthem didn't change its position.

"A review of the additional information from Astro Model Policies: Proton Beam Therapy (PBT) suggests that proton radiation is experimental/investigation for re-irradiation of anal cancer recurrence," a letter affirming the original denial issued to the Webers on Monday states.

In response to a Richmond Times-Dispatch inquiry, an Anthem spokesman used similar language: "At this time, there is not sufficient clinical evidence that supports the use of proton beam radiation for this type of cancer. As a result, the treatment is considered investigational and is not a covered benefit."

But, Jack Weber points out, just because his wife's cancer was in her anal canal does not mean the cancer, in essence, is different from any other type of cancer.

Dianne Weber's tumor is no longer in her anal canal, anyway, he points out. It's in her aortic bifurcation.

Right now, the Webers are pursuing an external appeal through the Bureau of Insurance. But that could take time they don't have, even on an expedited basis. She needs to start her radiation within the next two weeks.

In the background of this struggle is legislation that Virginia lawmakers passed this year prohibiting insurance companies from holding proton radiation therapy to a higher standard than it would a traditional type of radiation.

"The law says clearly, in my judgment, that if a doctor recommends radiation and the patient agrees to it, they have to cover it," said Bill Thomas, associate vice president of governmental relations at Hampton University, which has a proton therapy institute.

Thomas has been advocating on the Webers' behalf since he found out about their situation. He wrote a letter to Anthem's president, Jeff Ricketts, on Friday, urging him to approve Dianne Weber's treatment.

But the law specifically states that insurers are not required to cover the radiation.

Tom Bridenstine, manager of the Bureau of Insurance's life and health division, said that the legislation that was passed does not provide a clean path to increase coverage of proton beam radiation therapy in the state.

"I think it's going to lay the groundwork to enable us to conduct some closer reviews, and I think if we start fining insurers and start questioning their clinical criteria, the validity of it, then we have something in our code that we can point to if we have to ask the company to explain and justify its decision," he said.

Thomas and Jack Weber read the law differently, though. If Anthem's claim is that proton beam radiation therapy is experimental for Dianne Weber, despite what her providers at MD Anderson say, then they are holding it to a higher standard than other therapies, they argue, and are thus in violation of the law.

"This can't possibly be what the governor and the legislature intended when they passed this law, that we would have to go through this," Jack Weber said.

Hanging over all this, though, is Hurricane Harvey. It swept through Houston, where Dianne would have the treatment, just after the Webers received the letter of appeal from Dianne's physician. They might have to drive to Texas if they cannot fly, and pack their car with food and water, or they might have to find another place to get the treatment.

Dianne Weber finds it difficult to sleep. She gets panic attacks out of the blue.

"All of a sudden, everything just hits me at one time and I'm like, 'Oh, my God, Oh, my God,'" she said.

She describes herself as a stay-at-home mom, and she and her husband have two daughters. One is in college and the other is 13.

It's when she's talking about her teenage daughter that she chokes up.

"My 13-year-old is a 13-year-old, and basically just wants to be a teenager," she said. "But every once in a while the reality of the world hits her, and that makes me upset because I just want her to live her life

normally. She says, 'Mom, what happens if chemo doesn't work?' And chemo stopped working. Now it's, 'What happens if radiation doesn't work?'

"I hate having to go there with her, but I have to be honest in a simple way."

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