Medical Views of 9/11’s Dust Show Big Gaps

Fred R. Conrad/The New York Times
Joseph Jones, whose wife, Felicia Dunn-Jones, 42, a lawyer, worked near the twin towers, leaves flowers at the 9/11 memorial on Staten Island.

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In 2004, Kenneth R. Feinberg, special master of the federal Sept. 11 Victim Compensation Fund, awarded $2.6 million to the family of a downtown office worker who died from a rare lung disease five months after fleeing from the dust cloud released when the twin towers fell. That decision made the worker, Felicia Dunn-Jones, a 42-year-old lawyer, the first official fatality of the dust, and one of only two deaths to be formally linked to the toxic air at ground zero.

Ground Zero Dust and Disease

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Felicia Dunn-Jones, whose death was deemed a result of 9/11 dust.

The New York City medical examiner’s office, however, has refused to put her on its official list of 9/11 victims, saying that by its standards there was insufficient medical evidence to link her death to the dust.

Mrs. Dunn-Jones’s case shows how difficult it can be to prove a causal connection with any scientific certainty — and how even government agencies can disagree. With thousands of people now seeking compensation and treatment for dust exposure, the debate about the relationship between the toxic particles and disease will be a central issue in the flood of Sept.
11-related lawsuits. Health experts are starting to document the connections, but any firm conclusion is still years away.

Most of the suits involve workers who spent weeks and months on the pile at ground zero and say the city and other agencies failed to protect them from the toxic dust. Others involve residents who say they were made sick by dust that settled in their homes. Mrs. Dunn-Jones was among those downtown office workers caught in the initial fallout.

The question that arises in all these cases is straightforward: Can a link between the dust and disease be proved with scientific certainty? The answer is anything but simple.

“Certainty is a word we always dance around,” said Joseph Graziano, associate dean for research at the Mailman School of Public Health at Columbia University. For him, searching for the cause of disease is like developing film. “At first you see a faint image of what the real picture is,” Dr. Graziano said, “and then, over time, you see it with much more clarity. In these relatively early times, the image is still faint.”

It can take decades to approach any degree of certainty. For instance, only after years of observation did doctors agree that there was a strong link between asbestos and diseases like asbestosis and mesothelioma.

In legal cases, “a reasonable degree of medical certainty” is considered the gold standard in making a causal connection. Last week, a federal judge cleared the way for thousands of workers’ lawsuits to go to trial. When the cases are heard, any proof that does not meet that legal standard is likely to be challenged.

But outside the courtroom, scientists say, even a less rigorous link could be sufficient to warrant expanding the range of illnesses covered by treatment programs, and to serve as the basis for issuing cautions to people in high-risk groups. When the health effects are too new or the evidence is too vague for a strong link, lesser indicators like the concurrence of different studies have to be relied on.

For example, nearly every ground zero study shows that workers and residents exposed to the dust in the hours after the collapse have suffered the worst health problems. The consistency in that data has helped doctors monitor and treat people since Sept. 11.

And it may also help explain why Mrs. Dunn-Jones, a dynamic civil rights lawyer with the United States Department of Education, became so sick so quickly. As she was swallowed by a whirling dust plume filled with asbestos, benzene, dioxin and other hazards when the first tower
fell, all she could do was cover her nose and mouth as she fled from her office one block north of the World Trade Center.

It was night by the time she got home to Staten Island. “She was in a state of shock,” her husband, Joseph Jones, recalled. Her clothes were still dusty, but he didn’t pay much attention. “I was just so happy to see her,” he said.

For the next few months, life returned to normal, until Mrs. Dunn-Jones developed a cough. In January 2002, the cough grew worse. On Feb. 10, she suddenly stopped breathing and died.

Mr. Jones, 54, an assistant manager at a Brooklyn pharmacy, was stunned. Then, when he received the official death certificate months later, he was shocked to see an unfamiliar word — sarcoidosis.

“Even though I was in the medical field, I had never heard of it,” he said.

After reading several medical reports on sarcoidosis — including one by Dr. David J. Prezant, deputy chief medical officer of the New York Fire Department — Mr. Jones and his lawyer, Richard H. Bennett, wondered if Mrs. Dunn-Jones’s mysterious death could be linked to 9/11 dust because sarcoidosis, which produces microscopic lumps called granulomas, on vital organs, is often associated with exposure to environmental hazards.
They took the case to Mr. Feinberg and the victim compensation fund, which gave $7 billion to the families of those killed or injured on 9/11.

Mr. Feinberg initially expressed doubts about the claim and demanded to see definitive medical evidence linking Mrs. Dunn-Jones’s sarcoidosis to the dust.

Dr. Prezant, who declined to be interviewed for this article, was one of two experts who testified at a hearing conducted by Mr. Feinberg. In the first four years after 9/11, he found 20 cases of sarcoidosis in the Fire Department, a rate of 80 per 100,000 in the first year (with treatment, all are now stable), compared with a national rate of fewer than 6 per 100,000, according to the American Thoracic Society.

The other expert was Dr. Alan M. Fein, a clinical professor of medicine at the New York University School of Medicine. He, too, was skeptical at first, but he said he changed his mind after reviewing Mrs. Dunn-Jones’s medical record, including the autopsy report. “I’m comfortable saying her death was caused by exposure to the dust,” Dr. Fein said in an interview.

In March 2004, Mr. Feinberg agreed, making Mrs. Dunn-Jones’s death the only dust-related fatality recognized by the fund. Only one other death has been formally linked to the dust: In April, a New Jersey coroner determined that James Zadroga, 34, a New York City police detective, had died of a disease similar to sarcoidosis, also caused by his exposure to ground zero dust.

Mr. Jones welcomed the settlement from the victim compensation fund, and believes that his wife was a 9/11 victim as surely as if she had died in the towers. He sent Mr. Feinberg’s decision to the city’s chief medical examiner, Dr. Charles S. Hirsch, and asked that his wife be
put on the official list so that her name could be read on Sept. 11. Dr. Hirsch refused, a
spokeswoman said, because the available evidence did not prove the connection “with a
reasonable degree of medical certainty”— the highest medical standard generally used in legal
cases.

Mr. Feinberg’s decision had been based on a different standard: a preponderance of medical
evidence.

That was proof enough for the Staten Island Memorial Commission, which has engraved Mrs.
Dunn-Jones’s name on the bone-white memorial on the island’s north shore.

Representative Carolyn B. Maloney, who has fought to get medical care for 9/11 victims, said
the contradictory conclusions about Mrs. Dunn-Jones’s death underscored the importance of
deciding who has the final say on causal links. “They should be medical decisions, not political
ones,” she said, suggesting that city officials may have a conflict of interest in making such
determinations since the city is a defendant in the ground zero workers’ lawsuits.

She has introduced a bill to reopen the federal compensation fund to people whose illnesses
became known after the original eligibility period ended in 2003.

In the effort to collect definitive data, Dr. John Howard, the federal government’s 9/11 health
coordinator, recently circulated a draft set of autopsy protocols that directs pathologists to use a
standard of proof that establishes both biological plausibility and unequivocal evidence of a
causal connection to the dust. But doctors and elected officials have said those standards are
so restrictive that almost no death could be linked to the dust for years to come. A spokesman
for Dr. Howard said the guidelines were being refined.

In another effort, the Mount Sinai Medical Center, which has screened thousands of ground
zero workers, has begun a long-term study of the incidence of diseases to identify any rates that
exceed national averages.

“Right now we’re in the process of confirming every case of interstitial lung disease, every
cancer, every sarcoidosis that has been reported to us by responders in their visits,” said Dr.
Jeanne M. Stellman, director of the public health program at Columbia University, is leading the
data collection project.

“We are actively trying to determine whether Detective Zadroga and Mrs. Dunn-Jones are
alone,” she said. “And we are trying to find a way to do this that is scientifically correct while also
being responsive to the needs and fears of the communities involved.”