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Officials Slow to Hear Claims of 9/11 Illnesses

By ANTHONY DePALMA

Five years after the World Trade Center towers collapsed in a vortex of dust and ash, government officials have only recently begun to take a role in the care of many of the 40,000 responders and recovery workers who were made sick by toxic materials at ground zero.

But for many of the ill and those worried about becoming sick, government actions — coming from officials whom they see as more concerned about the politics of the moment than the health of those who responded to the emergency — are too limited and too late.

The delay in assistance along with a lack of rigorous inquiry into the magnitude of the environmental disaster unleashed that day is all the more disturbing, they say, as the country faces a future in which such disasters could happen again.

Dr. [John Howard](#), who was appointed by the Bush administration in February to coordinate the federal government's 9/11 health efforts, readily admits that costly delays and missed opportunities may have shattered responders' trust in the government.

"I can understand the frustration and the anger, and most importantly, the concern about their future," Dr. Howard said in an interview. "I can't blame them for thinking, 'Where were you when we needed you?'"

A review of recent federal initiatives reveals a pattern of the government's not fully delivering what was promised. Dr. Howard's office, for example, has no full-time staff members assigned to 9/11 health issues. For the first time, money for treatment — \$52 million — has been included in the federal budget, but even the officials

responsible concede that it is not nearly enough. And only last week did New York City release clinical guidelines that could help doctors properly diagnose 9/11-related illnesses.

“They seem to be running from the people who are sick, not standing with them and helping them,” said Representative [Carolyn B. Maloney](#), a Democrat who represents parts of Manhattan and Queens and has been critical of federal efforts at ground zero. “And that is just plain wrong.”

One of the thorniest problems, and one reason officials have given for the long delay in responding, is the difficulty of linking the dust and smoke to specific symptoms and diseases. Making a medical diagnosis for illnesses related to toxic substance exposure requires extensive and sophisticated tests. Simply measuring the toxicity of the dust has proved to be controversial.

And state workers’ compensation systems, designed to handle common workplace injuries like broken arms, are not well suited for determining an illness that may take months or years to emerge.

Even so, clinical evidence of a serious health problem surfaced not long after the attack. Initial studies of firefighters found that many had developed “trade center cough,” a stubborn hacking that caused them to cough up soot and dust particles.

A large-scale medical study came out in 2004, when the Mount Sinai Center for Occupational and Environmental Medicine reported that more than half of the first 1,138 workers it had examined had serious respiratory problems.

Workers also suffered gastrointestinal problems, acid reflux, [asthma](#) and mental stress. (Mount Sinai is scheduled to release a far larger study today, and it is expected to show serious ailments among many more workers.)

Successive studies through the years have found that the health hazards were more persistent than first thought.

A Fire Department study released this year showed that firefighters had suffered a loss in lung capacity in the first year after the attack equal to what they might have lost over 12 years of normal duty. The department has also found that the incidence of sarcoidosis, a serious lung scarring disease, rose to five times the expected rate in the first two years after 9/11.

An initial survey released in April of the 71,437 responders, residents and downtown workers who signed up for the World Trade Center Health Registry, run by the city and the federal government, showed that more than half said that they had experienced new or worsening respiratory problems since 9/11. And a Red Cross survey in May found that two-thirds of the responders and survivors who sought help in coping with emotional distress believe that grief still interferes with their lives.

One death — that of 34-year-old Detective James Zadroga in January — has been formally linked by a coroner's report to lung disease caused by trade center dust. The families of at least six other responders who died believe those deaths were also linked to toxic substance exposure at ground zero.

When Dr. Howard was appointed a few weeks after Detective Zadroga died, many in the city were relieved to have a federal czar in charge.

But Dr. Howard, who was trained as a pulmonary specialist and is the director of the National Institute for Occupational Safety and Health, has not assigned a single one of his 1,300 employees to work full time on ground zero medical issues, though about 20 work on such issues part time. And though the institute has a budget of about \$285 million, he has not received any additional money to address the complex medical issues involved.

“I'm a czar without a budget,” he said.

Meanwhile, the need for treatment assistance has grown as more people have become ill. While many rescue and recovery workers are covered by their own health insurance, that coverage may become inadequate in the years ahead. Many union workers, for example, can lose their coverage if they become too sick to work, while most illegal immigrants who worked there had no insurance.

Some 16,000 union workers and volunteers have been examined through the screening and monitoring program run by Mount Sinai, which began in 2002 with \$11.4 million in federal money and was extended in 2004 for five years with an additional \$81 million. (Information about the program is available at www.wtcexams.org.)

But until last year, there was almost no money available for treatment through the screening program. With \$9.4 million from the Red Cross, Mount Sinai doctors were able to treat 2,050 responders last year, offering them therapy, medications and medical procedures in some cases.

Ms. Maloney and other members of the New York Congressional delegation, in pushing for more federal aid, succeeded last December in getting the Bush administration to restore \$125 million in unused workers' compensation assistance that it had threatened to take back.

Of the \$125 million, about \$50 million was set aside for future workers' compensation awards and about \$52 million was split equally between two treatment programs — one for firefighters and another for injured police officers, union workers and other responders, but not office workers or neighborhood residents.

A working group appointed by Dr. Howard has not yet determined which diseases will be eligible for treatment with the new money or whether the money will cover hospital stays as well as office visits. But he recognizes that it is not nearly enough to cover New York's needs, let alone the national treatment program he intends to start.

“You don’t have to go to cancers years from now, or asbestosis, to be able to say ‘Gee, John, how far do you think this money is going to go?’ ” Dr. Howard said. “I don’t think it will go that far.”

Besides the lack of money for treatment, the absence of timely public health information made it more likely that doctors who initially saw sick responders would be unprepared to treat what they found.

Doctors at Mount Sinai have said that up to a third of the workers they examined were taking improper medications because their doctors had misdiagnosed their symptoms. Severe [sinusitis](#), for example, was treated with [antibiotics](#) even though that condition might have been caused by chemical burns from the caustic dust.

Yet it was not until Thursday, days before the fifth anniversary, that the city issued diagnostic guidelines for the unusual illnesses linked to ground zero dust, despite urging by medical specialists and labor leaders as early as December 2001.

“This is a significant failure of the public health system,” said Micki Siegel de Hernandez, health and safety director for District 1 of the [Communications Workers of America](#). Ms. Siegel de Hernandez contended that the city delayed releasing the guidelines because it was worried that acknowledging the extent of the health problems might increase its legal liability.

Dr. Thomas R. Frieden, commissioner of the city’s Department of Health and Mental Hygiene, said in an interview that the city had decided it made more sense for the doctors at Mount Sinai’s screening program to put guidelines on their Web site because they were seeing the workers while the city’s medical staff was not.

Mount Sinai did publish guidelines in early 2002, but they did not carry the weight of an official city advisory and had limited impact.

“We lost opportunities by not disseminating guidelines widely or at least putting out a caution,” Dr. Howard said.

Dr. Frieden agreed that if they had been released sooner, the guidelines might have helped clinicians make more accurate diagnoses.

“Would I rather have had the guidelines out sooner? Sure,” he said this summer. “But it’s important to get this right.” He said the delay had nothing to do with concerns about the city’s legal liability for sick responders.

About 8,000 responders have sued the city and the big contractors who worked for the city in the recovery operations, charging them with reckless disregard for workers’ health. The city has asked a federal court in Manhattan to dismiss the suit.

Although five years have passed, many questions about the environmental disaster at ground zero remain unanswered. To this day, the government has never precisely measured where the dust went, information that could help determine the health impact on residents near ground zero. And it is unclear whether cancers, possibly linked to the toxic materials, will arise in future years, or if some of the sick will get better.

For now, among the sick and their doctors, the faltering and delayed governmental response raises unsettling questions about whether the country is prepared to handle a similar catastrophe.

“I think of that every time I come to New York,” Dr. Howard said. “Given this betrayal of trust, this lack of being there at the time and all these other things, I don’t know. We can try with what we have, but it certainly is a different situation when you do it five years later.”

Documentary: 9/11: Toxic Legacy: *A documentary produced in conjunction with this article and examining the health impact of ground zero, will appear on the [DiscoveryTimes Channel](#) tonight at 8 p.m.*