

# An 'insurance warrior' fights to get pricey therapies covered

STAT

Reporting from the frontiers of science and medicine



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*H*er name is passed from one desperate family to another like an amulet.

In phone conversations and online chat rooms, she's mentioned at moments when the devout might call on a patron saint. A baby born with a deformed skull? "Call Laurie." An impossibly expensive cancer treatment? "Call Laurie."

Laurie Todd isn't a doctor, or a lawyer, or a hospital chaplain. She's a 66-year-old former massage therapist. Most of the time, she sounds cheerful and efficient. But if someone tries to pull the wool over her eyes, her voice gets low and a little bit threatening. "Do you know what I do for a living?" she asks. "I'm known as the Insurance Warrior."

The military metaphor is apt. When a health insurance company refuses to pay for a medical procedure, Todd goes to battle on behalf of the patient from her apartment outside Seattle.

She researches the scientific evidence behind the treatment. She parses the fine print of insurance policies. She scours the internet for the home phone numbers of the company's top executives, and she coaches her clients on when to call and what to say. Her strategy seems to be working: By her own count, she has won 165 of the 169 cases she's fought.

“I’m sitting here in my pajamas making decision-makers who get \$20 million a year do the right thing,” she said.

There are all sorts of reasons insurers might deny coverage: They might call a treatment experimental, or say it’s not medically necessary, or insist that a local doctor in their network do the work, rather than a distant expert.

Many health economists argue that insurers are right to deny coverage of some procedures in order to reduce America’s astronomical health care costs. But even they agree with Todd about one thing: the system is so hard to navigate that the typical patient feels powerless when facing denials.

“Health insurance is completely byzantine,” said George Loewenstein, an economist at Carnegie Mellon University. “Even insurance executives themselves ... have trouble making sense of the monster they’ve created.”

That’s where Todd comes in.

“I would be a widow if not for her,” said Diana Lentz.

## **“I am a story person. This work puts me at the epicenter of the world’s best stories”**

LAURIE TODD, THE INSURANCE WARRIOR

When Lentz’s husband, Matthew, was diagnosed with cancer, their insurance company would only pay for his surgery if he went to a local surgeon who had little experience with the procedure he needed. The Lentzes wrote an appeal themselves, demanding that Matthew be treated by a true expert. It was rejected. They enlisted Todd’s help with a second version. It, too, was rejected.

Only when Todd and the Lentzes gave speeches to a board room full of insurance executives and lawyers was the coverage approved.

Todd can speak legalese and knows her way around statistics, but she attributes her success to her master’s in 18th-century French literature. Her appeals can run 55 pages, and they interweave technical arguments with vivid details that make the patient’s story come alive.

“I wouldn’t win them if I took a legal approach. I win them because I take a literary approach,” she said. “I am a story person. This work puts me at the epicenter of the world’s best stories.”

## Reversing a death sentence

Todd wrote poems as a child. She studied French, and because she was good at languages, her guidance counselor told her to become a teacher. She did. She didn't like it much.

So she moved from state to state, taking jobs here and there, as a file clerk for a computer manufacturer, as a secretary for companies that sold everything from cookies to phones, insurance to medical devices. In California, she tried her hand at real estate, but it wasn't her cup of tea.

Todd was working as a massage therapist in Seattle when she fell ill in October 2004. First, she noticed the exhaustion: She started feeling dog tired even before she put her hands on a patient's back.

Then she realized her belly was getting bigger.

## “I would be a widow if not for her.”

DIANA LENTZ, WIFE OF CANCER PATIENT

She went to a doctor who said she was fine. But her symptoms kept getting worse, and in March 2005, she was diagnosed with late-stage ovarian cancer and rushed into surgery.

That diagnosis wasn't right either. It turned out she had appendix cancer, and it had spread into her abdominal cavity, creating tumors so voluminous that there was still plenty left inside her after 15 pounds were scooped out during the emergency operation.

Her oncologist told her there was no treatment. She decided to do her own research.

“The first place I went was PubMed, where all the scientific articles reside,” she said. “What I learned was that there's lots and lots of science about appendix cancer. And I learned that there was a certain surgeon in Washington, D.C., who stood head and shoulders above the rest.”

But her insurance company would not pay for him to operate because he was out-of-network. From an insurer's perspective, contracting with certain hospitals allows them to keep the price for each service reasonable.

From Todd's perspective, though, the insurance company's decision seemed like a death sentence. She knew this surgery was as intricate as defusing a bomb, and she'd seen research showing that a surgeon only got the best outcomes after performing the surgery at least 150 times.

She'd gone to see the in-network surgeon her insurance company recommended, and she wasn't impressed: "I said, 'How many of these surgeries have you done?' and he goes, 'Six.' And I said, 'How are your patients doing?' He said, 'Don't know, don't follow 'em.' And I said, 'Thank you very much, I'm out of here.'"

Todd went ahead and booked her surgery in D.C. But she was in a bind. She was self-employed, and she was too sick to work. She had almost no money.

Even without complications, her surgery could cost hundreds of thousands of dollars.

"I wasn't going to die because my insurance company refused to pay," she said. And so she set about writing an appeal.

"Where do you start with a strategy game? You study your opponent," she said.

She read the insurance company's entire website. She created a flow chart of the organization, listing its CEO, and its vice presidents, and its board members. She went to the public library, sat on the floor, and read everything they had on insurance law. She reviewed every article she could find on appendix cancer. Then she began to write.

"Treatments are denied with words," she said. "And denials are overturned with words."

She estimates that her entire hospital stay cost \$347,000 — and her insurance company paid for everything but \$9.

## **A warrior in purple flannel PJs**

The surgery was like getting hit by a bus, Todd said. She was in the hospital for 43 days. When she came back to Seattle, she couldn't climb the stairs to her apartment.

"It's like a tsunami had swept everything away: who I was before, my work, my stamina. I had no idea what was going to happen next," she said.

What happened next was a phone call, out of the blue, from a man named Bob. He had appendix cancer, and he needed the same surgery she'd just had. His insurance company was refusing to pay for it, not because it was out-of-network, but because they said the procedure was experimental. He'd heard from an appendix cancer support group that Laurie had just won an appeal. Could she help him?

She had nothing else to do. Using her appeal as a template, she wrote a document for Bob. "He called me three days later, and he said, 'Laurie, they are going to pay.' And my joy was immense."

Bob's was the first of 20 appeals she wrote that year, mostly sitting at home in her purple flannel pajamas. At first, her clients were all appendix cancer patients, referred to Todd by other families.

As she started ringing up wins, her confidence grew. In 2007, she wrote a how-to book and traveled the nation to speak at Rotary Clubs and cancer conferences. Soon she was getting calls from other kinds of patients. She only took on the ones, she said, that had “a mountain of science” behind them.

**“He said, ‘Laurie, they are going to pay.’ And my joy was immense.”**

LAURIE TODD

By then, she was charging for her services and earning a living writing appeals. Todd won’t talk about her fees, but former clients usually paid between \$1,000 and \$2,000.

“Best \$2,000 I ever spent,” said Lisa Frank of Anaheim, Calif.

Her daughter had a severe form of Tourette’s that resisted treatment. The tics came on with such violence that when she was 13, she fractured her own hip. But the tics just kept coming, the constant spasms preventing the bone from knitting back together. The pain, Frank said, made her daughter suicidal.

The insurance company wouldn’t pay for the experimental deep-brain stimulation that some doctors recommended.

“Initially, Laurie came off kind of clinical. She’s not overly friendly,” said Frank. But Todd won her over with a single question: What do you think “experimental” means? Frank gave her a definition. “No,” Todd said, “that’s not what experimental means. It means whatever your insurance company wants it to mean.”

Frank became an acolyte on the spot. She followed all Todd’s instructions — even when Todd told her they would wait until a week before her daughter’s surgery date to start working on the appeal.

That is part of Todd’s strategy. If you file an appeal months in advance, it becomes just another pile of paper caught in bureaucratic purgatory. It’s shuffled from one desk to another. The stakes are low.

Wait until you’re down to the wire, though, and your story has drama.

## Finding the 14 top targets

The first thing Todd does is to find 14 executives — the number is at once impressive, and also fits well on the cover page — that she can target with the appeal.

Some will be from the insurance company. Some will be from the patient's employer, because most Americans have self-funded plans, which means that the employer is the one paying for the medical treatment. Then she includes a few "outside eyes": usually members of the insurance company's board of directors. She picks them carefully: "I'm not going to choose heads of financial institutions, money men. I like presidents of universities, because they might be a little more impartial."

These will be the people who will receive the appeal. And the phone calls. And the follow-up phone calls.

When she sits down to write, Todd first lays out the facts of the illness, sparing little. She wrote, for instance, about the debilitating tics that wracked Frank's daughter, from biting her mouth to losing control of her bowels. She wrote of the social isolation caused by Tourette's. And of the 28 prescription drugs that had been tried, many of which had powerful side effects but provided little help.

Todd then picks apart the insurer's reason for denying coverage. In the Frank case, she mocked it for using "the coy new insurance company phrase 'Medical studies we have seen.'"

After scouring the research herself, she wrote, she believed the company "would be hard-pressed to produce these mysterious medical studies that show that deep brain stimulation is used to treat Tourette's, but is not suitable for Samantha's 'circumstances.'"

Todd also digs through patient support chat rooms to find precedents: past cases in which the company has agreed to pay for this procedure.

She likes to send her appeals to the insurance company on Sunday afternoons. The next morning, she and her client start in on what she calls "the phone attack."

"I'm behind the scenes directing the whole thing," said Todd.

Frank couldn't have asked for a better general. The insurance company capitulated, covering her daughter's brain stimulation and the subsequent courses of antibiotics and follow-up surgeries. The treatment was a success.

"I never thought my daughter would ever be able to finish school, to learn to drive, let alone to have a date," said Frank. "Now she has a part-time job, she's a senior, she has a boyfriend, she's a wonderful guitar player."

**“You have the right to independent medical review, but how good are you going to be at taking advantage of it if you’ve got cancer?”**

DUSTIN BERGER, ATTORNEY

Families like Frank’s could go to an attorney for help crafting their appeal. But “it’s not a lucrative thing for attorneys to do,” said David Trueman, a New York lawyer who taught medical law at Columbia. “It doesn’t fall within the traditional confines of health law. There aren’t a whole lot of us out there who do this.”

Patients can also demand an external review of their case. They have a fair shot at winning: In states that tabulate such statistics, a third to a half of insurance companies’ denials get overturned by external, independent review boards. But it’s hard to navigate that system alone.

“You have the right to independent medical review, but how good are you going to be at taking advantage of it if you’ve got cancer?” said Dustin Berger, an attorney in Wyoming who has written about health insurance appeals.

Every health system rations care one way or another. And some might say that a warrior like Todd is sucking the system dry. To her, that analysis is backwards: She believes she gets patients the treatments that have the best chance of working, instead of wasting their time — and the insurers’ money — on endless rounds of less effective interventions.

“People say, ‘The insurance companies might come and torch your car,’” said Todd, laughing. “But I’m the insurance company’s best friend. I’m saving them hundreds of thousands of dollars by finding the patient the best treatment for them.”

Many of Todd’s clients — she calls them “helpees” — have become friends, and they send a steady stream of other patients her way. Now, they are encouraging her to train a successor.

“She’s an older lady,” said Frank. “She’s in her 60s, working alone, and she’s not going to be around forever.”