

Still fighting: Vietnam vets seek help for rare cancer

November 11 2016, by Robin Mcdowell And Margie Mason



Mike Baughman sits for a photo at his home in Danville, Calif., on Tuesday, Aug. 2, 2016. The 64-year-old is among hundreds of veterans who have been diagnosed with cholangiocarcinoma, a rare form of bile duct cancer that may be linked to their time in the service and an unexpected source: parasites in raw or poorly cooked river fish. (AP Photo/Ben Margot)

Mike Baughman considered himself one of the lucky ones, returning

from Vietnam without any major injuries or psychological scars. But after falling ill nearly a half-century later, he found out he did not escape the war after all.

The 64-year-old is among hundreds of veterans who have been diagnosed with a rare [bile duct](#) cancer that may be linked to their time in the service and an unexpected source: parasites in raw or poorly cooked river fish.

The worms infect an estimated 25 million people, mostly in Asia, but are less known in America. They can easily be wiped out with a few pills early on. Left untreated, a cancer known as cholangiocarcinoma can develop, often killing patients just a few months after symptoms appear.

The U.S. government acknowledges that liver flukes, endemic in the steamy jungles of Vietnam, are likely killing some former soldiers. Ralph Erickson, who heads post-deployment health services at the Department of Veterans Affairs, said about 700 cholangiocarcinoma patients have passed through the agency's medical system in the past 15 years.

Less than half of those submitted claims for benefits, in part because they were unaware of a potential link to time in service. Of the claims submitted, 3 out of 4 have been rejected, according to data obtained by The Associated Press through the Freedom of Information Act.

The VA requires veterans to show medical conditions are at least "as likely as not" related to their time in service to receive financial help, but doctors note that often isn't easy with bile duct cancer caused by liver flukes.

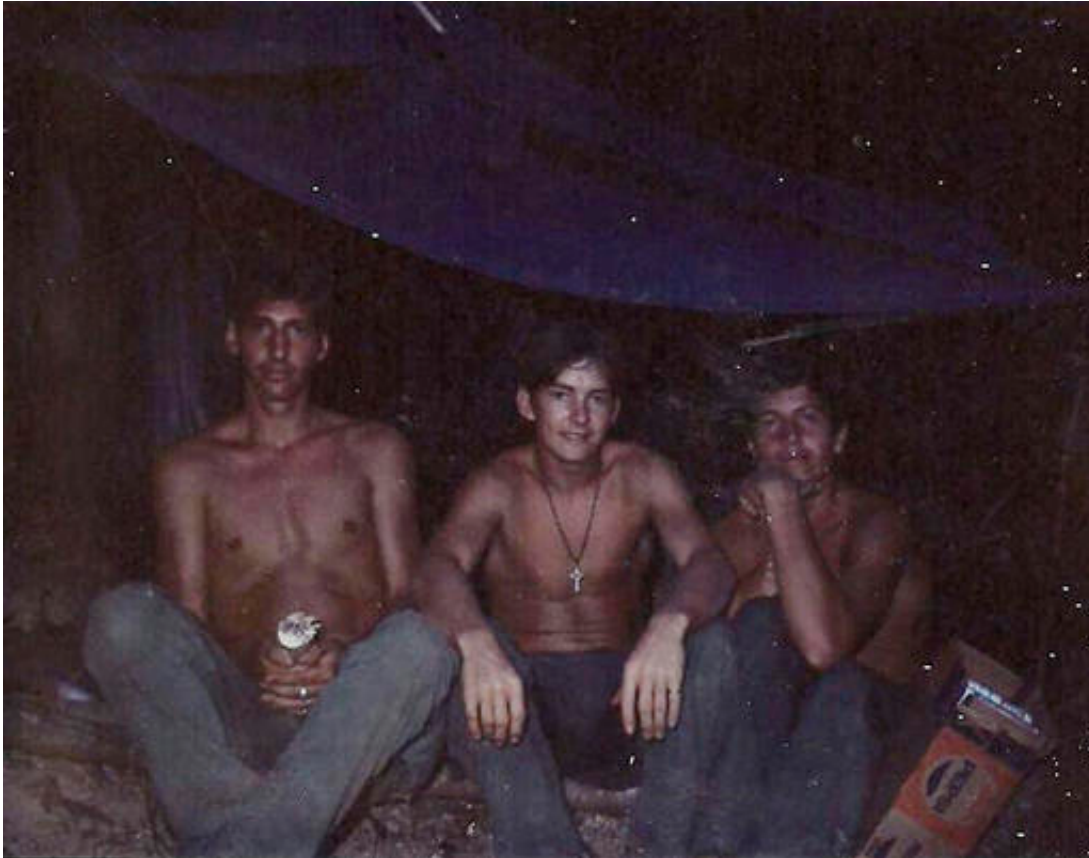
The parasites typically go undetected, sometimes living for more than 25 years without making their hosts sick. The body reacts by trying to wall

off the organisms. This causes inflammation and scarring and, over time, can lead to cancer. The first symptoms are often jaundice, itchy skin and rapid weight loss. By then, the disease is usually advanced.

If American doctors better understood bile duct cancer and the potential risks to those who served in Vietnam, they could use ultrasounds to check veterans for inflammation, and then surgery might be possible for some of them, said Jeff Bethony, a liver fluke expert at George Washington University.

"Early is key," he said, adding he regularly receives desperate letters from veterans' family members. "The VA should be testing for this."

Once diagnosed, most men don't realize there may be a connection to their service in Vietnam. The few who figure it out often spend their final months fighting for recognition and benefits, leaving them feeling angry and abandoned, as many did when they first came home from the war.



This 1970s photo provided by Mike Baughman shows him, center, with colleagues while serving in the U.S. Army in the Vietnam War. At 64, Baughman is among hundreds of veterans who have been diagnosed with cholangiocarcinoma, a rare form of bile duct cancer that may be linked to their time in the service and an unexpected source: parasites in raw or poorly cooked river fish. (Courtesy Mike Baughman via AP)

"Hard to believe," Baughman said in his living room, flipping through a photo album from his war days. "I dodged all those bullets, then get killed by a fish."

Baughman had just turned 19 when his draft number came up in late

1970. He was soon deployed to central Vietnam near Hue to do reconnaissance in the mountains. Although he was the youngest in his Army unit, he quickly became one of its most valuable members.

"The Vietnamese like to shoot the first guy in line, and last guy," Baughman said. "And so that's what I trained to do: Be the first guy in."

He would walk point clearing thick jungle with a machete and, thanks partly to growing up hunting in the hills of West Virginia, he proved gifted at noticing the smallest twig or leaf brushed out of place by the enemy. It was his job to spot booby traps and potential ambushes.

Often on long missions, sometimes forced to sleep outside with sheets of monsoon rain pelting down, his unit would run out of rations and go fishing for dinner near the border with Laos.

"We would throw a grenade in the water, and then scoop them off the river floor," Baughman said. "We called it 'fish on a stick.'"

The men would use a helmet and a tiny blue smokeless flame to cook the fish as best they could, but it never really got done.

Years later, when he returned home, those makeshift meals became just another story he would tell about roughing it in Vietnam. He went on to earn a master's degree and became a successful engineer in Silicon Valley working for Atari, Apple and others.

In October 2013, he was about to remarry and decided to get a long-overdue physical. He felt fine, but his blood work indicated there might be a problem with his liver. Further testing revealed he had bile duct cancer.



Mike Baughman holds a 1971 photo of himself in his U.S. Army uniform at his home in Danville, Calif., on Tuesday, Aug. 2, 2016. The 64-year-old is among hundreds of veterans who have been diagnosed with cholangiocarcinoma, a rare form of bile duct cancer that may be linked to their time in the service and an unexpected source: parasites in raw or poorly cooked river fish. (AP Photo/Ben Margot)

After researching the condition, Baughman discovered that worms ingested decades ago in that raw "fish on a stick" could be killing him. He turned to the VA for help, and his private physician wrote a letter

highlighting the potential connection between the worms and the disease.

He went to a VA doctor as well, who also acknowledged liver flukes were one of the main risk factors for the cancer but concluded there was "no evidence of infection" from Baughman's service time.

He was twice denied benefits in 2015, and is waiting for the results of his latest appeal.

Liver flukes are found mainly in parts of Southeast Asia, China and South Korea, where residents and tourists alike risk infection from specific types of freshwater fish such as tilapia and carp.

In one location in Laos, researchers found liver flukes—which can survive pickling and fermentation—in about 60 percent of villagers, and in some parts of Vietnam, up to 40 percent were infected. Experts say it's hard to know how many people in the region may be dying from cholangiocarcinoma caused by the parasites because there are few cancer registries.

In northeastern Thailand, where many villagers have a taste for the sour fish dish pla som, new bile duct cancers affect about 84 in 100,000 people, the world's highest recorded rate. Little research has been conducted outside of Thailand, where mobile clinics routinely perform bile duct ultrasound screenings in hard-hit areas.

Once cancer is detected, surgery is sometimes an option, depending on the tumor's location. Liver transplants typically aren't performed due to organ shortages and poor prognosis.

In the United States, cholangiocarcinoma is extremely rare, with roughly

5,000 people diagnosed each year, including some Asian immigrants who ate infected fish in their native countries. Liver flukes aren't the only risk factor for the disease; others include hepatitis B and C, cirrhosis and bile duct stones.

But some physicians say for Vietnam veterans diagnosed decades after U.S.-backed Saigon fell to communist forces in 1975, the cancer is "as likely as not" tied to their service time. And by VA standards, that should be enough to receive benefits.



This Sept. 7, 2016 photo shows a display of preserved liver fluke parasites at the Siriraj Hospital in Bangkok, Thailand. Cholangiocarcinoma, a rare form of bile duct cancer, is linked to liver fluke parasites in raw or poorly cooked river fish. (AP Photo/Sakchai Lalit)

Asked if it was likely men were infected on the battlefield, Dr. Banchob Sripa, a leading expert on the disease at Khon Kaen University in Thailand, said "it is the only way to explain it." He said doctors in the U.S. and Australia, which also sent troops to the war, have contacted him for help in determining whether the parasites are to blame for veterans' cancer.

More than 100 appeals for cholangiocarcinoma dating back to the early 1990s are on the VA's website. Though Erickson said there have been no significant case increases among veterans in recent years, data collected following an AP inquiry showed the number of benefit claims has increased sixfold since 2003.

Claims hit a high of 60 last year, with nearly 80 percent denied. Decisions appear to be haphazard. Some are approved automatically. Others, presented with the same evidence, are denied.

For instance, some rejections were based on the fact that parasites were not found in stool samples, but those tests were conducted years after the worms would have died. Other claims were dismissed because the veteran did not report his illness within a year of leaving Vietnam, yet symptoms typically don't appear until decades later.

VA officials say while they're sympathetic, it's up to the men to prove that liver flukes from Vietnam are killing them. They say because the cancer remains rare, it would be unrealistic and onerous to carry out regular screenings.

"This is still a legal process that both the VA and the veteran have to go through, and we will look at each case and all the evidence that is presented to us and make a determination at that point," said Steve Westerfeld, a spokesman for the VA's Veterans Benefits Administration. "Certainly any veteran has an opportunity to appeal."

Many do, sometimes two or three times before either getting approved or giving up.

"It's discouraging to fight for something that you think should probably be available for people who actually went over and served," Mike Brown of Valencia, California, told the AP earlier this year after learning he had [bile duct cancer](#). He died last month at age 68, just days after finding out the VA had approved his claim.

Often, it's the widows who are left fighting.

"It's bad enough," said Anne Petitti, whose husband, Mario, died from the disease in 2010, just a few months after being diagnosed. "They shouldn't be put through the wringer or have to go through all the red tape."



This Sept. 7, 2016 photo shows a section of a preserved liver with cholangiocarcinoma, on display at the Siriraj Hospital in Bangkok, Thailand. The rare form of bile duct cancer is linked to liver fluke parasites in raw or poorly cooked river fish. (AP Photo/Sakchai Lalit)

She eventually won her fight with the VA, and set up a Facebook page to help other veterans navigate the system while also cataloging new cases.

How much veterans, or their families, are compensated depends on many factors, including to what degree the illness is affecting their ability to have productive lives. An unmarried veteran can get nearly \$3,000 a month, but some spouses said they get about half that amount. For many, it's not about the money. It's about raising awareness, both among [veterans](#) and the VA, and receiving recognition for their service.

"Most vets understand very quickly it's a terminal disease and that they don't have much time," Petitti said.

Baughman talks about his own future with caution, even though he's already beaten the odds: He was supposed to have died last November.

The illness forced him to stop working, and his medical bills have skyrocketed from all the tests, radiation and chemotherapy. He's luckier than some because he has good insurance.

He's not in touch with most of the guys from his old unit, but he worries about them too. Unlike today's troops, those who served in Vietnam were shunned when they came home. It's one more reason having this medical condition recognized by the VA matters so much to him.

"It'd be nice to have me win my little battle," he said. "But ... I want the

government to do it for everybody."

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