

# Congress of the United States

Washington, DC 20515

August 09, 2006

The Honorable George W. Bush  
President  
1600 Pennsylvania Avenue, N.W.  
Washington, D.C. 20500

Dear Mr. President:

On June 17, 2006, we wrote to you on behalf of thousands of Americans who have documented health problems related to the collapse of the World Trade Center towers on September 11, 2001. In our letter we expressed our concerns that many responders, residents, area workers and school children who are sick or injured as a result of the 9/11 attacks are not receiving the help they need. Additionally, we asked for a meeting to discuss how the federal government may be able to better address the health-related needs of the "heroes of 9/11" and the community.

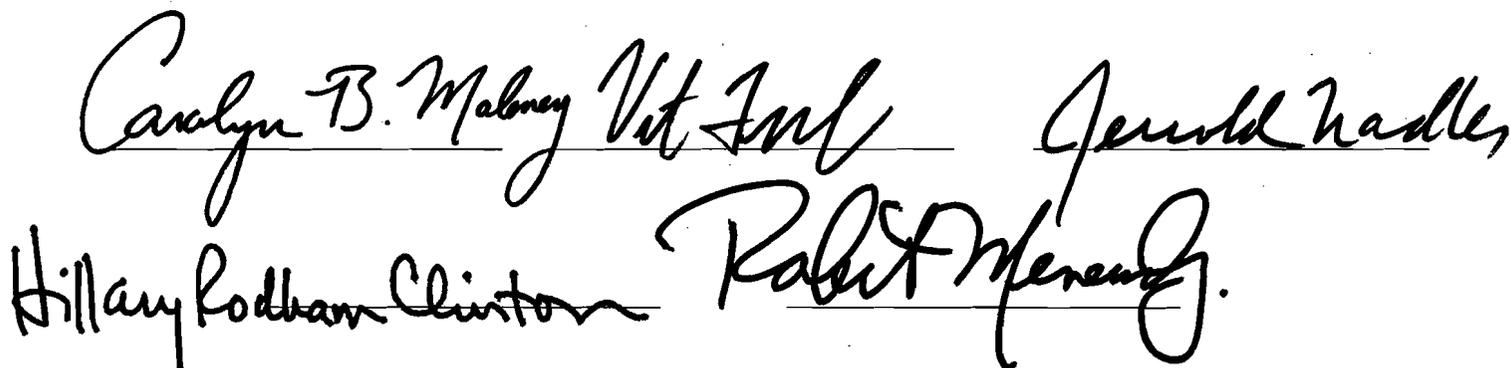
Since our June 17, 2006 letter, more information has come to light that further documents the needs of the many who were exposed. Much of this information has been reported in a series of editorials by the *New York Daily News*. Attached, please find a copy of these editorials.

We believe that we are in the middle of a gathering health crisis. Doctors at the World Trade Center Medical Monitoring Program report that each month, more and more Ground Zero responders are seeking treatment for the first time and that the illnesses of responders already in treatment are proving to be unexpectedly severe and persistent. Most ominously, as the attached editorials detail, 9/11 responders have died as a direct result of illnesses that in all likelihood were sustained at Ground Zero.

Once again, we respectfully request the opportunity to meet with you at your earliest convenience. At this meeting we would like to bring several Ground Zero responders so that you can hear their stories firsthand.

Once again, we thank you for your support of New York City and for your pledge to do whatever it takes to help our community recover from the terrorist attacks. We look forward to meeting with you soon.

Sincerely,

  
Carolyn B. Maloney, Jerald Nadler, Hillary Rodham Clinton, Robert Menendez.

James T. Walsh      Michael R. McMurtry

Joe P. Sevan      ~~Eric~~

Sherry Boehlert      Erin L. Enay

Sherry Kelly      Tim J.

~~Gregory Wickham~~      ~~Richard~~

Nita M. Loney      ~~Maureen~~

J.

New York Daily News - <http://www.nydailynews.com>

## Abandoned heroes

Saturday, July 22nd, 2006

They rallied for New York and America in the terrible hours after the World Trade Center collapsed - and ever since, thousands have paid with their health. Some have given their lives.

Forty-thousand-strong, they labored at Ground Zero under miserable conditions in a time of crisis, working 10 and 12 hours a day to search for the lost, extinguish underground fires and haul off 2 million tons of rubble. As a direct result, well over 12,000 are sick today, having suffered lasting damage to their respiratory systems.

In increasing numbers, they are the forgotten victims of 9/11. The toll has risen steadily over the past five years, yet no one in power - not Gov. Pataki, not Mayor Bloomberg, not the state and city health commissioners, not the U.S. government - has acknowledged the epidemic's scope, much less confronted it for the public health disaster that it is.

They cough.

They wheeze.

Their heads and faces pound with the pressure of swollen sinuses.

They lose their breath with minor exertion.

They suffer the suffocation of asthma and diseases that attack the very tissues of their lungs.

They endure acid reflux, a painful indigestion that never goes away.

They are haunted by the mental and emotional traumas of having witnessed horror.

Many are too disabled to work.

And some have died. There is overwhelming evidence that at least four Ground Zero responders - a firefighter, two police officers and an Emergency Medical Service paramedic - suffered fatal illnesses as a consequence of inhaling the airborne poisons that were loosed when the pulverized remains of the twin towers erupted seismically into the sky.

The measure of how New York and Washington failed the 9/11 responders starts with the fact that after a half-decade, no one has a grip on the scope of the suffering. The known census of the ill starts at more than 12,000 people who have been monitored or treated in the two primary medical services for Ground Zero workers, one run by the Fire Department, the other by the World Trade Center Medical Monitoring Program based at Mount Sinai Medical Center.

In the Fire Department, more than 600 firefighters - soon to be 700 - have been forced into retirement because they were deemed permanently disabled. Most suffer from asthma that disqualifies them from battling blazes. And fully 25% of the FDNY's active fire and EMS forces

have lung-related conditions - more than 3,400 people in all.

At the Mount Sinai program, where physicians are monitoring the health of 16,000 cops, construction workers and others, Dr. Stephen Levin estimates that from half to two-thirds of the patients are similarly sick. That works out to at least 8,000 people and pushes the tally of the ill over 12,000.

The count goes up from there among the thousands of responders who are not enrolled in either program. How far up, nobody knows. But doctors are all too aware that the general prognosis for the sick is not good. While treatment has helped many to improve, few have regained their health.

"I think that probably a few more years down the road we will find that a relatively small proportion will be able to say, 'I am as good as I was back on Sept. 10, 2001,' " said Levin.

Typical is the case of NYPD Officer Steven Mayfield, who logged more than 400 hours at the perimeter of what became known as The Pile and suffers from sarcoidosis, a disease that scars the tissues of the lungs; shortness of breath; chronic sinusitis, and sleep apnea. "My lungs are damaged; they will never be the same," said Mayfield, 44.

Still more frightening: Serious new conditions may soon begin to emerge. Top pulmonary specialists say lung-scarring diseases and tumors generally begin to show up five to 20 years after toxic exposure, a time frame that's about to begin.

Some responders have received excellent care. The FDNY's medical service, led by Dr. Kerry Kelly and Dr. David Prezant, has delivered first-rate monitoring and treatment to more than 13,700 active and retired firefighters and EMS workers. But the rest of the Ground Zero responders have not been nearly so well served.

Most of them - from police to construction workers - are eligible for monitoring and treatment through the Mount Sinai program. The center's leaders, Dr. Robin Herbert and Levin, are among the world's experts in occupational health, but they have been badly hobbled by a lack of funding. The wait for treatment is four months, and doctors are able to schedule followup appointments less frequently than they would like.

In even worse shape are an estimated 10,000 federal workers who participated in the Ground Zero effort. The government promised to create a program specially for them, and then reneged. The federal workers are on their own.

## **The big lie**

The betrayal of the 9/11 responders began with a lie that reverberates to this day.

When the twin towers collapsed, the remains of 200,000 tons of steel, 600,000 square feet of window glass, 5,000 tons of asbestos, 12,000 miles of electric cables and 425,000 cubic yards of concrete crashed to the ground and then spewed into the air. To the mix were added 24,000 gallons of jet fuel burning as hot as 1,300 degrees.

At The Pile, the air was "darker than a sealed vault and thicker than pea soup," in the description of one deputy fire chief. But officials pronounced that would-be rescuers were safe.

As then-U.S. Environmental Protection Administrator Christie Whitman put it in a press release on Thursday, Sept. 14, 2001: "Monitoring and sampling conducted on Tuesday and Wednesday

have been very reassuring about potential exposure of rescue workers and the public to environmental contamination." Two weeks later, Mayor Rudy Giuliani said rescue workers faced minimal risk because the air quality was "safe and acceptable."

In truth, those who rushed to the scene were at the epicenter of "the largest acute environmental disaster that ever has befallen New York City," according to a 2004 analysis by several dozen scientists in the journal *Environmental Health Perspectives*. In truth, every breath at Ground Zero was noxious to health and even to life.

## **A cauldron of toxins**

The *Environmental Health Perspectives* report cited the presence in the air of highly alkaline concrete dust, glass fibers and cancer-causing asbestos, as well as particles of lead, chlorine, antimony, aluminum, titanium, magnesium, iron, zinc and calcium. The flaming fuel and burning plastics released carcinogens including dioxins, polycyclic aromatic hydrocarbons, polychlorinated biphenyls and polychlorinated furans.

Almost immediately, the toxic cloud began burning the lungs of the responders because most were not provided with, or did not wear, proper respiratory protection. Hundreds soon started coughing up pebbles and black or gray phlegm, and, for most, symptoms steadily worsened.

The false assurance of safety and the failure to adequately equip the workers has opened the city and its construction contractors to potentially huge liability. More than 8,000 responders have joined a lawsuit that has targeted a \$1 billion federal insurance fund established after 9/11 to facilitate the recovery work. So the lawyers, not the doctors, have taken charge.

The city's chief attorney, Corporation Counsel Michael Cardozo, says, for example, that he is confident Ground Zero workers have been provided with appropriate medical attention and disability benefits. This may be wise to argue for the purpose of limiting liability, but it's destructive denial as a public health strategy.

Never did the state health commissioner, Dr. Antonia Novello, or the city health commissioner - Dr. Neal Cohen in the days immediately after 9/11, Dr. Thomas Frieden since January 2002 - step forward to lead a crusade that marshaled the resources of New York's vast public and private health systems.

Nor did Cohen or Frieden ever issue protocols advising physicians on recognizing and treating syndromes generated by World Trade Center exposures. Inexcusably, Cohen failed to disseminate advisories at a time when the Giuliani administration was declaring all was safe at The Pile, and Frieden's staff is only now getting around to completing its first bulletin.

Nor did the Police Department establish a system for tracking the prevalence of illnesses such as asthma among the thousands of cops who worked at The Pile. The police surgeon, Dr. Eli Kleinman, says he believes there hasn't been more than "a blip" in lung-related ailments - which would be a truly remarkable outcome compared with the 25% of the Fire Department that is counted as having 9/11 aftereffects.

The city Health Department in 2003 did establish the World Trade Center Health Registry, inviting people who worked at Ground Zero or lived in the area to report their health conditions. More than 71,000 provided information, and the department is in the midst of conducting a followup survey. The data are likely to prove highly valuable when the department finishes crunching the numbers. But that milestone is planned for next year, astonishingly long to wait when the unaddressed needs of the sick have been building since 2001 and are so large at this very

moment.

Frustrated by the response to 9/11-related illnesses, Reps. Carolyn Maloney and Vito Fossella in February won the appointment of Dr. John Howard as federal Ground Zero health coordinator. Howard's valuable presence should be taken as a rebuke to all the local officials who allowed this health crisis to fester for half a decade.

But Howard is hardly the solution. As director of the National Institute for Occupational Safety and Health, the doctor has a schedule that is quite booked. Nor does Howard have the capacity to *do* a great deal. He has no special budget and no special staff, and he can only study and recommend. Far more is required.

## **A cry for leadership**

What's urgently needed is dynamic leadership by someone with the muscle and brains to tackle the World Trade Center health crisis on all fronts - medical, legal, social, political and more. The person who best fits the bill today is Michael Bloomberg.

As the 108th mayor of the City of New York, Bloomberg commands vast municipal resources, occupies an unparalleled bully pulpit from which to prod other levels of government, has a deep, long-standing commitment to public health and, most important, knows how to get things done. And it is simply inconceivable that he would not act were he to inquire deeply into the facts.

Were the mayor to ask Herbert and Levin, he would find out that Mount Sinai's doctors succeeded only this year in getting the okay for the first federal funding for treatment, that patients frequently arrive at Mount Sinai after being misdiagnosed or improperly treated by family physicians and that Ground Zero responders are seeking help in increasing numbers because they haven't gotten better with time or have developed new illnesses.

Were the mayor to speak with Dr. Alison Geyh, assistant professor at his namesake Johns Hopkins Bloomberg School of Public Health in Baltimore, he would learn that a program aimed at tracking the health of Ground Zero's "invisible" recovery workers - heavy equipment operators, sanitation workers, truck drivers and laborers - stopped for lack of money after less than two years.

"It took a year to get this labor-intensive project up and running, only to have its funding stream cut off 18 months later," said Geyh. "It's been frustrating and a lost opportunity."

Were the mayor to talk to Kelly and Prezant at the Fire Department, or to Herbert and Levin at Mount Sinai, or to their colleague Dr. Alvin Teirstein, an eminent lung specialist, he would hear calls for long-term monitoring for cancers and other diseases that could emerge among Trade Center responders in the coming years.

And, were the mayor to spend time with any of the 8,000 responders who are suing the city, he would hear the voices of fury and fear. Their anger is well grounded in that they were lied to, but it is far less clear that each of their illnesses, among them brain and blood cancers, is attributable to Ground Zero exposures. Still, lacking authoritative, trustworthy information, they live under agonizing shadows.

It is vitally important for Bloomberg to take charge.

To take the full measure of this growing epidemic.

To devise appropriately funded treatment programs so that all 9/11 responders have access to the quality of care provided to firefighters.

To establish monitoring systems that can detect swiftly the emergence of new diseases or improved treatments.

To create a clearinghouse that would inform workers and physicians about illnesses and proper treatments, and keep them up to date on the latest developments.

To begin to acknowledge that service after 9/11 did, in fact, cause fatalities, rather than let city officials keep insisting that there is no absolute, total scientific proof that anyone died from illnesses contracted at Ground Zero.

To galvanize the federal government into supporting long-term monitoring and treatment programs.

To review disability and pension benefits afforded to 9/11 responders with an eye on eliminating gross inequities. While firefighters and cops have been granted extremely liberal, even overly liberal, line-of-duty retirement benefits, thousands are trapped in a workers' compensation system that is ill-suited to treat them fairly.

When the call came, the instant the first hijacked jet knifed into the north tower of the World Trade Center, the Ground Zero recovery army surged to the aid of their fellow human beings without a thought as to their own safety. After the buildings collapsed, they worked long and hard to bring New York back from the worst attack on U.S. soil. But they were lied to and they were badly equipped, and then, when they became sick, as many physicians predicted they would, far too many were abandoned.

Decency demands better.

## **TOMORROW The fatalities among the forgotten**

**New York Daily News - <http://www.nydailynews.com>**

# **Death sentence**

Sunday, July 23rd, 2006

Stephen Johnson served New York with valor for 21 years as a firefighter on the nation's preeminent force. He was a man who put the safety of others above his own. He loved the work - and it cost him his life.

On Aug. 6, 2004, Stephen Johnson died from service in the line of duty at age 47. Yet the rolls of honor do not bear his name, nor has the mayor or the fire commissioner stood in public tribute to this fallen hero.

For Stephen Johnson is a forgotten victim of 9/11.

The official record carries Johnson as a retired firefighter who passed away after a heart attack and a bout with a lung ailment two years after he left the force. This is because, callously and in disregard of overwhelming evidence, the City of New York has refused to acknowledge even the likelihood that working around the smoldering rubble of the World Trade Center proved fatal to anyone.

But that is precisely what killed Johnson, whose death stands as the earliest Ground Zero fatality from disease for which cause and effect has been established.

And it is precisely what killed Police Officer James Godbee.

And it is precisely what killed Detective James Zadroga.

And it is precisely what killed Emergency Medical Service Paramedic Debbie Reeve.

They were among the 40,000 people who pulled together in the drive to restore New York's footing after 9/11. Today, more than 12,000 members of that brave army are ill because they were exposed to the toxic cloud that hovered over what became known as The Pile.

Officials falsely assured them the air was safe. Most were not provided with or did not wear respiratory protection.

The vast majority of the sick suffered damage to their respiratory tracts from breathing air thick with particles, including concrete dust, pulverized glass and asbestos. The materials, in effect, burned the air passages, causing inflamed sinuses, bronchitis and reactive airways dysfunction syndrome, or RADS, an irritant-induced asthma.

A smaller number of Ground Zero responders contracted even more serious illnesses, and some died. How many developed their conditions as a consequence of working at The Pile cannot now be established, and medical experts are skeptical about proving a causal relationship in most cases.

But there can be no reasonable doubt that Ground Zero service cost Johnson, Godbee, Zadroga and Reeve their lives. Where Johnson and Reeve are concerned, the FDNY's top physicians, Drs. Kerry Kelly and David Prezant, say they believe this is so. The evidence is just as strong for Godbee and Zadroga.

"How else do you account for it?" Kelly said, referring to Reeve's death.

It is long past time to set the record straight about fatalities among the forgotten victims of 9/11 — to honor those who have died, to keep faith with history and to provide the sick with the fullest information.

It's time for Mayor Bloomberg to recognize Johnson, Godbee, Zadroga and Reeve as heroes who died from illnesses sustained in the line of duty, and to express New York's gratitude to their loved ones.

It's time for the mayor, upon whom we have called to lead a campaign for all forgotten victims of 9/11, to declare that New York owes the Johnson, Godbee, Zadroga and Reeve families every possible benefit — and to order city lawyers to stop unconscionably fighting against giving the

families their due.

It's time to confront what happened to Johnson, Godbee, Zadroga and Reeve in the knowledge that medical experts say others may well develop serious, even fatal, illnesses as the 9/11 health disaster unfolds. Let them not be forgotten, too.

## **Stephen Johnson**

Heroism came naturally to Stephen Johnson — as Linda Kalodner learned firsthand.

On March 11, 1999, Kalodner was the mother of 6-month-old twins, and she and the babies were trapped by a fire on the ninth floor of a Manhattan building. Up a fully extended tower ladder came Johnson and his partner Matt Barnes.

Strapped to the top of the aerial, arms and legs stretched as far as possible, Barnes took the infants from Kalodner and passed them to Johnson, who carried the babies to safety. The partners were feted at City Hall, and the Daily News named Barnes its Hero of the Month. Less than two years later, Barnes was killed on 9/11 and Johnson went to work at Ground Zero, there when the toxic cloud was thickest, there when the job required wading in dust up to his knees. He was a big, strapping guy, fit and healthy, and his every breath moved him closer to death.

In April 2002, still healthy, Johnson retired from a job that was a joy of his life. "Next to me, it was the only other thing he loved," said his widow, Rose.

Early in 2004, Johnson became short of breath while shoveling snow. Over the next few weeks, his shortness of breath worsened. That March, he went to a hospital, where doctors feared he was suffering a heart attack. That wasn't the case, and that May he was diagnosed with interstitial lung disease, or ILD.

Caused by inhaling irritants, ILD is a rare condition found, for example, in miners who work amid coal dust. The presence of particles in the lung provokes the body to try to combat them as it would fight a germ. The immune system surrounds the particles with cells that build up into nodules known as granulomas. Granulomas retard breathing, can cause lesions and lead to irreversible scarring, called fibrosis, on oxygen-extracting tissues.

By the time Johnson was diagnosed, 80% of his lungs had been destroyed. He required oxygen 24 hours a day, and joined the waiting list for a lung transplant. But he never got that far. Suffocating, Johnson suffered a fatal heart attack.

After 15 years of marriage, Rose Johnson lives by herself in Queens. She shies from criticizing city officials for their failure to honor her husband as the first Ground Zero responder to die from an illness contracted there. Nor does she complain that, until today, the circumstances of her husband's illness and death have never been reported. But the pain is obvious in her voice when she recounts her memories of his loss. Only when she points out that the Bravest at her local firehouse give her all the support she asks for does her voice brighten.

Rose Johnson has her husband's pension, but not the full-salary death benefit given to the widows of firefighters who die in the line of duty. Spouses of retirees are not eligible.

## **James Godbee**

James Godbee was the next responder to die after contracting an interstitial lung disease.

A 19-year NYPD veteran and father of two, Godbee worked at Ground Zero for 12 to 15 hours a day for 80 days from Sept. 13, 2001, to June 2002. Never did he wear respiratory equipment.

In November 2003, Godbee developed a cough, shortness of breath, joint pains, fever, weight loss and swelling in his salivary and tear glands. Based on a chest X-ray three months later, his doctors suspected sarcoidosis, a form of ILD.

Dr. Frank Accera, a pulmonary specialist at Beth Israel Medical Center, performed a biopsy, during which Godbee's lung collapsed. The test confirmed the diagnosis.

Sarcoidosis is believed to be caused by contact with irritating foreign substances, but no irritant has ever been identified as its trigger. In addition to the lungs, the illness attacks organs such as the heart, skin and kidneys. Treatable and rarely fatal, sarcoidosis can lead to "progressive multi-organ failure in an unfortunate minority" of cases, according to a 1997 study published in the New England Journal of Medicine.

High dosages of a steroid got Godbee's symptoms under control, but the drug made him sick to his stomach. Over the next seven months, Godbee's lung distress fluctuated as he tried to wean off the steroid, and, feeling generally better, he stopped seeing Accera in October 2004.

Godbee's wife, Michelle, a school guidance counselor, said her husband continued to work. On Dec. 30, 2004, he felt "a little down, a little sick," but he nonetheless took the couple's daughter to a Jim Carrey movie, Michelle Godbee said. At 9:45, he returned to the family's apartment in Manhattan's Stuyvesant Town, gave his daughter "a long hug good night," and minutes later suffered a seizure.

"I called 911. They told me to put him on the floor," Michelle Godbee said. "I heard his lungs go down. He was pronounced DOA at the hospital."

James Godbee was 44. An autopsy found granuloma in his lungs, colon and heart. In his report on the case, Accera wrote: "It is with a reasonable degree of medical certainty that I conclude that Mr. Godbee's exposure to and inhalation of the toxic materials present at the WTC site after the events of Sept. 11, 2001, either caused or aggravated his sarcoidosis and ultimately caused his death."

Regardless, the NYPD pension board ruled Godbee had not contracted sarcoidosis in the line of duty, stating the condition is "not known to be related to employment in the police force." The board denied his family the enhanced benefits afforded to cops who die in the line of duty. When Michelle Godbee took the matter to court, city lawyers fought her petition — even barring FDNY doctors, experts in sarcoidosis, from testifying. A judge returned the matter to the board for further review.

## **James Zadroga**

On Jan. 5 of this year, homicide Detective James Zadroga became the third responder to succumb to interstitial lung disease.

On the force for six years, Zadroga was inside 7 World Trade Center as the building began to collapse. He escaped and returned to Ground Zero, spending more than 450 hours there and at the Staten Island landfill, where the rubble from the Trade Center was carted. He wore only a

paper mask.

Within a few weeks, Zadroga began to cough. Over the next months, the formerly healthy 29-year-old developed severe shortness of breath, acid reflux and sleep apnea. He began passing out and, coughing incessantly, was unable to walk more than 100 feet without gasping.

Zadroga's downward spiral forced him onto extended sick leave. By 2003, he required oxygen 24 hours a day. He was rejected three times for a line-of-duty disability pension; the retirement system's medical board said he hadn't proven a connection between his Ground Zero work and his illness.

Only on Zadroga's fourth appeal did the doctors come around. He retired Nov. 1, 2004. Fourteen months later, with his 4-year-old daughter Tylerann asleep by his side, Zadroga died at age 34. He was a widower with \$50,000 in medical bills. Grandparents took custody of the orphaned Tylerann.

The coroner's report listed the cause of death as "granulomatous pneumonitis."

"It is felt with a reasonable degree of medical certainty that the cause of death in this case was directly related to the 9/11 incident," wrote Ocean County, N.J., pathologist Dr. Gerard Breton. His report, often cited as the first official confirmation that service on The Pile had proven fatal, was dismissed by city officials as inconclusive.

## **Debbie Reeve**

Debbie Reeve joined the EMS in 1989, working first as an emergency medical technician and then as a paramedic. Assigned to a haz-mat unit, she spent more than six months collecting human remains from The Pile and staffing a Ground Zero morgue.

Early in 2004, Reeve developed a cough and shortness of breath after exertion. Her doctor diagnosed flu and pneumonia and prescribed antibiotics that proved useless. Out of sick time, she asked for clearance to return to work, which required a chest X-ray because of her haz-mat status. The X-ray led to the discovery of mesothelioma, a rare cancer caused by asbestos.

From late 2004 until late 2005, Reeve underwent chemotherapy, followed by removal of her right lung and part of her diaphragm. She had radiation and was declared cancer-free.

Six weeks later, Reeve starting having pain in her leg and hip, and X-rays showed mottling in her thigh bones — a sign the cancer had returned. In January 2006, doctors removed infected marrow from her legs, but a month later they found cancer in her back, lung and spine.

On March 15, Reeve died at age 41, leaving an 11-year-old daughter and a 6-year-old son.

Before her death, Reeve had become the first WTC responder to be granted a three-quarters disability pension under a special bill signed in Albany, but she died before receiving a single check. Her husband, David, also an FDNY paramedic, is now battling for workers' compensation coverage of \$90,000 in medical bills. Opposing him is the city Law Department, where attorneys have argued both that he didn't file his claim within a required deadline and that there's no proof Reeve developed mesothelioma from working at Ground Zero.

Johnson, Godbee, Zadroga and Reeve are but four of the 9/11 responders who have suffered serious illnesses. David Worby, a lawyer waging a suit on behalf of 8,000 WTC responders and

their survivors, says, for example, that more than 170 of his clients have developed cancers and 57 have died.

Whether those cancers trace to Ground Zero is a matter of conjecture, but fear is widespread among those who served. This is understandable. What is not understandable has been the refusal of city officials to admit even a probability that 9/11 service led to any death.

Health Commissioner Thomas Frieden exemplified the attitude when he said he would be "surprised" if Zadroga's suffocation could be conclusively linked to particles breathed in at Ground Zero. The coroner, he said, had not tested the materials in Zadroga's lungs to see if they matched exactly with substances at The Pile.

True enough, but that hypertechnicality is far outweighed by the body of evidence.

Johnson, Godbee, Zadroga and Reeve were healthy, relatively young nonsmokers before they spent hundreds of hours in the poisonous cloud at The Pile.

They contracted diseases triggered by inhaling substances that irritate the lungs.

Other 9/11 responders came down with the same rare illness, interstitial lung disease, suffered by Johnson, Zadroga and Godbee and survived. Two firefighters and a civilian worker got the type of ILD that struck Johnson and Zadroga; 20 firefighters got the variation, sarcoidosis, that felled Godbee. Among the survivors, the conditions are generally accepted as being caused by WTC toxins.

Mesothelioma, Reeve's cancer, is found overwhelmingly in people who have breathed in asbestos. What's surprising is only the speed with which the disease came on after Reeve was exposed, said the FDNY's Kelly.

Stephen Johnson, James Godbee, James Zadroga and Debbie Reeve died because they served New York in a time of need. Then they were forgotten. Now Mayor Bloomberg must give them the honor they deserve.

**New York Daily News - <http://www.nydailynews.com>**

## **The making of a health disaster**

Monday, July 24th, 2006

**Ground Zero workers were sent into 'the largest acute environmental disaster that ever has befallen New York City' without proper respiratory protection - and thousands are paying the price.**

For Christopher Hynes, life as a forgotten victim of 9/11 is a battle for breath.

Five years ago, Hynes was a 30-year-old, healthy, nonsmoking New York City police officer. Then, in September and October 2001, he was assigned to Ground Zero duty, spending more than 100 hours patrolling the perimeter of the smoldering rubble of the twin towers. The air was thick with dust and smoky particles.

Today, Hynes, married and the father of a 4-year-old son, has sarcoidosis, a disease that scars lung tissues, and asthma, a disease that inflames and obstructs the airways of the lungs. He

coughs constantly and cannot exert himself without losing breath. He survives with the help of steroids and performs restricted duties for the Police Department.

"I will probably have this for the rest of my life," he says.

For Winston Lodge, life as a forgotten victim of 9/11 is the torment of chronically inflamed and bleeding sinuses.

Five years ago, Lodge was a 44-year-old ironworker who helped build things. Then, called on to help dismantle The Pile, he pitched in at Ground Zero for 12 hours a day, seven days a week, for a month.

Today, Lodge's nose runs constantly and often bleeds. He suffers headaches from sinus pressure, has shortness of breath from chronic bronchitis and is bedeviled by acid reflux, a painful heartburn. He has undergone surgery to relieve sinus difficulties and is awaiting a second operation. Since 2004, Lodge, a divorced father of four, has been unable to work.

"I am sick to my bones and I need help," he says.

For Jeffrey Endean, life as a forgotten victim of 9/11 is a struggle with scarred lungs and ruined sinuses.

Five years ago, Endean was a 51-year-old division commander for the Morris County, N.J., sheriff's office. He was healthy, able to run several miles. Then, he was pressed into Ground Zero service because he had experience helping first responders cope at horrific scenes. He worked 12-hour shifts from Sept. 11 to Nov. 22, 2001.

Today, Endean has reactive airways dysfunction syndrome, or RADS, a rare, irritant-induced form of asthma, his sinuses often bleed and he is prone to headaches and upper-respiratory infections. Married, the father of three and grandfather of three, Endean retired in 2002.

"I start the day with four to five inhalers and a pill," he says. "Will I have cancer at 66? Will I live my life as long as I should?" The forgotten victims of 9/11 are legion among the 40,000 people who massed at Ground Zero in New York's hour of greatest need. Well over 12,000 are afflicted with conditions similar to those that plague Christopher Hynes, Winston Lodge and Jeffrey Endean.

They gasp for air with asthma or illnesses that scar deep in the lungs. They lose their breath from exertion. They endure pain from persistently swollen sinuses and constant burning from acid reflux. At a minimum, they cough and cough, hacking with a syndrome known fittingly as World Trade Center cough.

And, beyond all doubt, at least four responders - Firefighter Stephen Johnson, Police Officer James Godbee, Detective James Zadroga and Emergency Medical Service paramedic Debbie Reeve - died as a direct consequence of their service.

The magnitude of the epidemic has worsened for five years as every level of government has failed to face the reality of what happens when large numbers of people without proper respiratory protection are exposed for long periods to air thick with toxic substances.

Responsibility runs from the federal government, where then-Environmental Protection Administrator Christie Whitman falsely assured 9/11 responders that the air was safe, to the New York State Health Department, which abandoned a program designed to monitor the health of

9,800 state and National Guard personnel, to the New York City Health Department, which has yet to issue treatment guidelines for physicians.

The failure to create the comprehensive public health campaign that was so obviously called for is especially outrageous because public health officials have long had access to evidence of a public health disaster in the making. Medical researchers have published at least 27 studies detailing how the toxic cloud that erupted with the collapse of the World Trade Center ate at the lungs of the workers who labored to find survivors and cart away the massive rubble.

To read the studies is to confront both governmental inaction and a question: Why? Why were recovery workers put in harm's way, falsely assured they were safe and lacking respiratory protection? And why has so little been done to aid them? The answers, it seems certain, were, first, ignorance; second, a determination to get New York moving at all costs; third, bureaucracies that let everyone dodge responsibility, and fourth, a desire to minimize liability.

All of which should have been swept aside as scientists reported their findings; all of which must be swept aside today. Too many people have gone without proper monitoring and treatment, and too many are threatened by worse illnesses, to allow further denial and lethargy.

The reports are available in publications such as the New England Journal of Medicine, the Journal of Occupational and Environmental Medicine, the American Journal of Respiratory and Critical Care Medicine, Chest, and the Centers for Disease Control and Prevention's Morbidity and Mortality Weekly Report. Many were written by the Fire Department's own doctors, who are among a handful of officials who have performed in exemplary fashion since 9/11.

The collapse of the twin towers was, in the words of a 2004 report in the journal Environmental Health Perspectives, "the largest acute environmental disaster that ever has befallen New York City." The air became laden with highly alkaline concrete dust, glass fibers and particles of lead, chlorine, antimony, aluminum, titanium, magnesium, iron, zinc and calcium. Flaming fuel and plastics released carcinogens including dioxins, polycyclic aromatic hydrocarbons, polychlorinated biphenyls and polychlorinated furans.

Three days after the attack, rain helped cleanse the atmosphere, but particulate levels rose and fell for weeks, dropping at night when the air was still and rising with flareups in The Pile. Construction machinery added diesel exhaust to the stew, and caked gray-white dust was omnipresent. It was not until December 2001 that the fires were extinguished and dioxin levels returned to normal. The final pieces of steel were trucked away five months later.

The devastating consequences of laboring amid poisons became immediately evident.

In the first 24 hours, 240 firefighters and Emergency Medical Service workers sought treatment, half for dire respiratory symptoms. Three were hospitalized for life-threatening inhalation injuries, two of whom went into acute respiratory arrest.

Within 48 hours, more than 9,000 firefighters - 90% of the FDNY's earliest responders - suffered acute cough, nasal congestion, chest tightness or burning. Three out of four told researchers that for the first week, they didn't wear respirators, which cover the nose and mouth and filter out contaminants. Some used paper masks that were practically useless.

Two weeks after 9/11, a 38-year-old firefighter was admitted to Bellevue Hospital with acute eosinophilic pneumonia, a rare disease caused by exposure to extreme amounts of dust, according to the description of his case published in the American Journal of Respiratory and

Critical Care Medicine. He had ash, fiberglass, silica, metal particles and asbestos in his lungs.

The firefighter, whom the FDNY declined to identify, had arrived at the Trade Center 20 minutes after the collapse and worked 16 hours a day for 13 days, wearing no respiratory protection for at least the first week. Early on, he coughed up black phlegm, and for two days before he was hospitalized he complained of fatigue, muscle pain, fever, dry cough, chest discomfort and breathlessness. He required three weeks of treatment before recovering.

A team of doctors, including David Prezant, the Fire Department's deputy chief medical officer, wrote up the case as an example of a condition known as interstitial lung disease. ILD affects tissues deep in the lungs that extract oxygen and is far rarer than illnesses that obstruct breathing passages, such as asthma. It is the type of illness that led to the deaths of Johnson, Zadroga and Godbee.

In October, doctors diagnosed almost 60 firefighters as suffering from airway hyperreactivity, a narrowing of breathing passages commonly found in miners after years of exposure to airborne particles. The firefighters' conditions worsened over the next six months. In November and December, researchers for Beth Israel Medical Center and Johns Hopkins and Columbia universities examined hundreds of cops and cleanup workers and found that they, too, had coughing, wheezing and other lung ailments. For example, Beth Israel doctors checked 240 Emergency Service Unit cops and found that 77% had developed new or worsening respiratory symptoms within days after 9/11, and that one-quarter of the 240 still had symptoms three months later.

In February 2002, a study of 97 ironworkers who were at Ground Zero during the first five days found 77% had respiratory symptoms such as cough, chest tightness and wheezing.

Symptoms emerged among people who had not been on The Pile. Two-thirds of the residents in 414 randomly selected households in Battery Park City, Southbridge Towers and Independence Plaza reported eye or throat irritation six weeks after the attack, and nearly half had persistent coughs.

A survey of downtown women who were pregnant on 9/11 found shorter gestation periods and smaller babies than normal. The maternal and cord blood of women who lived within a mile of Ground Zero had elevated levels of PAHs in the month after the attack. PAHs are associated with genetic damage.

One woman told researchers at the Johns Hopkins Bloomberg School of Public Health in Baltimore that she had had an abortion because she feared birth defects.

Still, the Ground Zero recovery workers suffered the worst illnesses. Thirteen firefighters contracted pneumonia in the first three months, and by month six more than 30 firefighters had come down with reactive airways dysfunction syndrome, the asthma that struck Jeffrey Edean. An additional 332 firefighters and one EMS worker had a severe enough cough to require four weeks of sick leave - the first medical definition of what became known as World Trade Center cough.

All of them had coughed up black or gray phlegm containing pebbles or particles in the first days after the attack, and one year later, more than half of those 332 showed only partial improvement. Almost nine out of 10 also suffered from persistent, severe heartburn or acid reflux, an ailment common among the forgotten victims of 9/11.

(Doctors believe that breathing concrete dust inflamed lungs and sinuses, and swallowing it

damaged digestive systems, causing the release of acids. Vapors generated by those acids then worsen the respiratory inflammation, creating a vicious cycle. One retired firefighter had a cough so severe that the constant jarring of his teeth knocked out most of his fillings, said the FDNY's Prezant.) Most stunningly, FDNY doctors calculated that the average lung capacity of Ground Zero firefighters and EMS workers had decreased by the equivalent of 12 years of aging. The doctors also saw sarcoidosis, the lung-scarring disease that afflicts Christopher Hynes, at more than five times the usual rate in the first two years.

That's where the scientific measurements of the Ground Zero health crisis end for the moment, but more is known because Fire Department physicians and doctors at the Mount Sinai World Trade Center Medical Monitoring Program have monitored or treated tens of thousands of patients.

Their conditions are similar to those suffered by Hynes, Lodge and Endean: asthma, RADS, interstitial lung diseases, bronchitis, sinusitis, acid reflux and, most commonly, World Trade Center cough. The doctors say that while aggressive treatment has helped many to improve, few have been restored to the health they enjoyed before 9/11. Many are severely debilitated.

The Daily News is calling on Mayor Bloomberg to lead a public health drive on behalf of the forgotten victims of 9/11. His long dedication to public health, his command of municipal resources and his ability to get things done ideally suit Bloomberg for the job. Not incidentally, he also occupies a position from which to mobilize the state and federal governments into fulfilling their responsibilities to the Ground Zero responders.

And those responsibilities are, indeed, huge. They belong to, among others, Gov. Pataki and his successor in Albany come January, state Health Commissioner Antonia Novello and her successor come January and U.S. Health and Human Services Secretary Michael Leavitt, who assigned Dr. John Howard, head of the National Institute for Occupational Safety and Health, to serve as federal WTC health coordinator. All must begin to accept their obligations.

Bloomberg responded to our call with a commitment to study "whether we are doing everything that we can," and a promise to do what he can "consistent with what our resources are, to make sure that this city acts responsibly and recognizes the great sacrifice and the hard work that people made down at the World Trade Center site."

To which we say, "Good, Mr. Mayor, take a close, hard look." Action will surely follow, and we look forward to seeing the start of a comprehensive, aggressive crusade, because the facts demand it. Even a cursory study will show that Trade Center responders were falsely assured the air was safe. And that they didn't get or use proper respiratory protection.

And that the primary medical program for most responders, the one run by Mount Sinai, has never been adequately funded so that cops and construction workers must wait four months for an appointment for treatment.

And that doctors at Mount Sinai and affiliated hospitals are experiencing a surge of new patients five years after 9/11.

And that many of Mount Sinai's patients arrive after having been misdiagnosed or ineffectively treated.

And that medical experts, including Dr. Kerry Kelly, FDNY's chief medical officer, and Prezant; Dr. Robin Herbert and Dr. Stephen Levin, who run Mount Sinai's program, and Dr. Alvin Teirstein, a noted Mount Sinaipulmonary specialist, are concerned that the forgotten of 9/11 may be on the

verge of more serious illnesses. Tumors and lung-scarring diseases have been known to emerge between five and 20 years after a toxic exposure. The responders are about to cross that five-year milestone.

They served New York and it cost them their health and even their lives. They deserve nothing less than long-term, gold-standard health care - now.

**New York Daily News - <http://www.nydailynews.com>**

## **Save lives with \$150 lung exam**

Sunday, August 6th, 2006

What happened to Mark DeBiase - the sudden emergence of a rapidly fatal lung disease - is the nightmare that shadows the forgotten victims of 9/11.

And the story of how this 41-year-old husband and father of three descended to death in less than four months this year is a case study in why public health authorities must establish comprehensive medical screening and treatment programs for Ground Zero responders, complete with advisories about perils that may be coming.

Too many of the 40,000 people who served after 9/11 are sick now, and too many are at risk of more serious illnesses, and too many face even a chance of death to allow for further inaction. Even basic steps could save lives.

Chief among them: seeing to it that everyone who labored amid the pulverized remains of the Twin Towers has their lungs checked - and finding the money to test people who aren't covered by health insurance.

The procedure is simple - little more than breathing in and out of a hand-held tube - and at \$150, relatively inexpensive. It measures how well lungs are functioning and, repeated over time, will signal whether they're deteriorating. (For more information, please see the explanatory graphic on opposite page.)

As Dr. Neil Schluger, chief of the division of pulmonary, allergy and critical care medicine at Columbia Presbyterian Medical Center, put it, "Every person who was down there should have a baseline lung function study, and be followed closely over the coming years for signs of pulmonary symptoms. They should see a doctor and get a lung function test."

DeBiase's death tragically proves the point.

Summoned to duty because he installed and maintained cellular networks for what was then AT&T Wireless, DeBiase worked for 64 hours at Ground Zero and at the Fresh Kills landfill, where the dust of the Trade Center was carted. Like most other recovery workers, he was not equipped with respiratory protection.

According to his medical records, DeBiase spent 16 hours at The Pile on Sept. 12, when the air was thick with atomized concrete, glass fibers and particles of lead, chlorine, antimony, aluminum, titanium, magnesium, iron, zinc and calcium, among other toxins. In the ensuing days, he was stationed for 48 hours at the landfill as an endless convoy of trucks began arriving with the same materials.

Then he resumed life as a husband and father in Jackson, N.J., and more than four years passed without any sign that helping to establish emergency communications was taking a toll. DeBiase

was active in Little League and the Knights of Columbus, and as late as last December he and his wife, Jeanmarie, enjoyed ballroom dancing lessons. By all outward appearances, he was robust and fit, as evidenced in the photograph to the right.

Actually, DeBiase was on the verge of death. Inch by inch, his lungs were turning into scar tissue, slowly losing the ability to infuse his blood with oxygen and to cleanse it of carbon dioxide.

As 2005 turned to 2006, he began to experience shortness of breath. He went to the doctor Jan. 10 for what became the start of a losing 89-day battle for air. He died April 9 while hoping for a lung transplant.

The cause of death was interstitial lung disease, or ILD, an insidious condition that typically shows up in workers who are exposed to concentrations of inhaled substances - coal miners, for example.

"It is my opinion to a reasonable degree of medical certainty that exposure to dust from the World Trade Center disaster site was the cause of Mr. DeBiase's respiratory disease, which was the cause of his death," wrote Dr. James Strauchen, a professor of pathology at the Mount Sinai School of Medicine who was retained by DeBiase's family to review why he had died such a sudden, suffocating death. DeBiase's family declined an autopsy, the results of which could have pushed Strauchen's finding beyond a "medical certainty" into conclusive fact.

That DeBiase's death in the University of Pennsylvania Medical Center went unnoticed until now testifies to how poorly the public health system has tracked the aftereffects of 9/11. It comes to light only because his father contacted the Daily News after reading this series of editorials.

"I believe the same thing could happen to many others and they don't know it, just like my son had no reason to think anything was wrong," said Angelo DeBiase, a retired truck driver from Staten Island.

In fact, the same thing has happened to others: DeBiase is now the fourth World Trade Center responder known to have died of interstitial lung disease. Firefighter Stephen Johnson, Police Officer James Godbee and Detective James Zadroga all preceded him to the grave.

In fact, the same tragedy may well occur again: Numerous medical experts have predicted that interstitial lung disease will afflict an increasing number of World Trade Center recovery workers in the five to 20 years after they were exposed to the cloud at Ground Zero. The disease is rare enough that no one expects a vast outbreak, but, when the condition does show up - perhaps in just a relative handful of people - the consequences could be fatal.

To quell unwarranted fears, some distinctions are in order. More than 12,000 WTC responders are already sick, but not with ILD. The vast majority damaged their air passages by inhaling toxins, leaving them with inflamed sinuses, bronchitis and reactive airways dysfunction syndrome, or RADS, an irritant-induced asthma. These conditions do not transform into interstitial lung disease.

ILD, which has a variety of forms, attacks not the airways but the very tissues of the lungs. Typically, the body senses the presence of foreign particles and tries to combat them as it would fight a germ. The immune system surrounds the particles with cells that build up into nodule-like bodies known as granulomas. Granulomas lead to fibrosis, an irreversible scarring that prevents the lungs from extracting oxygen from the air. Some ILDs are very treatable. Others are uniformly fatal.

The need for a public health campaign is obvious. So, too, the need for someone to take charge. We have urged Mayor Bloomberg to be that person. Citing his long commitment to public health, his command of vast government resources and his ability to prod other levels of government into action, we have called on the mayor "to tackle the World Trade Center health crisis on all fronts - medical, legal, social, political and more."

Establishing full-scale health monitoring and treatment programs must be a priority, starting with a drive to have all 40,000 responders undergo lung function tests and building toward a sophisticated system for tracking the progress of the epidemic. For it is only by taking the measure of the epidemic that authorities can both tailor treatment strategies and provide reliable information to responders and physicians - perhaps saving the life of the next Mark DeBiase.

There's much work to be done. No one maintained a master list of the Ground Zero workers, making it impossible now to inventory their conditions. The U.S. Department of Health and Human Services began and disbanded a surveillance program for 10,000 federal workers. The state Health Department dropped a similar effort covering 9,800 state and National Guard personnel.

And despite a long battle by Sen. Hillary Clinton and Reps. Carolyn Maloney and Vito Fossella, the Bush administration and Congress have balked at providing the primary health resource for cops, construction workers and others - the World Trade Center Medical Monitoring Program at Mount Sinai Medical Center - with remotely sufficient funding.

Since 2001, it has had to beg for every dollar. And the federal government's latest promised funding will allow doctors to monitor and care for patients for only a year.

The program has affiliated doctors at medical centers around the metropolitan area and across the country. It is open to all responders except firefighters, who are covered by the FDNY, but it would quickly run out of money if large numbers began enrolling for yearly medical screening and treatment referrals. Even so, large numbers should consider taking advantage of the services. For information, call (212) 241-3355.

DeBiase's father speaks with bitterness about the fact that then-Environmental Protection Administrator Christie Whitman and Mayor Rudy Giuliani falsely assured the Ground Zero workers that the air was safe to breathe. And the family has consulted attorney Joseph Belluck about a possible suit.

Jeanmarie DeBiase said she and her husband had no sense he was in danger, or that services were available at Mount Sinai - until it was too late.

She said her three sons, Nicholas, 12, Christopher, 9, and Michael, 7, were, of course, hit hard by the death of a father to whom "everything was about the boys." And she described his decline as a bewildering, ever more painful downhill rush. First a worry about shortness of breath, then visits to doctors, then an attempt to keep working with an oxygen tank, then admission to the Deborah Heart and Lung Center in N.J., then a biopsy and a collapsed lung, then consultations with a doctor at the Mayo Clinic, then prayers for a lung transplant at the University of Pennsylvania Medical Center, then gasping for air, then organ failures as her husband's body was starved for oxygen, and then, finally, a decision to let go.

"I sometimes think it is a dream," said Jeanmarie DeBiase. "The only thing that gets us through is that it came from 9/11, and we had him five more years than the people who died that day."

Her son Christopher shares a similar gracious philosophy.

"Christopher's fear is that there are going to be a lot of other children who will lose a parent," she said. "He just feels that maybe this can help somebody."

It must.