

Why It's So Hard To Predict How Much Funding 9/11 First Responders Need

The Senate recently voted to extend the September 11th Victim Compensation Fund for decades to come.

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The idea of getting cancer from searching through the rubble of Ground Zero after the 9/11 attacks — and then standing guard over it for months — didn't occur to Kevin Zweigbaum.

It did cross his mind that the swirling dust and fumes from the shattered World Trade Center might be unhealthy. Now retired, the New York City police sergeant vividly remembers raising the idea with workers from the Environmental Protection Agency who were at the site.

"The biggest thing that stuck in my head was just dealing with the EPA and asking how the air was, and them just smiling and saying it was fine," recalled Zweigbaum, who now has lymphoma. "I was so naive and stupid because just everything was covered with that soot, and me, I was writing my name in the windows."

On Tuesday, the Senate voted 97-to-2 to extend the September 11th Victim Compensation Fund for decades to come. It was a long, slow road to passage.

Zweigbaum, now 46, is like a lot of people outraged that nearly 18 years after the attack, former late-night TV host Jon Stewart and a dying retired New York City police detective named Luis Alvarez had to testify to Congress to hammer home the need to fully fund compensation for the victims of 9/11.

They wondered: How could it be that a cancer-stricken first responder has to travel to Washington to plead for something he and others manifestly deserve? As Stewart put it, Alvarez had to sacrifice the one thing he couldn't spare: time.

Part of the answer is the ugly politics of moving anything expensive through Congress — the Congressional Budget Office estimated it will cost \$10.2 billion for the first decade. Another less obvious reason is that 9/11 created a slow-moving epidemiological nightmare that has been as difficult for scientists to study as it has been easy for politicians and many others to overlook. It took scientists a decade to make the first connections of cancers like Zweigbaum's to 9/11, and it has taken Congress nearly 18 years to pass a permanent bill to compensate responders and

survivors, as it finally did on July 23.

“Connecting 9/11 exposures and health conditions is an extremely challenging task, in part because this was a unique exposure and because some health conditions may not occur for many years following the event,” said Dr. John Howard, the director of the National Institute for Occupational Safety and Health at the Centers for Disease Control and Prevention.

Howard, who oversees the 9/11 treatment program, was putting it mildly. After the planes struck the towers on that bright September morning, the ensuing chaos saw tens of thousands of people fleeing and thousands of responders and volunteers from around the country rushing in. The rubble — known as “The Pile” in New York — smoldered for months and smelled like molten steel and burning plastic. There was no way to track most of the people exposed or what they were breathing.

“You can’t do standard epidemiology on a disaster like this,” said Dr. Michael Crane, the medical director of the World Trade Center health program at Mount Sinai in Manhattan. “For a scientist, it’s a messy situation.”

And government officials actively resisted aggressive study of environmental threats, researchers recalled. “Early on, we weren’t allowed to do data collection and report on it. We couldn’t spend any federal dollars doing research,” said Dr. Jacqueline Moline, who runs the Northwell Health Queens World Trade Center health program.

It meant studying which illnesses stemmed from 9/11 exposure got off to a slow start. The one exception was a study done by the New York City Fire Department.

The fire department’s data “made a lot of the case about the terrible, terrible nature of this exposure,” said Crane. “It was so, so valuable for clinicians to know.”

Even that study, released in 2011, covered only data from the first seven years after the terror attacks. There was detailed information on firefighters, but it had to be compared against data from the general population. That information takes two to three years to be compiled from state registries, said Dr. David Prezant, the FDNY’s chief medical officer.

“Epidemiological research, scientific research takes time,” Prezant said. “There needs to be a volume of disease greater than expected with aging to be demonstrated as proof positive that something is World Trade Center-related.”

The science has proceeded apace, and since 2012, [dozens of cancers have been covered](#) in the compensation and treatment programs for trade center rescue workers and survivors.

When Congress renewed both programs in 2015, it extended the treatment program until 2090. The September 11th Victim Compensation Fund, which is run separately by the Justice Department and covers economic losses as well as pain and suffering, got funding for only five years.

It was the CBO's job to estimate how much money the fund would need to care for the sick, the dying and their survivors. But science could not draw a perfect picture. The CBO estimated \$7.4 billion would be needed. With cancer diagnoses and applicants both surging past expectations, only about \$2 billion was left at the end of 2018, and in February the fund cut payments by at least half.

Prezant said the number crunchers probably worked from information from 2010 and 2011 that couldn't possibly foretell the future.

The science is still slowly progressing. Crane compared it to the "three yards and a cloud of dust" saying by legendary Ohio State football coach Woody Hayes.

"That's research in environmental and occupational medicine. It's five yards, get hit on the head, fall down. Another five yards, get hit on the head, fall down," Crane said. "It's by its nature very slow."

While Congress finally [passed new legislation](#) to extend the compensation fund, there's no guarantee it will be able to swiftly address every problem that still could emerge, even based on the best current data. Indeed, the CBO said in its estimate that given so much uncertainty, and still not considering conditions such as neuropathy and autoimmune diseases being studied, higher-end scenarios could add \$4.1 billion to costs in just the next 10 years. The bill ensures money will be available, but it can't speed the science, govern the bureaucrats or control politicians who will make decisions years from now.

"I find myself sometimes lying awake just like everybody else, and saying, 'Why the hell can't we do better?'" Crane said, adding: "We are doing it just about as well as anybody could, I think."

Kevin Zweigbaum ignored his exposures until 2016, registering with the health program only after a police officer who worked for him died of 9/11-linked cancer.

Zweigbaum was diagnosed by chance in 2018 with diffuse large B-cell non-Hodgkin lymphoma.

He is in remission and retired in April, and was able to travel to Washington with [Lou Alvarez](#). Alvarez, who had stage 4 colon cancer, went into hospice after the trip and died on June 29. Zweigbaum still has a lump under his collarbone and a port for medicine embedded under his skin.

Doctors will never be able to say for sure that Alvarez or Zweigbaum's cancers were caused by their work at the trade center, only that it raised the odds significantly. Zweigbaum now has a deep appreciation for that threat, though, and he hopes later Congresses, bureaucrats and doctors will keep the epidemiological threats and impacts foremost in their minds, whatever the future holds.

"I just hope 20 years from now, people don't have to walk their way down to D.C. to try to do this all over again," Zweigbaum said.

As of July 23, they probably won't have to.

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