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News

Clearing the Air

9/11's toxic dust obscures answers about cancer and other health claims

by Graham Rayman

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To understand how deeply New Yorkers hold the conviction that 9/11 environmental fallout is killing people, you need only to have attended the August 21 public meeting that was held in a chamber across from City Hall.

The topic was the disastrous August 18 fire in the heavily contaminated Deutsche Bank building at 130 Liberty Street, which killed two firefighters. Only three weeks before the sixth anniversary of the terror attacks, here were city, state, and federal officials once again trying to downplay the possibility that the fire released environmental toxins into the neighborhood.

But the air was so thick with skepticism from the crowd that the assertions couldn't gain any traction. One resident described the debacle as a "religious kind of shame." Marc Ameruso, a lower-Manhattan community-board member, said, "The ghost of the World Trade Center is rearing its ugly head once again."

It was hard to blame the doubters. The Bush, Pataki, and Giuliani administrations have either misled or poorly informed the public about the toxic dangers of what has been described "as the largest acute environmental disaster that ever has befallen New York City."

In the early days following the attacks, even the men and women who worked on "the Pile" expressed skepticism about the negative health effects of 9/11's toxic cloud. But that initial doubt has given way to a popular view that blames the dust cloud for virtually every ailment experienced by someone who was at or near Ground Zero. And broad public acceptance of the notion that the cloud has sickened people is creating a powerful momentum for long-term government support for the vast number of people affected.

Based on a *Voice* count, more than 52 illnesses have been mentioned in connection with the 9/11 toxic cloud, either anecdotally in press reports, more broadly in government comments, or with some scientific underpinning in research studies. "In the six years since the attacks, we have accumulated a mountain of evidence that tens of thousands of those exposed are suffering from chronic respiratory disease and, increasingly, a variety of rare cancers," said Representative Jerrold Nadler, who has emerged as a leading advocate on the issue, during a June 25 congressional hearing.

More than 100 scientific papers have been written exploring a link between 9/11 and health ailments. Many of those strongly suggest that the dust was a factor in increased respiratory illnesses among people exposed to the cloud.

Even as they suggest a connection, however, researchers also often hedge their language, describe flaws in the research, or suggest that definitive links will be hard to establish. The question of what we know about those links—and what we don't know—is a subject that likely will occupy researchers and those affected for years to come. "More than 5 years after the World Trade Center disaster on September 11, 2001, uncertainty and controversy remain about the health risks posed by inhaling the dust from the collapse of the twin towers, the subsequent fires, and the cleanup effort," epidemiologists Jonathan Samet and Alison Geyh of the Johns Hopkins Bloomberg School of Public Health wrote in May in *The New England Journal of Medicine*.

The hard data leave little doubt that heavy exposure led to documented respiratory ailments, but

there's far less certainty about more severe respiratory ailments, particularly the cancers that some have linked to Ground Zero.

"What's clearest and strongest is in the immediate persistence of effects on the respiratory system of the more exposed," Samet told the *Voice* in a recent interview. "Where the uncertainty begins is when one tries to understand the consequences for the broader public and the longer-term effects."

The World Trade Center health crisis is a saga told on a massive scale. Consider: 10,000 people have signed up for the pending class-action lawsuit against the city, and 71,000 for the city's World Trade Center Health Registry.

Nearly 20,000 people have been screened in Mount Sinai's medical-monitoring program. More than 1,300 people have been treated at the city-funded WTC clinic at Bellevue Hospital.

The estimated number of Ground Zero responders is 40,000, and the estimated number of people who came in contact with the dust is 410,000.

More than 600 firefighters have taken early retirement because of permanent, disabling respiratory illness, along with an unknown number of police officers, city workers, construction workers, and members of other groups.

In courtrooms, hearing rooms, and government offices, there is a paper war raging between people who claim they are sick, and the city, state, and federal agencies that must decide whether to pay for their medical coverage.

More than 3,000 police officers have filed disability claims, but the NYPD has approved just 116 cases, *The New York Sun* reported recently.

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Last month, it was reported that 19,000 people had signed up with the state for workers' compensation benefits, but the true eligible population is believed to be 100,000. Take just one workers' comp case, that of former Sanitation Department employee Jack Saltarella, who drove barges filled with WTC dust and debris from Ground Zero to the Fresh Kills landfill.

Claiming respiratory illness, Saltarella and a dozen other barge workers sued the city, but a judge tossed the case out, citing a lack of evidence. However, that decision came before public opinion began to look more favorably on arguments linking the dust and illnesses.

"I used to be able to go for hours without stopping," Saltarella says. "Now I get exhausted just from breathing." He was subsequently diagnosed with chronic respiratory disorder, which the doctors concluded was related to dust exposure. Saltarella filed for workers' compensation; years later, he is still fighting for those benefits. A judge ruled in his favor five months ago, he says, but the city filed an appeal.

The experience has left him with a profound sense of bitterness. "The city acted like I was the only person complaining, but there's a whole bunch of people," Saltarella says. "They made you feel like you're a piece of shit—someone looking to take the city. There's a whole bunch of those guys. We didn't cause this; they caused us to have this."

At least 12 deaths from lung ailments and cancer have been blamed on the dust cloud in press reports. Among them is firefighter Ray Hauber, 47, who died of esophageal cancer. Friends and family say Hauber was a healthy man who didn't smoke.

In two of the cases—those of Police Officer James Zadroga, who died of pulmonary fibrosis, and lawyer Felicia Dunn Jones, who died of sarcoidosis—local medical examiners agreed that exposure to the dust was a factor.

Another was that of Cesar Borja, a police officer who died of pulmonary fibrosis. Initial reports said that he'd worked 16-hour shifts at Ground Zero, but records subsequently showed that he worked there only 17 days, starting in December 2001—casting doubt on whether his fatal illness stemmed from his time at Ground Zero.

Not long before she died from lung cancer, lower-Manhattan resident Etta Sanders wrote an essay blaming her own illness on the WTC exposures.

"If the government had said we're not sure about the safety of the air and it would be prudent for residents to stay away, I don't think I would have this cancer," she wrote in the essay, which was later published in the *Tribeca Tribune*. "I dearly hope that I am in a small minority of people who were so gravely harmed by the aftermath of the WTC attacks, but I fear otherwise."

In all, the deaths of 170 people who spent time at Ground Zero have been reported to the New York State Department of Health as part of an ongoing WTC fatality study. But it is unclear whether any of those deaths are related to the dust.

Indeed, there is much that remains unknown about the health effects of 9/11. The Samet and Geyh paper, for example, highlights a number of those questions. Even the actual size of the exposed population, they write, is still unclear.

Also, the government's failure to sample the air immediately after the disaster in a comprehensive manner means that hard data are missing on the types and levels of contaminants in the cloud during the period of the worst exposures, they write.

Paul Lioy, a professor of environmental and occupational medicine at Rutgers University, echoes that point in a paper published in a medical journal in November: "Five years after the attack, many people still do not know that the complex mixture of dust and smoke initially suspended in the air remains somewhat of a scientific mystery."

Even though people exposed to the cloud may be inclined to blame any future illness they contract on that exposure, Samet and Geyh write that the only way to confirm a link is through epidemiological studies that examine a large enough population of exposed people and compare it to a similar population of people who weren't. But that vast and difficult study has yet to be done.

"Even the full suite of research efforts in progress may never produce the evidence needed to answer all of the questions that will be raised about the long-term health effects of September 11," the authors conclude.

In March, Jeanne Stellman, a well- regarded epidemiologist at Columbia University, also sounded a cautionary note: "The current studies . . . cannot possibly provide us with insight into the overall burden of disease and disability because the diseases associated with WTC-like exposures are chronic and take many years to manifest themselves.

"Thus it is too early to know the full extent to which exposure to carcinogens and other toxic and stressful working conditions will lead to elevated rates of cancer or whether the rescue, recovery and cleanup workers will suffer from more cardiovascular disease or other chronic diseases."

The city's health registry, Stellman wrote, is useful but "far from complete. . . . No government or private agency has identified all the workers who participated in the operations."

Stellman compared the situation to that of the soldiers exposed to Agent Orange during the Vietnam War, an environmental calamity she's spent decades studying.

"Some 30 years after the end of the Vietnam War and more than 35 years after Agent Orange was sprayed, we still cannot tell our veterans and their loved ones what the effects of exposures to the herbicides are," she wrote.

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David Carpenter, a professor of environmental health and toxicology in the School of Public Health at SUNY Albany, also notes the problems confronting researchers. "You need some limit on who was exposed, where they were, how long they were there," he says. "There's no reliable chemical measure, and we don't have a comprehensive list of the diseases we are going to be concerned about.

"It's pretty clear in adults that there is a greater increase in chronic respiratory disease, but it's very

difficult to quantify that," he adds.

A common thread in the World Trade Center research has been a reliance on surveys. The city's World Trade Center Health Registry, for example, is basically a very large collection of surveys.

Some in the research community have raised questions about the validity of such data. Epidemiologists David Vlahov and Sandro Galea of the New York Academy of Medicine, for example, questioned the results of another study that used a self-administered survey to conclude that there were much higher rates of respiratory symptoms after 9/11 among the residents of lower Manhattan than among people on the Upper West Side. Vlahov and Galea caution that people in lower Manhattan would be more far likely to respond to the survey, since they have a greater interest in the results. Just over 2,300 people responded from lower Manhattan, and only 291 from the Upper West Side.

Because the survey was done some eight to 16 months after September 11, the accuracy of the memory of those surveyed is also questionable, the authors state.

"This study in some ways raises more questions than it answers," Vlahov and Galea write. "Inferences about individual exposures must be drawn with caution."

In April, using survey data from the registry, the city published a study of 8,418 survivors of the Twin Towers. That study found that half of those people reported one or more new respiratory symptoms after 9/11.

The authors of the study went on to list all of the problems with their conclusions. For one thing, they say, the total number of building survivors is unknown. For another, the data are based on the memories of people taking a survey two or three years after the fact. And the survey never established the boundaries of the dust cloud.

Finally, the people in the study were those who signed up for the registry—possibly biasing the sample. "This effect has been observed in other environmental studies in which persons who believed they were exposed tend to over-report health problems," the authors write.

In the spectrum of scientific knowledge, the strongest evidence of a link between the dust and respiratory illness is provided by the city's firefighters.

The FDNY had been collecting respiratory data on its members years before 9/11. As a result, doctors were able to compare the lung conditions of their patients before and after the attacks.

More than 3,000 firefighters have sought respiratory treatment since 9/11. Retirements based on lung problems have risen by four times the previous average. The observed drop in lung function after 9/11 was 12 times greater than the average annual decline in the five years before 9/11. More than 25 percent of firefighters showed symptoms of asthma or reactive airway dysfunction.

The most recent study of firefighters, published in March, concluded that 26 firefighters contracted a respiratory disease, sarcoidosis, in the five years after 9/11—a rate higher than in the 15 years prior to 9/11. Half of those firefighters got the disease in the first year after the attack, and the remainder over the next four years.

"It's striking data—way above the norm even for their population," Carpenter says. For most of the other affected groups, however, data for the period prior to 9/11 generally do not exist, which makes it much more difficult to make judgments with the same kind of precision.

The New York Police Department, for example, is only now seeking funding to do a wide-ranging study of the thousands of police officers who worked at the site. That effort has been criticized by police unions for coming too late—and at a time when the NYPD is fighting disability claims.

In a study released last week, the city reported that 3.6 percent of 25,000 Ground Zero workers said that they had developed asthma after working at the site—a rate 12 times higher than that of the general population.

The survey also found that workers who were caught in the cloud or worked on the debris pile reported higher rates of asthma, and that those who wore dust masks reported asthma at a lower rate than

those who did not. In other words, the higher your exposure, the greater your likelihood of reporting asthma.

The research evidence on severe respiratory disease, however, is limited. Other than the study of sarcoidosis in firefighters, there are just three other studies on severe respiratory disease, with each one examining a single specific case of three separate illnesses.

"It's hard to document and identify small elevations in rare events, so it takes a lot of work," says Lorna Thorpe, deputy commissioner of the city's health department. "Of the broader, more common ailments—cough, asthma, wheezing—they are very common in the general population, so it's not as easy to verify. The question of persistence of symptoms is of paramount importance."

The most persuasive study to date was released in September 2006 by the Mount Sinai WTC Medical Monitoring Program.

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The study concluded that Ground Zero responders suffered exposure-related increases in respiratory- and pulmonary-test abnormalities that lingered up to 2.5 years after the attacks, with those who reached the site within the first two days of the attacks experiencing the worst symptoms.

Of the 9,442 responders tested between July 2002 and April 2004, 69 percent reported new or worsened respiratory symptoms after being involved in WTC work, the study found. The symptoms persisted in 59 percent of those workers. And 61 percent of the workers without prior symptoms developed breathing troubles after 9/11.

One in four had abnormal breathing-test results. Among nonsmokers, 27 percent had abnormal results, compared with 13 percent in the general population. The prevalence of low lung capacity among nonsmokers was five times greater than in the general U.S. population.

"There should no longer be any doubt about the health effects of the World Trade Center. Our patients are sick," says Dr. Robin Herbert, co-director of the Mount Sinai program.

Phillip Landrigan, one of the study's authors, says that the caustic dust caused burning and scarring in the lungs, leading to the shrinking of tissues and "functional abnormalities."

"There is a high likelihood that a lot of this impairment is going to be permanent," says Landrigan.

The authors of the study proposed that WTC workers should be tracked for "at least 20 to 30 years." About 6,500 people are being treated in Mount Sinai and other hospitals by a federally funded consortium.

The authors acknowledge limitations in the study, the chief one being that they did not have pre–September 11 clinical data. And they note that the sicker responders were more likely to sign up for the clinic, which could skew the percentages.

Officials with the city's health department have also attempted to describe the array of illnesses cropping up in the WTC population.

In March, city health commissioner Thomas Frieden wrote an article in which he listed persistent mental-health ailments and mild to severe respiratory problems. Some people found that pre-existing conditions like asthma got worse, he wrote; others developed new symptoms or illnesses. People who were caught in the dust cloud had the highest risk of exposure.

But Frieden said the exact number of people who developed severe respiratory illness is still unknown. Also unknown is how many people have respiratory symptoms today, which illnesses are most common, and what factors other than dust-cloud exposure contributed to those illnesses.

The Frieden article came six months after the health department finally issued guidelines for doctors that listed 12 "potentially WTC associated conditions," including asthma, heartburn, throat irritation, acid reflux, and shortness of breath. More serious illnesses, such as interstitial lung disease, chronic bronchitis, and pneumonia, were listed as "currently under evaluation"—in other words, not necessarily

related to the dust. The document also includes a giant disclaimer: "The physical health problems discussed in this publication are common and may not be WTC-related even among persons exposed to the disaster."

Kathy Burns, a Massachusetts-based toxicologist, says the guidelines should have been released much sooner.

"An awful lot of the patients were repeatedly misdiagnosed, partly because there wasn't an awful lot of information being put out by the state or the city," Burns says. The DOH guidelines, she adds, came "way too late. . . . And it covered only a small subset of what in the long run will be a problem."

Other advocates say that the reason more isn't known about these WTC-related ailments today is that the Bush administration acted too slowly, or even resisted funding research and monitoring programs.

"The main reason we don't have more information is that the federal government hasn't done the research," Maloney says. "The answer is not unknowable."

When it comes to cancer, obtaining the data that will either establish or disprove a link with toxic WTC dust is still years away, researchers say. But that hasn't stopped advocates from pressing the point that the dust has already caused the disease to show up in responders.

David Worby, the lead attorney in the class-action lawsuit, has said in the *Voice* that among his 10,000 clients are at least 400 cancer cases—a fact, he asserts, that demonstrates a clear link between the dust cloud and cancer. A series of other media reports have also made that connection.

The theory goes that the unprecedented toxic mixture of chemicals in the dust weakened the immune systems of Ground Zero workers to the point that they have become far more susceptible to serious illness—especially if they'd been exposed to toxins earlier in their lives.

In particular, dozens of cases of blood-cell cancers—like lymphoma and multiple myeloma—among relatively young Ground Zero workers have raised these concerns. Herbert, the Mount Sinai researcher, was quoted as suggesting that such cancers could become a "third wave" of ailments.

"Doctors have told me that this cocktail of poison could very well cause cancer," says Representative Carolyn Maloney, who has become a leading advocate on the issue.

For the families of Ground Zero responders, the link with cancer is very real and deeply troubling. Just ask Michelle Shore, whose husband Robert, a city correction officer who worked at Ground Zero, died of pancreatic cancer in August 2005.

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Shore did have heart problems, but otherwise he was fine, his wife says. "He was a healthy man, but he was misdiagnosed and forced into retirement. Now I've lost my house—everything—and I'm living with my parents. We're all struggling."

Nearly two years after Shore died, the city agreed to pay workers' compensation to his family. Michelle will get $400 a week, but the payments stop if and when she remarries.

But despite the certainty of Michelle Shore and others, tying cancer to the 9/11 cloud is a tricky thing. People in this city routinely succumb to the disease as a matter of course; among New Yorkers, cancer is the second leading cause of death. According to local mortality rates, in a random population of 70,000—about the number of people enrolled in the WTC registry—you would expect roughly 90 cancer deaths per year, primarily from lung, colon, breast, and prostate cancers.

And in a population of 400,000—the estimated number of people exposed at Ground Zero—you could expect as many as 3,000 people to die of cancer over a six-year period.

No one has yet done a study that attempts to compare cancer rates or cancer fatalities in that Ground Zero population to other groups.

Thorpe says that no data currently exist to show that people exposed to the 9/11 dust cloud are dying

of cancer at a higher rate than any random sample of New Yorkers.

"Irrespective of their exposure, some of these people would have developed cancer," Thorpe says. "One or two years later, there's some cause to be cautious in making that leap. That said, this was an intense exposure, it has health ramifications, and we need to stay focused on it."

Similarly, the same FDNY doctors who detailed the increase in respiratory ailments among firefighters say that a preliminary analysis shows "no clear increase" in cancers since 9/11.

Johns Hopkins researchers Samet and Geyh write in their paper that asbestos exposure is "unlikely to have been sufficient to cause asbestosis or a measurable increase in the risk of lung cancer." An increased risk for mesothelioma—the disease commonly tied to asbestos exposure—"would not become evident for decades." And the long-term risk of cancer, the authors say, "will be difficult to measure with any precision."

A May 31 study in *The New England Journal of Medicine* concluded that Ground Zero dust samples did contain fire-related carcinogens, but that "any associated increased risk for respiratory tract and most other cancers will not become apparent for decades." And city health commissioner Frieden likewise has said that it is unknown whether cancers will develop as a result of exposure.

The irony is that even in the best of circumstances, it is extraordinarily difficult to prove that a specific source has caused cancer. In fact, studies of cancer clusters are often inconclusive simply because the mechanism that causes such ailments is still unknown.

In order to verify the relationship, researchers say, one would have to compare the Ground Zero population to a similar but unexposed group and see whether the cancer rates are higher. But there are so many unknowns and variables at play that it would be a very difficult study to do with precision. Even identifying a group of people that could be compared to the Ground Zero population would be difficult.

"In the ideal world, you might try to gather up people exposed and try to understand what they were exposed to," Samet says. "The question is: How well can we reconstruct what people were exposed to, and could enough people be assembled to do that? The hard part would be finding these people. We'll have to see."

In many ways, the very scale of the issue—to say nothing of the uncertainty and cost—has created something of a muddle and left government officials pursuing a schizophrenic course.

The city is a great example of that. Even as it funds the Bellevue clinic, backs the WTC registry, and pursues further research, it is also fighting a rear-guard action against disability and workers' comp claims—arguing, according to a lawyer involved in those cases, that there is no concrete proof that individual workers have gotten sick from a specific illness related to the dust.

And in papers filed opposing the class- action lawsuit brought by 10,000 ailing people, the city has argued that it is immune from lawsuits because it was acting in an emergency. In legal papers, lawyers for the city slam the plaintiffs for "second-guessing decisions made during a time of crisis."

Joel Shufro, of the Committee for Occupational Safety and Health, acknowledges that all of the outstanding health questions may never be answered. "But it does seem to me that at some point, if you have significant numbers of people developing illness, you have a problem," he says. "To take the other side of it—to say, because there is no scientific certainty, that people aren't entitled to treatment—is equally presumptive."

For Shufro, the research is almost a secondary question: "Talk to people who lost their homes, who had to take kids out of college, and ask them whether this is a result of their exposure," he says. "Their lives changed overnight. In the final analysis, what we're talking about here is how does this society respond to people—and where do you draw the line in terms of care for people who are ill?"

Many have looked to the federal government to fund a long-term health-care program for the workers. Nadler, Maloney, and Senator Hillary Clinton have all submitted bills that would make 9/11 health expenditures part of the annual federal budget—but estimates of the cost of that program vary widely.

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A city report estimated that the cost of medical care for Ground Zero workers could be as high as $392 million a year. A federal estimate placed the total at $230 million to $283 million a year, but also said the total could be much higher—$400 million, or even as much as $700 million—if a lot more workers sign up. Even at $283 million a year, the costs, over 20 years, total $5.7 billion.

The September 11th Victim Compensation Fund has already paid out $573.2 million for 1,377 asthma and other respiratory claims. Some are seeking to reopen that fund.

There is also a $1 billion federal insurance fund set aside to pay out judgments in the event the city loses in court to the thousands of people suing. In July, a group of responders sued the fund (known as the WTC Captive Insurance Co.), demanding that the money be released.

The feds have contributed $125 million for study and treatment, and they've allocated another $50 million earlier this year. A bill that would provide for another $55 million has passed the House and is now in the hands of the Senate.

The estimate to continue the current programs just for first responders and New York City residents is $178 million a year. That money wouldn't include people outside New York City or federal workers.

But Carpenter, the SUNY Albany epidemiologist, and others say that the government has little choice but to fund care and treatment—in other words, to give everyone the benefit of the doubt. Waiting for conclusive proof would come far too late for people who need help now.

"I think we are going to see people develop illnesses 20 to 30 years down the road," Carpenter says. "I think we need to follow everyone exposed."

"The commitment to all of the workers has to remain a sustained commitment over time," adds Thorpe, the city deputy health commissioner.

Samet, the Johns Hopkins researcher, argues that the government must take a long-term view: "What government should be doing here is the best possible surveillance and tracking, so they can say whether this is different from any other population. That's not going to be easy."