Statement of Tamiru Mammo Senior Advisor for Health Policy Office of the Deputy Mayor for Health and Human Services

Oversight: Examining the NYC World Trade Center Medical Working Group 2009 Annual Report on 9/11 Health

December 7, 2009

Committee on Civil Service and Labor,
Committee on Lower Manhattan Redevelopment and
Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse
and Disability Services

New York City Council

Introduction/Overview

Good afternoon. I want to thank Chairman Gerson, Chairman Nelson and Chairman Koppell, as well as the other distinguished members of the Council for convening this hearing examining the NYC World Trade Center (WTC) Medical Working Group 2009 Annual Report on 9/11 Health.

My name is Tamiru Mammo and I am Senior Advisor for Health Policy to New York City's Deputy Mayor for Health and Human Services, Linda Gibbs. I was also a staff member of a panel convened by Mayor Bloomberg at the fifth anniversary of the attacks to assess the health impacts of 9/11. The panel issued a February 2007 report with recommendations supported in full by the Mayor.

One of those recommendations was that the Mayor should establish a WTC Medical Working Group made up of a diverse membership of up to fifteen public health, mental health, environmental health, and medical professionals and researchers from within and outside City government to advise the Mayor, and others, about health issues that are related or potentially related to the September 11, 2001 terrorist attacks on the World Trade Center. The group is co-chaired by the Deputy Mayor for Health and Human Services and the Commissioner of the Department of Health and Mental Hygiene, and it includes thirteen experts, including a representative from each of New York City's three WTC Centers of Excellence; the FDNY and Mt. Sinai programs and the WTC Environmental Health Center.

The Medical Working Group reviews existing and emerging scientific data on the potential health effects of WTC exposure to identify evidence of clinical risks and potential gaps in information; makes recommendations about research and health and mental health service needs; and advises city government on approaches to communicating health risk information. The first Medical Working Group was established by Mayor Bloomberg in June 2007 and reports have been issued for 2008 and 2009.

Today I will review recent findings from the Medical Working Group's 2009 report on 9/11 Health and also discuss its key policy recommendations.

Review of 2008 findings

Before I detail the findings of the 2009 report, I'd like to summarize the 2008 Medical Working Group report. For this first report, nearly 100 studies published from 2001-2007 were reviewed. Most of these studies examined the health of rescue and recovery workers one to three years after their exposure to the WTC disaster, although some studies also included effects on residents and building evacuees. The key physical and mental health findings were remarkably consistent across studies:

Both the clinical studies and population-based surveillance indicated that symptoms of posttraumatic stress disorder were highly prevalent among rescue and recovery workers and Lower Manhattan residents, two directly affected populations. Studies of rescue and recovery workers also indicated that respiratory problems, asthma and gastroesophageal reflux disease (GERD) are common among this group, particularly those who arrived early at the WTC site. Similarly, Lower Manhattan residents and area workers, including those workers who may live elsewhere, reported elevated levels of respiratory problems and new onset asthma. At the time of the report's publication last year, treatment for WTC-related conditions was available for exposed groups, including children and adolescents, in the New York City area.

Mayor's 2009 WTC Medical Working Group Annual Report

After the release of its first annual report, the 2009 Medical Working Group identified forty-eight published, peer-reviewed studies examining WTC health impacts or exposures that were relevant to the purpose of its report. Among those studies, the majority (36) examined mental health and 13 addressed physical health.

Some new findings from this research address mid-term health effects among adults, five to seven years after 9/11. It suggests that, while the vast majority of people exposed to the attacks on 9/11 and its immediate aftermath are healthy and symptom-free, thousands of exposed individuals continue to suffer from WTC-related mental or physical health conditions, and some of these conditions are likely to be chronic.

Of particular note are new epidemiological findings by the WTC Health Registry, which has been tracking the health of a large, voluntary sample of 71,000 individuals since 2003 through periodic surveys. In August, the *Journal of the American Medical Association* published Registry findings which indicate high levels of new asthma diagnoses since the attacks, especially during the first 16 months after 9/11, and sustained and late-emerging post-traumatic stress symptoms.

At the time of the second survey, five to six years after 9/11, one in ten adult enrollees reported having been diagnosed with new asthma. New onset symptoms of asthma five to six years after 9/11, however, were comparable to expected levels and were not linked to the degree or intensity of WTC exposure. In the same survey, nearly one in five enrollees reported experiencing symptoms of post-traumatic stress. Many of those developing symptoms years after 9/11 also had experienced other life stressors subsequent to the attack, such as losing a job or having inadequate social support.

Several newly published studies suggest that WTC-related mental and physical health conditions often can occur together, and in fact, 10-25% of the more than

14,000 people who sought care at the WTC Centers of Excellence during FY 2009 received treatment for both mental and physical health conditions. Fortunately, monitoring and treatment continues to be available in the New York City area for those whose health has been affected by 9/11 thanks to a combination of federal and City funding.

As in 2008, the 2009 report notes that whether there is relationship between WTC exposure and other longer-term illnesses, including cancer, is unknown but clinicians, epidemiologists and other researchers are actively studying this. Ongoing studies conducted by the WTC Centers of Excellence and the WTC Health Registry are looking at cancer rates in the WTC-exposed population against a "background" or expected rate among people of the same gender and age group. The Medical Working Group will discuss this research in its next annual report.

Pediatric Research

In its 2008 annual report, the Medical Working Group recommended that more research be conducted on the physical and mental health of children who lived or went to school in Lower Manhattan. The WTC Health Registry's cohort of 3,000 children and adolescents who were enrolled by their parents offers an excellent data source to follow the health effects on this population over time.

In 2007, the Registry released findings suggesting that 2-3 years after 9/11, children under the age of five caught in the dust cloud were twice as likely to have newly diagnosed asthma as children not caught in the dust cloud. Late last year, the Registry concluded its second survey of child and adolescent health, which examined the health effects that occurred six to seven years after 9/11 and assembled a team of researchers who will release their findings next year. Analysis of these findings is more complicated because three different versions of the survey were used so that parents could respond on behalf of young children or adolescents, or older adolescents could respond on their own.

The Registry also encourages external researchers to use this valuable data source. Currently, Columbia University is studying the children of first responders to learn how second-hand exposure to terrorism may affect their mental health.

Several studies cited in the 2009 Medical Working Group report examined the impact of the terrorist attacks on the mental health of schoolchildren two to three years after the attacks. While small, two of these studies suggest that children who were exposed to additional trauma either before or after 9/11 were more vulnerable to PTSD. A larger Mount Sinai study of adolescents who attended the schools closest to the World Trade Center and who had high levels of exposure to the disaster—including those who personally knew anyone killed in the

attacks—suggested that their use of alcohol and other substances had increased 18 months after the attacks.

While continued research is needed, particularly in the areas of cancer, treatment efficacy and the impact of 9/11 on child and adolescent health, our state of knowledge about the short-term health effects of 9/11 has come into sharper focus since the formation of the WTC Medical Working Group. We now better understand the longer-term health care needs of exposed individuals, in particular those who may have developed chronic conditions that can seriously affect quality of life.

New York City's Outreach Efforts

Research indicates that many people with 9/11-related PTSD symptoms are not receiving treatment despite the availability of publicly funded services. Nearly 5,000 WTC Health Registry enrollees who reported PTSD symptoms in 2006-2007 also reported that they hadn't seen a mental health provider in the previous year. Approximately half of these persons were residents, office workers, or individuals other than rescue and recovery workers who were in the vicinity of the WTC site on the morning of 9/11.

In response to the apparent gap between the PTSD burden in New York City and mental health service utilization, DOHMH and the New York City Health and Hospitals Corporation partnered to do a targeted outreach to people in the New York City area and actively refer them to 9/11-related health services at the WTC Environmental Health Center at Bellevue Hospital Center, Elmhurst Hospital Center and Gouverneur Healthcare Services. Enrollees in the WTC Health Registry are receiving personalized mailings and phone calls informing them that they are eligible for both physical and mental health services with no out-of-pocket costs at the WTC Environmental Health Center (EHC). The Registry staff then offers enrollees assistance in scheduling appointments. In our outreach efforts, as a first step we have prioritized enrollees with probable PTSD and comorbid physical symptoms who indicated that they had not seen a mental health provider in the year before they were surveyed.

In addition to various broadcast media approaches such as television and radio the WTC EHC also recently concluded its third wave of subway advertising to promote its services as widely as possible. The multilingual campaign, which uses the tag line "Lived There? Worked There? You Deserve Care" has been particularly effective in attracting Lower Manhattan residents, area workers and students who are eligible for services.

Recognizing that a subway advertising campaign was likely to reach rescue and recovery workers who are eligible for services at Mount Sinai, information about this program was incorporated into the City's 311 referral system. This has made

it possible for hundreds of callers to be directly transferred to appropriate service providers for the first time.

Additionally, last summer DOHMH published *Clinical Guidelines for Children and Adolescents Exposed to the World Trade Disaster* for distribution to pediatricians in the New York City area. The guidelines were developed to raise awareness among pediatricians about the potential health effects of WTC exposure among children, to provide evidence-based recommendations about the treatment of those exposed children, and to encourage referral to the specialized services available through the pediatric program at the WTC Environmental Health Center. DOHMH mailed the guidelines to 33,000 doctors, nurses, psychologists and other providers citywide.

As part of its continuing effort to increase awareness of WTC-related problems and services, DOHMH used its flagship publication, *Health Bulletin*, to educate the general public about WTC-related health issues and to urge individuals who may have been affected to seek specialized treatment for posttraumatic stress disorder and asthma. More than 65,000 subscribers received the WTC Health Bulletin electronically and copies are available in English, Spanish or Chinese at all public hospitals and can be ordered by calling 311.

City Advocacy Efforts for Long Term Federal Funding

Most 9/11 health programs are federally funded through annual appropriations adopted by Congress and approved by the President. This means the future of these programs is uncertain from one year to the next. The 9/11 Health and Compensation Act, introduced in the House (H.R. 847) and Senate (S. 1334) provides long term federal funding for:

- medical monitoring and treatment for those affected by 9/11;
- scientific research about 9/11-related health conditions;
- re-opening the September 11 Victim Compensation Fund for people who may have been injured or become sick as a result of the WTC disaster.

The 9/11 Health and Compensation Act is an important step forward, and New York City has stepped up its outreach efforts to encourage Congressional support of federal 9/11 health legislation. Although the 9/11 Health and Compensation Act (H.R. 847 and S.1334) has the support of the entire New York Congressional delegation, it must be approved by a House committee, with members from 31 states, before the full House can vote on it. The Senate version has been referred to the Health, Education, Labor and Pensions Committee.

With legislative action likely after Congress finishes work on health care reform, the City, with cooperation from the FDNY, is urging mayors from key cities and fire departments across the nation that participated in the WTC rescue and

recovery effort to ask their local representatives to support the bill. Almost every member of Congress represents a district that is home to first responders and volunteers who served after 9/11, or residents who have since relocated outside of New York City. We are providing a breakdown of Registry enrollees by geographical area to show members of Congress how passing the 9/11 Health and Compensation Act can benefit their constituents directly.

In addition to its partnerships with labor and community leaders to support permanent funding for 9/11 medical monitoring and treatment, the City's efforts include:

- a meeting between WTC Environmental Health Center staff and patients to the House Energy and Commerce Committee to stress its services for people who lived, worked or went to school in Lower Manhattan and are now sick;
- standing with the responders and the community at fall events in New York City and Washington, DC;
- making information about federal 9/11 health legislation easily accessible through the City's 9/11 health website at www.9-11health.org.

The 9/11 Health and Compensation Act directly addresses the current and future health problems created by 9/11 and also provides important relief for past injuries and illnesses. The City looks forward to working with the Council to advocate for all New Yorkers who are affected or who may be affected by the 9/11 attacks.





FACT SHEET

9/11 Benefit Program for Mental Health and Substance-Use Services

New York City's New Program Provides Coverage for Those Who Need Help

The New York City Health Department is offering an insurance-like benefit to help cover mental health and substance-use treatment for NYC residents still affected by the terrorist events of September 11, 2001.

HOW DOES IT WORK?

If you're still suffering psychological symptoms related to the events of 9/11, you may qualify for coverage under the NYC 9/11 Benefit Program. To find out, call 311 or visit www.nyc.gov/9-11mentalhealth. A benefit coordinator will work with you to establish whether you are eligible and explain the process for submitting claims.

If you are found eligible, you will receive reimbursement for out-of-pocket costs, up to the maximum amount allowed under the NYC 9/11 Benefit Program fee schedule for mental health or substance-use treatment.

If you have insurance, you must first apply your insurance benefit toward the cost of treatment. The NYC 9/11 Benefit Program will reimburse for the remaining out-of-pocket costs.

If you don't have insurance, you can receive reimbursement for the fees you pay to providers, up to the maximum amount allowed under the NYC 9/11 Benefit Program's fee schedule.

The Benefit Program will directly reimburse providers if they file claims for services they provide to eligible patients. If a provider's fee exceeds the reimbursable amount for a given service, the patient will be responsible for the balance.

WHO IS ELIGIBLE?

Two groups of NYC residents are eligible for the program.

Group A includes individuals or family members of those who:

- Lost a family member, were seriously injured, or lived below Canal Street
- Worked in the WTC area or at the Pentagon whether or not they were at work that day. Or were evacuated from the WTC area or the Pentagon
- Attended a school near the WTC, or are the parent of a child who attended nearby
- Were a rescue, recovery, or reconstruction worker assigned to a "restricted site"
- Were an emergency dispatcher on 9/11 or worked in the morgues serving the attacks sites
- Worked south of Canal Street or at Ronald Reagan Airport, and before January 11, 2002 lost their job or earned less than 70% of their pre-9/11 income
- Have a family member, or shared a home with someone, who meets the criteria above and
- Reside in NYC

Group B includes NYC residents who are not in Group A but who have psychological symptoms that are likely related to the attacks. Individuals in this category will be screened, and their treating providers will be asked to submit a letter affirming that their conditions are likely related to the events of 9/11.

WHAT SERVICES ARE COVERED?

The NYC 9/11 Benefit Program reserves the right to modify covered services at any time. Covered services include:

- Outpatient mental health and substance-use services: The benefit program covers out-of-pocket costs associated with outpatient treatment. There is no dollar cap on reimbursement for members of Group A. For members of Group B, reimbursement is limited to \$3,000 over the lifetime of the benefit.
- Medication and laboratory work related to mental health and substance-use treatment: Additionally, the benefit covers reimbursement for medication and/or laboratory work up to \$1,500 over the lifetime of the benefit.
- <u>Psychological evaluations and testing</u>: The benefit covers up to eight hours of evaluation and testing for children age 21 and under.

The benefit program does not cover the following:

- Inpatient services
- Emergency-room visits and related services
- Acupuncture
- Art therapy and other expressive therapies
- Missed appointments
- Non-related mental health/substance use medications

WHO CAN PROVIDE TREATMENT?

To receive reimbursement, you must receive services from a provider who is licensed/certified in New York State, or who works under the supervision of a New York State-licensed provider in the same field of practice.

Services delivered by the following licensed or certified professionals are covered under the NYC 9/11 Benefit Program:

- Physicians
- Psychologists
- Social workers
- Nurse practitioners
- Certified alcoholism or substance-use counselors
- Mental health counselors
- Marriage and family counselors
- Licensed psychoanalysts (state license holders only; national certification is not sufficient)

HOW CAN I APPLY FOR THE BENEFIT?

Any eligible person can enroll by calling 877-737-1164 (877-SEP11MH) or (TTY) 212-982-5284. Group A enrollment is also available online, at www.nyc.gov/9-11mentalhealth.

IMPORTANT DATES:

- April 2008: Enrollment begins
- January 2, 2007: Coverage begins (retroactively)
- July 7, 2010: Enrollment ends
- January 7, 2011: Coverage ends
- March 31, 2011: Last day to submit claims

Note: Terms are subject to modification based on available resources and the success of the program. For more information, visit www.nyc.gov/9-11mentalhealth. This program is funded and overseen by the New York City Department of Health and Mental Hygiene, with benefit access coordinated by the Mental Health Association of NYC.



PROGRESS REPORT:

Mayor's 9/11 Health Panel Recommendations

All 15 Completed or Underway

- ✓ Appoint a medical working group to provide advice and issue annual reports on the state of 9/11 health
- Advocate for federal resources to monitor and treat people with World Trade Center (WTC)-related mental and physical health problems
- ✓ Advocate for the reopening of the Victim Compensation Fund authorized by Congress in 2001
- ✓ Appoint a WTC Health Coordinator to foster 9/11 health communication and outreach
- ✓ Establish a comprehensive 9/11 health website to provide information about research and services
- Expand the distribution of Clinical Guidelines for Adults Exposed to the WTC Disaster for use by physicians
- Expand and promote the services offered by the WTC Environmental Health Center at Bellevue Hospital Center
- ✓ Offer financial assistance for 9/11-related mental health and substance use treatment services to all New Yorkers in need
- ✓ Expand outreach to 9/11-affected communities about construction and deconstruction projects that could pose environmental hazards
- Review the environmental, health and safety aspects of the City's disaster response plans
- ✓ Appoint WTC Health Liaisons at City agencies to track and disseminate information about 9/11 health issues
- Identify City employees who participated in WTC rescue, recovery and clean-up operations and provide 9/11-related health information to them
- ✓ Offer excused absences on City time to City employees who wish to make
 appointments to be screened or treated for the first time at the WTC Centers of
 Excellence if they are eligible for services
- ✓ Encourage City employees with 9/11-related mental health and substance use needs to enroll in treatment programs
- Encourage City employees who participated in WTC rescue, recovery and clean-up operations to register with the New York State Workers' Compensation Board

My name is John Gallagher. I'm a retired Captain that spent 34 years with the New York City Fire Dept. On Sept. 11/2001 I arrived at the World Trade Center at app. 4 PM and spent the next 30 hrs. digging in the pile before I was relieved. Between Sept. 11 and Dec 4/2001, I worked pretty much full time at what became known as ground zero. On Dec 4th. I was diagnosed with a heart ailment and was forced to retire. Almost five years later, In November of 2007 I was diagnosed with an untreatable, incurable Lung disease, pulmonary fibrosis. My only chance for survival is a lung transplant. I consider myself one of the lucky ones. Because the government acknowledges that my illness is WTC related, all of my medical expenses are covered. There are a large number of people suffering illnesses that are not acknowledged to be WTC related. Cancers and auto-immune diseases are two areas we need to get coverage for. Can anybody look at the list of toxins that were released during the collapse and honestly say there's no link to the cancers and other diseases we see today?

The WTC medical working groups 2008 report recommendations called for advocacy for long term 9/11 health programs. The 2009 report echo's that call. As I speak here today, there is bill stalled in the congress, HR 847 which would provide medical expenses for people who become ill from WTC related diseases and reopen the victims compensation fund to those

who didn't file with the first fund because they weren't sick at that time. We have the votes to pass the bill, unfortunately Speaker Pelosi will not allow a vote at this time. I'm asking the council members to become our advocates and reach out to the mayor to urge him to arrange a face to face meeting with the speaker on this issue. So that HR847 can be voted on and sent to the Senate. Further I would ask the council to reach out to members of congress and urge them to intercede with the speaker on our behalf. HR 847 would provide proper health care options for the 9/11 sick. In closing I would ask the council to inquire of the Fire Commissioner, if the 7.5% medical leave numbers he recently used to reduce manning included any members suffering chronic WTC illnesses and if so why these members are included. Due to the events of Sept. 11 the fire dept. now has a permanent percentage of members who suffer chronic illness. Their illness should not be used as a weapon against them. Thank you for allowing me to speak here today.



The Council of the City of New York
Committees on Lower Manhattan Redevelopment, Civil Service and Labor and Mental Health
Oversight Hearing on
Examining the NYC World Trade Center Medical Working Group
2009 Annual Report on 9/11 Health

Testimony by Catherine McVay Hughes, Vice Chairperson Manhattan Community Board One

Monday, December 7, 2009 at 1 p.m. Council Chambers at City Hall, New York, NY

Good afternoon. I am Catherine McVay Hughes, the Vice Chairperson of Community Board One (CB1). Thank you for the opportunity to testify today about the City's WTC Medical Working Group 2009 Annual Report on 9/11 Health.

As more and more studies document serious 9/11-related health impacts to the community, some of which have become chronic, Lower Manhattan residents remain concerned about negative health effects due to the World Trade Center attacks on September 11, 2001. Uncertainty about what the future holds for residents and workers of our community, especially for those exposed to WTC pollution as children, continues to linger. CB1 has passed numerous resolutions in the years since 9/11 to advocate for medical programs and resources needed by our community.

The September 2009 report carries great importance in light of impending budget cuts at the City, State and Federal level. It documents WTC-related physical and mental health conditions. These data reinforce the need for passage of the 9/11 Health Act which would address health care for both first responders and the community, but also raise questions about whether the bill will adequately meet the health needs of the community. The 9/11 Health Act is currently stalled in the House behind health care reform.

CB1 agrees with the report that "Many studies rely on self-reports of symptoms and conditions to measure the burden of these conditions in exposed populations without verification of diagnoses." (Page 9) This is especially true for the community population since there has never been a monitoring program for non-responders comparable to the Mount Sinai WTC Medical Monitoring program. As a result, there is no comprehensive program to screen, monitor and, where warranted, treat residents, students, and workers who remained in the area in the



City of New York

Julie Menin Chairperson | Noah Pfefferblit district manager 49 Chambers Street, Suite 715, New York, NY 10007-1209 Tel 212 442 5050, Fax 212 442 5055, Email cbl@cbl.org, www.cbl.org aftermath of 9/11 and in subsequent years. Instead, epidemiology on health impacts to the community has relied on limited community involvement.

The registry's first survey was not sent out until late 2003 & early 2004, instead of closer to 9/11/01, when exposure assessment would have been more accurate. In addition, the first survey did not include any questions that would elicit information about exposures to WTC dust in homes, schools and offices – exposures that we now know now may have resulted in illness. Finally, as a November 23, 2004 New York Times article noted, even though the survey was issued years after the WTC attacks, it failed to ask people about whether they were still suffering from respiratory symptoms. As a result, the City lost the opportunity to capture 9/11-related unmet health needs. As a result, we remain concerned about the likelihood of undiagnosed illnesses and the missed opportunity for early intervention and needed treatment. We have long held that getting timely and thorough information on health effects from exposures in environmental disasters is one of the critical lessons learned from 9/11.

As the evidence has continued to mount that the effects of exposure have been significant for those who weathered the days, months, and years following the attacks, the local Community Boards put the small numbers of patients receiving treatment at the Bellevue WTC program into perspective. In a September 4, 2008 letter to the Mayor's Office, CBs 1, 2, and 3 stated, "Nearly 3,000 of our neighbors are receiving care through the Community Program at Bellevue Hospital, and many more have chosen to receive care elsewhere... While we cannot truly know the number of people who were affected, a 2007 report by the City of New York estimates that as many as 318,000 community members were most heavily exposed to toxins from the World Trade Center."

Over 4,000 patients have visited the World Trade Center Environmental Health Centers, which have been expanded from Bellevue to two additional sites at Elmhurst and Gouverneur Hospitals. An advertising campaign with extensive community input was launched to reach out to residents and workers whose health was impacted by 9/11 and make them aware that the WTC EHC was providing expert treatment at no out-of-pocket cost. The Health and Hospitals Corporation (HHC)-funded outreach projects by trusted community and labor organizations have been especially critical, since after years of government denials of WTC environmental health risks, many people were skeptical about the government response to WTC environmental health issues. These efforts, begun recently, have only just started to show results. However, we are now faced with the fact that currently the 9/11 Health and Compensation Act only covers treatment to an additional 15,000 community members, and we do not know whether this will be adequate, especially given the potential for emergent diseases. In fact, the City's own report estimates (Page 3),

"Based on its 2006-2007 survey findings of physical and mental health impacts, the WTC Health Registry has estimated that among the 409,000 people who were most heavily exposed to the disaster on 9/11: Between 17,400-40,000 adults may have been newly diagnosed with asthma five to six years later."

So then, where are these people going for medical treatment?

For the past eight years, CB1 has continually and strongly supported federally funded health services for residents and workers exposed after 9/11. In May, 2005, Community Board 1 passed a resolution calling for a comprehensive study comparable to the Mount Sinai Medical Center WTC Rescue Workers Program to be conducted for residents and workers. On November 20, 2007, CB1 passed a resolution in support of the 9/11 Health and Compensation Act of 2008 (H.R. 3543) in order to provide necessary services to those directly affected, including those who lived, worked, volunteered, and attended school in Lower Manhattan. We reiterated our support for the Act in a resolution in March 2009.

In particular, we have supported the 'Centers of Excellence' approach where care is provided by WTC specialists, and we find that the Environmental Health Center, the community program, has been a tremendous resource. Furthermore, CB1 has opposed cuts to this resource. On December 16, 2008, CB1 spoke out strongly against a federal proposal to replace the programs at the Centers of Excellence with outsourced contractors (Resolution, December 16, 2008). CB1 believes that beyond the basic maintenance and expansion of these essential resources, it is essential to build public awareness of the programs and encourage those potentially affected to utilize them.

CB1 had been concerned that needed programs for youth affected by 9/11 have not been in place. In a resolution passed in February 2009, we commended the 2006 New York City Department of Health and Mental Hygiene for the publication of "Clinical Guidelines for Adults Exposed to the WTC Disaster," but expressed dismay that guidelines had not yet been developed for the more than 30,000 children and adolescents who lived or attended school in Lower Manhattan on 9/11, as we advocated in a resolution of April 2007.

When pediatric guidelines were eventually released in July 2009, CB1 encouraged the Department of Education to coordinate outreach with the Department of Health and Mental Hygiene and the WTC Environmental Health Centers (EHC) to ensure that the guidelines and information about the availability of treatment at the WTC EHC Pediatric Clinic would be provided to parents of all potentially affected children and adolescents (Resolution, July 28, 2009). The City stated as much in the key recommendations made in its 2008 Annual Report on 9/11 Health, "Develop and disseminate clinical guidelines for children exposed to the WTC disaster" as part of its efforts to increase the awareness of WTC-related symptoms and the availability of clinical resources among health care professionals and people exposed to the WTC Disaster (p. 4). We believe that it is imperative that the DOE conduct this long-overdue outreach to households with children who were attending Lower Manhattan public schools on 9/11 in the very near future.

Finally, CB1 is concerned about the adequacy of the government response to possible latent or late-emerging 9/11-related illnesses that could afflict responders and non-responders. For example, a recent Mount Sinai-based study on the emergence of a rare bone marrow cancer among police officers who served at Ground Zero was reported in "Multiple Myeloma in World Trade Center Responders" (American College of Occupational and Environmental Medicine, August 2009). We question the absence of any reference to the study or its troubling findings in the City report. The study concluded that,

"In this case series, we observe an unusual number of MM [Multiple Myeloma] cases in WTC responders under 45 years. This finding underscores the importance of maintaining surveillance for cancer and other emerging diseases in this highly exposed population."

The authors noted that they are in the process of verifying an additional 8 cases in Mount Sinai's Monitoring Program database. It seems clear that without the active surveillance of a screening and monitoring program, this unexpected disease pattern would not have come to light. This highlights our concern that the community never had a monitoring program. We ask that every time an illness is covered for the responder program, it is also covered comparably for the community program.

We are grateful to all of our advocates and allies who have worked tirelessly to address the physical and mental and health needs of *all* those who were affected by the 9/11 attacks We hope today's hearing will encourage increased support and expansion of the WTC EHC and the other Centers so that they can keep pace with the needs of those who are sick now and in the future. Thank you for the opportunity to testify today.

9/11 Environmental Action

Testimony of Kimberly Flynn
City Council Hearing December 7, 2009
Committees on Lower Manhattan Redevelopment; Mental Health; Civil Service
Oversight - Examining the NYC World Trade Center Medical Working Group
2009 Annual Report on 9/11 Health.

Thank you for the opportunity to testify today. I am Kimberly Flynn and I make these comments on behalf of 9/11 Environmental Action, a community-based organization of downtown residents and school parents and environmental health advocates formed in April 2002 to end the federal Environmental Protection Agency's cover-up of the toxic substance release in the WTC disaster. For the past eight years, 9/11 EA has fought for comprehensive cleanup of WTC contamination by the federal EPA and for federally funded medical monitoring and treatment for everyone harmed by exposure to WTC smoke and dust.

As we understand it, the City of New York, as part of its advocacy efforts on behalf of the WTC treatment programs and the WTC Health Registry, presents its annual reports to Congress as reviews of the state of the 9/11 unmet health needs. Unfortunately, we find that the City's 2009 Annual Report, like those that preceded it, leaves many important questions about the true scope and the real range of 9/11 environmental health impacts not only unanswered, but unasked. When the City does report, for instance, on the scope of new asthma diagnoses likely linked to 9/11, it provides estimates of affected adults that beg a few questions: Notably, where are these thousands and thousands of people receiving treatment? Why isn't the City doing its utmost to ensure that they are being seen at the WTC Environmental Health Center?

The City's inadequate effort to promote treatment at WTC EHC is a running theme, but I will focus my comments for the most part on the population of people exposed as children, and begin at the beginning:

On 9/11, when the World Trade Center was destroyed, more than 1.2 million tons of toxic dust, contaminated with asbestos, lead, PAHs, PCBs, mercury, fiberglass, silica and more, were released into the air. A massive collapse cloud engulfed Lower Manhattan and penetrated into buildings of all sorts – residences, workplaces, schools. The cloud was carried by the wind over western Brooklyn. Over the succeeding weeks and months, an acrid plume of smoke rose from fires that continued to burn at the site, hanging over neighborhoods near Ground Zero and well beyond.

The Environmental Protection Agency (EPA), which had responsibility for protecting the public from the toxic air, and for conducting indoor cleanup of buildings contaminated in the collapse, chose instead to lie about the dangers in the dust and smoke, declaring, within days of 9/11, that the air was safe to breathe. The City of New York quickly followed suit, as Mayor Giuliani reiterated Christine Todd Whitman's now infamous declaration. In the succeeding weeks and months, downtown residents were given wrong, dangerous and illegal advice to clean up the toxic WTC dust themselves "with a wet rag or mop," by the New York City Health Department.

The WTC disaster exposed as many as 46,000 children, who lived or attended schools downtown, to toxic smoke and dust. From the beginning, the environmental health risks to children were either ignored or denied outright in public statements by federal, state and city government agencies. It has been understood for decades that because of their developing lungs, brains and other body systems, children are especially susceptible harmed from exposures to environmental toxins, even from low-level or short-term exposures. But in a Frequently Asked Questions advisory issued shortly after the WTC disaster, the City asked a question on the minds of many: "Do pregnant women and young children need to take additional precautions?" Then, sweeping aside everything that was known about children's vulnerability, the City made the following, we would say 'conscience shocking' answer:

"No. Pregnant women and young children do not need to take additional precautions."

I recount this history because it is still very much with us. The City's denials of health risks of breathing WTC smoke and dust, its unsafe recommendations, and its refusal to make a mid-course correction after the EPA Inspector General's 2003 report, denouncing both the EPA and the City for putting New Yorkers at risk, had established that the first EPA cleanup was flawed and inadequate, are all reflected in the City's report, the City's WTC guidelines for physicians, the City's insufficient efforts to informed sick New Yorkers of the availability of treatment at the WTC Environmental Health Center, a resource that the City hopes the federal government will fund.

We have found as we pressed the City to honestly address the environmental health consequences of 9/11 that the City is operating with two conflicting sets of priorities. One reflects the City's understanding that we are in the midst of a mounting 9/11 health crisis, and that it is in the best interest of the City to gather information about any health problems that may have resulted and to ensure that federal funding will be adequate to address the need for care, now and in the future. These are the right priorities. But there is another set of wrong priorities that have to do with the City's desire to minimize its own liability for illnesses that it might have prevented, had it mandated the use of respirators on the pile, had it told the truth about the risks of exposure, had it called on the EPA to conduct a thorough, effective cleanup of all contaminated indoor spaces, etc. These priorities continue to be reflected in policy and guidance, and in the reports that the City considers to be its advocacy primer for Congress.

I will state a few examples.

The City's desire to deny the emergence of illness for those people who listened to its false assurances and followed its bad advice is strong. Looking at the City's 2008 report, we see that even as the City had committed to developing WTC pediatric guidelines, it is language that minimizes the importance of the studies by Columbia University and Mount Sinai researchers documenting serious health impacts to children exposed in utero to WTC pollutants, including reduced fetal growth, which is associated with neuro-cognitive problems and future health risks. The report concludes that the "clinical relevance" of these findings "remains unclear."

The community had to fight very hard to keep that kind of language, language that denies or distorts the evidence of illness, out of the WTC pediatric guidelines. We were not entirely successful.

We learned from the City's 2009 report that the City has stepped up its efforts to conduct studies that emphasize the role of stress as the primary causal factor in a range of WTC health problems, including fetal growth restriction and its associated effects. Prompting one former Stuyvesant High School parent to quip: "can't wait til they say that about the cancers!"

Another example: In November of 2008, the City issued its physicians guidelines on "Managing Asthma." Buried on the final page, last in a list of "special situations," is a paragraph on "Individuals exposed to the World Trade Center disaster." Physicians are advised only to consider referring a patient to the WTC EHC "if symptoms fail to improve or concomitant physical or mental health conditions are present." The document should prominently display a box on the first page with language that states that any patient with asthma, or other conditions, that may be related to 9/11 should be referred to WTC EHC for evaluation. Why isn't the City making it best efforts?

Another example: my group and other downtown parents have been struggling with the City Department of Education for more than a year to get DOE to inform all the families of the most heavily exposed school children about the treatment available at the WTC Pediatric Program at no out-of-pocket cost. Only the DOE has the database with these contacts. Negotiations have taken more than a year. Even after the DOE agreed to do the outreach, it has failed to move forward. Two of the three Lower Manhattan Community Boards have unanimously passed resolutions calling for this effort, with the third board to move this month. Why isn't the City making its best efforts to bring sick children to the City's treatment program?

What are the predictable consequences of the government's failure to document the full scope and nature of the pediatric health impact? What are the consequences of the City's failure to create a WTC pediatric program until 2008, to issue WTC pediatric health guidance until 2009? A patient population that is 1000 times smaller than the number of exposed children. Without this base of knowledge, many parents remain unaware of their children's 9/11-related illnesses and will not seek care for their children at the WTC EHC's pediatric program. Without adequate monitoring, children, youth and young adults will net receive the attention they need to address evolving 9/11 health problems in the future. The end result is, once again, that families, kept in the dark, will have to fend for themselves.

So the City has two sets of priorities, one of which is to protect the health of residents, workers, students, anyone exposed as a child, by making sure that everyone sick from 9/11 gets tracked, treated and covered. Unfortunately, the wrong set of priorities continues to intrude, resulting in dramatic undercounts of the sick and a failure to monitor people who were exposed guaranteeing that the unexpected disease patterns resulting from these unprecedented toxic exposures will go undetected. That runs the risk that any intervention will be too late to be fully effective.

At this critical moment, before the James Zadroga bill is marked up by the House Energy and Commerce Committee, we are calling on you, our elected representatives on the City Council to protect the health of all affected New Yorkers by rescuing the first set of the City's priorities from the second.

Right now, since the community has no screening/monitoring program comparable to the Mount Sinai WTC Worker and Volunteer Medical Monitoring program, residents and others are at the mercy of the WTC Health Registry's epidemiology. Detecting new diseases with a link to WTC have not been a focus. We cannot put off the creation of a monitoring program for the community, at the very least for those exposed to WTC toxins as children. We urge you to advocate for one standard of care at all three WTC Centers of Excellence, for monitoring and treatment for all those who are sick from WTC exposures. We believe there should be one list of covered conditions. Finally, we urge you to call for the Zadroga bill to be amended to make the key improvements my organization and six others call for in our letter to Congress. The federally

funded community program created by the 9/11 Health and Compensation Act must count and provide for everyone who is sick from the WTC disaster.

Thank you,

Kimberly Flynn 917 647-7074 Beyond Ground Zero
9/11 Environmental Action
Concerned Stuyvesant Community
New York Environmental Law and Justice Project
South Bridge Parents and Youth Association
StuyHealth
World Trade Center Residents Coalition

December 7, 2009

Dear Senators and Representatives:

The eighth anniversary of September 11 passed with no federal commitment to rebuilding the health and lives of 9/11-affected workers, residents and students. Current legislation, the James Zadroga 9/11 Health and Compensation Act (HR 847 and S 1334), is an important first step, but it falls short in key areas. As representatives from and advocates for 9/11-affected communities, we call on you and President Obama to guarantee lifelong treatment and financial compensation to all those suffering from current and emerging 9/11 illnesses.

Our health continues to suffer. — Tens of thousands suffer from debilitating health problems, some of which are evolving at a faster rate than our medical specialists' knowledge. In its current form, the James Zadroga Act fails to guarantee that those with emerging health problems will receive timely treatment. As new patterns of disease develop, it is critical that care for those who are sick does not come too late.

9/11 health care should be inclusive — The bills before Congress would limit the numbers of 9/11-affected persons entitled to receive treatment at the community's Center of Excellence, the World Trade Center Environmental Health Center (WTC EHC) in at least two important ways:

- The bills exclude from treatment those exposed above Houston Street, even though the toxic smoke and dust permeated
 a wide geographic area, and despite peer-reviewed evidence of 9/11-related illnesses beyond this arbitrary boundary
 line.
- The bills improperly rely on the current number of patients at the WTC EHC to set the number of future eligible enrollees. The limit of 15,000 future enrollees would guarantee treatment to only 5% of the most heavily exposed civilian population, as defined by the City of New York. A recent 9/11 community health survey in New York City (attached here) confirms what community groups already know: significant numbers of workers and residents are not receiving specialized treatment at the WTC EHC, but from private doctors, so they are not being counted by Congress as 9/11-affected.

The federal government must take responsibility for the full scope of the 9/11 health disaster. — We remind you that it was the federal government that told residents, workers and students in lower Manhattan that the air was safe to breathe after 9/11, a lie that unnecessarily exposed hundreds of thousands to deadly 9/11 toxins. It is time for the federal government to take responsibility for its reckless failures to protect the health of residents, workers and responders alike.

BGZ's member organizations include the Asian American Legal Defense and Education Fund, the Chinese Staff and Workers' Association, the Commission on the Public's Health System, the National Mobilization Against SweatShops and the Community Development Project of the Urban Justice Center.

^{9/11} EA is a community-based organization of downtown residents, school parents, and occupational-safety and environmental-health advocates who have fought for comprehensive clean-up of WTC contamination by the federal EPA and for federally funded medical monitoring and healthcare for everyone harmed by exposure to WTC smoke and dust.

The long-overdue federal response to the 9/11 health crisis must reach all affected persons, providing them treatment, monitoring, financial compensation, and support services. We call on you, our elected representatives, to make 9/11 health a priority by passing comprehensive legislation that will enable all those affected by 9/11 to rebuild their health and lives.

Sincerely yours,

BGZ, the Beyond Ground Zero Network
9/11 Environmental Action
Concerned Stuyvesant Community
New York Environmental Law and Justice Project
South Bridge Parents and Youth Association
StuyHealth
World Trade Center Residents Coalition

BGZ's member organizations include the Asian American Legal Defense and Education Fund, the Chinese Staff and Workers' Association, the Commission on the Public's Health System, the National Mobilization Against SweatShops and the Community Development Project of the Urban Justice Center.

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Statement of the Patrolmen's Benevolent Association (PBA) of the City of New York, by Frank Tramontano, Research Director for the PBA for the Oversight hearing on the 2009 Annual Report on 9/11 Health from the World Trade Center Working Group of New York City – December 7, 2009.

Good Afternoon my name is Frank Tramontano and I am the Research Director for the Patrolmen's Benevolent Association. I am here with Chris McGrath an attorney for the Patrolmen's Benevolent Association who has been working on 9/11 health issues for over 3 years. I would like to thank the Speaker and her staff for having this important oversight hearing. I would also like to thank the Chair persons of the respective committees conducting this hearing, Councilmember Alan Gerson, Councilmember Mike Nelson and Councilmember Oliver Koppell and of course a most appreciative thank you to the committee's staff whose hard work contributes to this hearing being both informative and comprehensive.

As the Committee may know, the PBA has been in the forefront of efforts to identify illnesses resulting from exposures at the WTC, to report and raise the public's awareness of those illnesses and in seeking to hold government to its obligation to treat and care for responders suffering from WTC-related illnesses. Since September 11th, the PBA's efforts have included pressing the City Health Department to release protocols for treatment of WTC illnesses that had been delayed in City bureaucracy. When programs for the monitoring of illnesses were slow to publish data, the PBA established its own public WTC- illness registry at the PBA website. In each of the PBA's quarterly magazines, the PBA has highlighted the stories of New York City police officers who the PBA believes were made ill, and some who have lost their lives, as a result of WTC exposures. I ask that these stories be made part of the record. Most recently, the

PBA has taken the public position that the Zadroga Bill, which I will discuss more in a moment and which is now pending in Washington should provide funding to cover cancers and other serious ailments, not presently provided for in the pending bill.

I am here to share with you the PBA's views about this issue and other issues related to exposures at the WTC. We believe this testimony is important because cancer and cancer-related issues are not addressed in the 2009 Annual Report on 9/11 Health.

In the August 2009 issue of the Journal of Occupational and Environmental Medicine, a report titled *Multiple Myeloma in World Trade Center Responders: A Case Study* was published. Multiple Myeloma is a cancer of the white blood cells that usually affects people aged 60 and above with an average worldwide rate of four cases per 100,000 according to Harrison's Principles of Internal Medicine. This study, which eventually confirmed 16 cases of Multiple Myeloma from a base of approximately 28,000, we maintain is significant and sufficient to establish a link. Being a blood cancer, Multiple Myeloma would be expected to be one of the first cancers to manifest itself in those who were exposed at the WTC sites. Any results in this area may foreshadow what is coming with respect to other cancers. We understand that the finding in this study will result in a recommendation by the WTC Steering committee that Multiple Myeloma be added as a medical condition eligible for treatment under the current WTC program at Mount Sinai and other locations.

Links to cancer from exposure at the World Trade Center sites can be found elsewhere. The number of cancer cases approved for disability by the Police Pension Board has almost tripled since 2005. In years prior to 2006, the number of cancer cases averaged around 6 per year, while in years starting in 2006 the number of cases grew to an average of 17 a year. Does this increase in Police members who can no longer work because they have become ill with

cancer suggest a link? In many of these cases, doctors have stipulated that exposure at the WTC sites was a significant and contributing factor that more reasonably than not resulted in causing cancer.

We have seen further evidence. In early October, there were four 9/11 responders (2 NYC Police officers and 2 NYC Firefighters) who died from cancer within a week of each other, three of them were 44 years of age and the fourth was only 37 years old. In fact, the story as reported in the Daily News, quoted Mayor Bloomberg as saying "Probably--- nobody's sure--- but probably contracted during breathing the air down at the World Trade Center site".

Additionally the NYPD recently added the name of ten uniformed members of the NYPD who died of illnesses related to their rescue, recovery, and cleanup work at Ground Zero and the Fresh Kills Landfill to the Police Wall of Remembrance. Every one of these ten uniformed officers died of cancer. The Police Wall of Remembrance bears the names of all NYPD police officers who have died in the line of duty since 1849. Police Commissioner Raymond W. Kelly stated the following at the October 13, 2009 ceremony:

The addition today of these officers underscores the reality that this tragedy is something the department and City will endure for a long time to come. Men and women of different ranks and commands united in a common mission to aid in the recovery effort. They brought closure to the loved ones of those who were killed and restored order. But they too became casualties.

The issue of cancer as a related 9/11 illness is important because the current program at Mt. Sinai does not currently provide treatment for cancer and the federal legislation in Washington HR 847 in the House and S 1334 in the Senate does not list cancer as a qualifying medical condition eligible for treatment. That legislation, also known as the Zadroga Act, named

after James Zadroga a New York City detective, will provide permanent funding for monitoring, evaluating and treating victims of the terrorists attack in New York City.

If that bill were to pass as currently drafted the procedures for adding any new medical conditions eligible for treatment would take at least 8 months to more than a year. The proponents of the bill have stated they need indisputable scientific studies linking cancer before they can include it as a medical condition eligible for treatment. Yet the fact that Carpal Tunnel Syndrome is a listed medical condition covered under the Zadroga bill without any similar indisputable scientific studies being required, leads us to conclude that cancer is being held to a much higher standard. In the PBA's view, this may have more to do with the cost of treating cancer than with meeting a required standard for approval.

To take the position that we must wait for indisputable scientific proof before we can offer treatment to those responders with cancer would have the effect of denying quality medical treatment to WTC victims at a time when they are diagnosed and when it can be most effective. Epidemiological studies of which the proponents of the Zadroga bill insist upon will take 10 to 20 years to complete during which an ailing responder would not qualify for aid. As an example, several of the responders in the Multiple Myeloma study were diagnosed in 2004, we are now approaching 2010 and these victims are still not being provided cost free quality medical care despite the scientific proof. The policy also raises other interesting questions. Does each type of cancer need an exhaustive study comparing its prevalence to that of the general population before it can be treated under the federal program? There are at least 18 different cancers that have been approved at the Police Pension Board as WTC related. Are 18 separate studies needed before these sick former members of the NYPD can be provided cost free quality treatment?

We believe the facts are clear. Carcinogens cause cancer and some of the highest levels of carcinogens ever recorded for one of the longest period of time ever recorded were at the WTC sites. Responders, especially police officers, were at those sites without any protective gear. Cancers have and will continue to be a result of exposures in that environment. The proof of Multiple Myeloma, a blood cancer with a relatively short latency period, and the increase in other cancers being diagnosed every day in a relatively young worker population is indicative of the linkage to WTC exposures.

It is our request that the City Council call upon Congress to amend the Zadroga bill to have cancer included as a qualifying medical condition eligible for treatment. As stated earlier, that bill as it currently is drafted, does not list cancer as a qualifying medical condition eligible for treatment. However, the bill does permit the payment of compensation for cancer victims under the Victims Compensation Act of the bill. This anomaly is disturbing. A bill that permits the federal government to compensate families for cancer deaths related to 9/11 but not for treatment for those same victims while they are alive does not make sense.

We believe there is sufficient evidence to advocate for the addition of cancer under the Zadroga bill. The State Legislature and then Governor Pataki recognized the cancer link back in 2005 and approved a presumptive accident disability bill for City and State employees who contracted cancer and were at the WTC sites. The evidence is greater now and while it may not be easy to convince Washington to include cancer we think having the City Council stand up on the right side of this issue will help us in that process.

Thank you for your time and attention today, and Chris McGrath and I will gladly answer any questions you have at this time.

NEW YORK CITY COUNCIL

COMMITTEE ON CIVIL SERVICE AND LABOR

COMMITTEE ON LOWER MANHATTAN REDEVELOPMENT

COMMITTEE ON MENTAL HEALTH, MENTAL RETARDATION, ALCOHOLISM, DRUG ABUSE, AND DISABILITY SERVICES

HEARING ON

Oversight: Examining the NYC World Trade Center Working Group 2009 Annual Report on 9/11 Health

December 7, 2009

Testimony of James Melius MD DrPH

I am James Melius, an occupational medicine physician and epidemiologist, who works as the Administrator of the New York State Laborers' Health and Safety Trust Fund. Our union represents thousands of worker who were employed in the rescue and recovery efforts at the World Trade Center and surrounding areas in the aftermath of the terrorist attacks on September 11, 2001. For the last several years, I have served as chair of the Steering Committee for the WTC Medical Monitoring and Treatment Program which oversees the federally funded medical program for WTC rescue and recovery workers. I also co-chair the Labor Advisory Committee for the WTC Registry and serve as a member of the Community Advisory Committee for the WTC Environmental Health Center and as a member of the New York State 9/11 Worker Protection Task Force. I have also been active in the advocacy for federal funding for these programs and for a comprehensive federal legislative approach.

The 2009 Annual Report on 9/11 Health is for the most part a summary of published medical studies related to workers and community residents who have suffered adverse health effects from exposures following the WTC terrorist attacks. The 2009 report updates similar reports from earlier years. Although the report contains other information on the WTC medical programs, it largely relies on published medical literature for its conclusions and recommendations. This focus of the report may be appropriate from the perspective of a scientific report, but it leaves out much important information that is critical to understanding the overall impact of WTC exposure on the health of workers and community residents and limits the utility of the report for developing the medical and other programs needed by those whose health has been adversely impacted by these exposures.

.First, the report does not address the large number of workers and community residents who are disabled and can no longer work because of the severity of their WTC-related health conditions. Although an appendix of the report includes some information on disabled NYC workers, this information is incomplete and does not include the many private sector workers and many non-uniform NYC workers. The New York State Workers' Compensation Board has published some information on this including the

long time period it takes for compensation claims to be recognized, largely due to the claims being contested by the employers and insurers. We know that there are thousands of workers unable to work because of their WTC-related conditions. The long delays in getting workers compensation or disability pension benefits place an extreme hardship on them and their families. Most of the charity funded safety net for these people has been discontinued. We need to do a better job of addressing their needs through more responsive compensation programs and through the reopening of the Victim's Compensation Fund in the federal legislation.

Secondly, the current federal and city health programs provide care for only a limited number of health conditions. These include mainly respiratory disease and mental health conditions (such as post traumatic stress disorder). These programs currently treat several thousand workers and community residents for these conditions. Many of these people have chronic health problems that will most likely require treatment for the rest of their lives.

However, we are also starting to recognize other health conditions that have resulted from these WTC exposures. This is not unexpected given the "soup" of toxic materials that these people were exposed to including many known carcinogens (including asbestos, benzene, etc.). For example, researchers at Mount Sinai School of Medicine recently published a scientific paper reporting on several cases of multiple myeloma (a type of cancer) among WTC responders that the Mount Sinai investigators had found among the people being treated for other conditions in their clinic. The Mount Sinai report only extended through 2006. Since then Mount Sinai has found several more additional cases of multiple myeloma among their patients. One of the functions of the WTC steering committee is to review this information and make recommendations to NIOSH for adding additional conditions to the list of covered conditions being treated by the WTC medical program. This review is currently underway and should be completed in the next few months. Data recently received from the NYS cancer registry will also be utilized in this review.

It is extremely important that we develop the list of covered WTC health conditions in a flexible manner that is responsive to the emerging scientific evidence but more importantly responsive to the needs of the workers and community residents whose health has been affected by these exposures. We must not wait until all of the scientific evidence has been completed to make decisions on who should receive treatment under this program. We may not have definitive scientific evidence on this impact for many years, and, if we wait, many people will have been denied treatment coverage while waiting for this determination. We must take into account what we know from the scientific studies but be ready to make decisions before all of the scientific evidence has been completed. This applies to not only to multiple myeloma,, but to many other types of cancer and other possible health conditions.

In summary, I think that it is important to recognize the limitations of the Task Force Report. In limiting the type of information included in the report largely to published scientific studies, it provides a useful but incomplete report on the health impact of the WTC disaster. These limitations need to be recognized in utilizing the report to guide current decisions on what needs to be done to fully address the needs of those workers and community residents whose health ahs been impacted by this disaster.

Testimony for the Joint Hearing at City Council Chambers Monday December 7, 2009

The Lower Manhattan Redevelopment Committee; The Committee on Civil Service and Labor; and the Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services

Testimony By: Mika Nagasaki, Organizer

Chinese Staff & Workers' Association 55 Chrystie Street, New York, NY 10002

Beyond Ground Zero Network

My name is Mika Nagasaki and I represent Chinese Staff & Workers' Association, a workers' center based in the Chinatown community. Immediately after 9-11, we were door-knocking and providing relief assistance for residents inside and outside boundaries of federal relief assistance programs. For the past 8 years, we have seen how the government arbitrarily excluded thousands of affected workers and residents from the Health Registry by establishing eligibility cutoffs at Canal and Chambers Streets. The City has consistently ignored the most vulnerable – the low income communities of color - through constant exclusion from government relief (FEMA, LMDC, Red Cross), and even from the protection of the rezonings under the Bloomberg administration. In the past 8 years we have seen how the government has displaced 9-11 affected workers and residents by prioritizing luxury development in the aftermath of 9-11, and most recently by passing a racist rezoning plan to displace low-income residents of color. The 2008 East Village Rezoning Plan is already displacing countless residents and businesses from Chinatown. Many sick workers and former residents affected by 9-11 now live in outer boroughs far from the Environmental Health Centers and must decide whether to pay for private medical attention or to let their ailments go untreated.

To address the lack of adequate studies on our communities, we recently released the *We Count!* Survey as part of the Beyond Ground Zero Network. The survey findings show that a significant number of workers and residents experience persisting illnesses that are undermining their ability to work and thus affecting their income. On the other hand, those who are seeking private medical attention are not being counted as affected by 9-11. I urge you to look over the *We Count!* Survey that we are submitting to you today along with this testimony.

Everyone affected, including patients who seek private medical attention, must be included in studies, treatment, and compensation and relief efforts. Furthermore, the City must stop rezoning plans that displace working people from their communities.

Documenting the 9/11 Health Crisis 8 Years Later



9/11 ENVIRONMENTAL ACTION

WE COUNT!

Documenting the 9/11 Health Crisis 8 Years Later

9/11 ENVIRONMENTAL ACTION

www.911ea.org



BGZ GROUPS INCLUDE:

Commission on the Public Health's System
National Mobilization Against Sweatshops
Chinese Staff and Workers' Association
Community Development Project of the Urban Justice Center
Asian American Legal Defense and Education Fund

Many thanks to everyone who participated in surveying and in the writing of this report, especially Chris Fernandez, Tosh Anderson, Kimberly Flynn, Aliyah Vinikoor, Laine Romero-Alston, Molly Slavin, Alexa Kasdan, and Tammy Kim. This report was designed and typeset by Chris Chaput.

September 2009

I. INTRODUCTION

The collapse of the twin towers on September 11, 2001 sent more than 1.2 million tons of hazardous contaminants and toxins into lower Manhattan and western Brooklyn, penetrating buildings and setting off massive fires that would pollute the area for months. Eight years after the World Trade Center ("WTC") disaster, tens of thousands of workers, residents, and students in the New York metropolitan area continue to suffer profound health consequences. WE COUNT!, a 9/11 community health survey, aims to document the myriad impacts of 9/11 toxic air and dust on local communities.

Despite the progress that has been made in the fight for 9/11 health, the WE COUNT! survey indicates that many residents, workers, WTC first-responders, and children are chronically ill. Survey responses demonstrate the need for the federal government, in collaboration with the medical community, to further research 9/11 health conditions and for those suffering from 9/11-related health problems to better understand the effects of the toxins on their bodies. Residents and workers have also voiced their need for innovative, quality treatment and ongoing medical monitoring.

The WE COUNT! survey is a joint project by the Beyond Ground Zero network ("BGZ") and 9/11 Environmental Action ("9/11 EA"). This survey represents a community effort to investigate the extent and scope of the 9/11 health crisis in the absence of an adequate government response. In sharing these survey results at a time when Congress and President Obama are considering both national healthcare reform and 9/11 health legislation, BGZ and 9/11 EA call on the federal government to formulate a just and comprehensive long-term response to this ongoing public health disaster.

Beyond Ground Zero and 9/11 Environmental Action

BGZ is a coalition of community-based organizations that came together shortly after September 11, 2001 to address the severe health and economic impacts of the WTC's collapse on the low-income and immigrant communities in New York City, particularly the Lower East Side and Chinatown.² The member groups of BGZ are the Asian American Legal Defense and Education Fund, Chinese Staff and Workers' Association, Commission on the Public's Health System, National Mobilization Against Sweatshops, and the Community Development Project of the Urban Justice Center. BGZ has organized thousands of residents and workers to fight for relief benefits, health insurance, and quality treatment for their 9/11-related health problems. Thanks to the organizing and advocacy of affected workers and residents organizing through BGZ, an early form of the World Trade Center Environmental Health Center ("WTC EHC") began serving 9/11-affected patients free of charge.3 Years later, BGZ still represents many residents and workers who are patients in the WTC EHC. These community members continue to experience evolving 9/11-related health problems—which began with respiratory, mental health, gastrointestinal, and dermatological problems, and have now expanded to cardiac, skin, eye, and gynecological problems, as well as cancers.

9/11 EA is a community-based organization of downtown residents, school parents, and occupational-safety and environmental-health advocates that formed in April 2002 to end the federal Environmental Protection Agency's ("EPA") cover-up of the toxic substances released in the WTC disaster. For the past seven and a half years, 9/11 EA has fought for comprehensive clean-up of WTC contamination by the federal EPA and for federally funded medical monitoring and healthcare for everyone harmed by exposure to WTC smoke and dust.

Why WE COUNT!

To date, government and academic studies have failed to document the extent and scope of 9/11-related health problems affecting those excluded from the WTC Health Registry (see below). While many 9/11 health studies have been conducted,4 the vast majority address the health impacts on first-responders. The relatively few studies of residents, area workers, and students have examined only a limited cohort of those affected. In addition, research has focused exclusively on well-established WTC respiratory, gastrointestinal, and mental health impacts, ignoring a host of other health problems that may be 9/11-related. After years of organizing and advocacy, workers and residents are currently able to receive quality, expert treatment at the WTC EHC sites in the Bellevue, Gouverneur, and Elmhurst hospitals, but this treatment is not enough. Patients face increasingly complex and debilitating health problems that have already left a growing number of them unable to work, and neither existing health clinics nor the New York State Workers' Compensation are fully responsive to these concerns. If, at this crucial time of congressional debate over health legislation, 9/11-affected workers and residents do not renew their call for long-term health care, monitoring, compensation, and support services, the federal government will continue to downplay their 9/11-related health and economic needs.

II. BACKGROUND

Failures of the 9/11 Response

When the WTC towers collapsed, the local, state, and federal governments failed to warn or protect New Yorkers from the overwhelming environmental threat to public health. Top federal officials, including former EPA Administrator Christine Todd Whitman, and Mayor Giuliani encouraged the return of hundreds of thousands of workers, residents, and students to lower Manhattan without first ensuring that the air was safe to breathe.5

In 2003, the New York City and federal governments jointly established a "health registry" in the face of community outrage at the governments' failure to clean up lower Manhattan or to track and treat those who became sick. When the registry was announced, residents and workers demanded the inclusion of everyone exposed to the environmental disaster in order to document the nature and scope of 9/11-related health impacts and unmet needs. However, as discussed below, the resultant New York City WTC Health Registry effectively minimized the 9/11 health crisis by excluding many affected workers and residents from its purview.

WTC Health Registry and Limited Geographic Boundaries

The New York City Department of Health's WTC Health Registry began with a large-scale telephone and mail survey that purported to identify and gather information about 9/11-related exposures and long-term mental and physical health effects. 6 Due to geographic and other restrictive eligibility criteria, however, the program has excluded many people whose health was greatly diminished by the disaster. The information gathered is therefore inadequate and presents a myopic view of the range and scope of health impacts.

The WTC Health Registry arbitrarily set Canal Street as its northern boundary, cutting out significant segments of the affected population.7 This continues to define the eligibility area, notwithstanding studies showing that many residents north of this boundary line were also affected by 9/11 toxic dust and air.8 Historically, residents and workers, especially community members of the Lower East Side and Chinatown, have been underserved or excluded from 9/11 relief programs, clean-up programs, and federally funded treatment, and the Health Registry has been no exception. In addition, the Registry restricts eligibility for office workers, accepting only those who were south of Chambers Street on 9/11. The Registry's future longitudinal research will continue to exclude the experiences and health impacts of many people living and working in Chinatown and on the Lower East Side. WE COUNT!, therefore, demonstrates a community-based, symbolic rejoinder to the Registry's neglect.

World Trade Center Environmental Health Center

The WTC EHC, the only government-funded treatment and study program available to residents, students, and area workers (non first-responders), was won through community organizing and advocacy. Notably, the WTC EHC utilizes 14th Street as its northern eligibility boundary and serves residents throughout the New York City metropolitan area, as many residents and workers have moved out of lower Manhattan since 9/11. Had workers and residents not organized to demand such a program, the current federal legislation (see below) would not include a "community program." Even in its current form, this legislation reflects a too-narrow view of the "community" patient population, Thus, the future of the only 9/11 health treatment and study program for workers and residents is far from secure.

Federal 9/11 Health Legislation

After years of fighting for federal recognition, workers and residents have succeeded in pushing Congress to propose legislation that could fund a 9/11 community health program. Companion versions of the "James Zadroga 9/11 Health and Compensation Act" (HR 847 and SR 1334) are currently being debated in the House and Senate.9 Significant components of these bills include:10

- Establishing the World Trade Center Health Program:
 - a medical monitoring and treatment program for WTC responders and
 - a medical monitoring, screening and treatment program for the community (area workers, students, and residents):
- Providing funding for research into 9/11-related conditions;
- · Supporting New York City Department of Health and Mental Hygiene programs; and
- Reopening the September 11th Victim Compensation Fund ("VCF") to again provide financial compensation to family members of deceased victims as well as to injured persons meeting certain criteria.11

As discussed later in this report, although these bills represent a significant step forward, they omit certain segments of the affected population and do not guarantee that all 9/11-related illnesses will be covered, which ultimately excludes people from obtaining needed healthcare. New York City's police union, the Patrolman's Benevolent Association, has similarly observed that the bill "has many flaws, the most serious being its failure to include cancer and blood disorders as qualifying medical conditions entitling the victim to treatment and compensation."12

In August 2009, Mount Sinai-based clinical researchers reported higher than expected cases of a bone marrow cancer, multiple myeloma, in WTC first-responders, with an unusual number of cases in police officers under 45 years of age. An additional eight cases in WTC first-responders are in the process of being verified. Researchers point to dust samples taken from lower Manhattan as confirming that "the air contained many known carcinogens," and caution that exposures to combinations of the toxic substances released as a result of the disaster may have "new and unexpected health effects," including altered disease patterns. 13

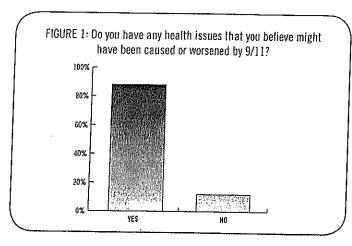
III. METHODOLOGY

Over approximately 18 months, BGZ's and 9/11 EA's used the WE COUNT! survey to conduct outreach to residents, workers, and students in various locations across New York City, but with a focus on lower Manhattan. The survey was designed to capture a snapshot of some of the health and economic problems faced by workers, residents, WTC first-responders, and children exposed to 9/11 toxins. The findings confirm and build upon BGZ and 9/11 EA's collective knowledge of the staggering health impact of the 9/11 environmental disaster and echo the medical literature. In total, 211 surveys were completed and form the basis of the analysis in this report. Unless a subset of the respondent pool is specified, the statistics and percentages below reflect responses to each question by the total surveyed pool of 211 people. BGZ continues to collect additional surveys and will conduct ongoing monitoring of the health and economic impacts of 9/11 on affected communities.

IV. FINDINGS

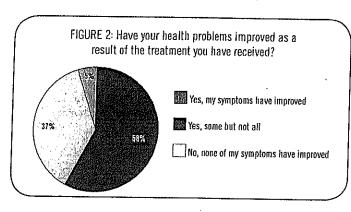
1. The health of many workers and residents suffering from 9/11-related health problems is not improving.

Diverse 9/11-related health problems continue to devastate the health of affected workers and residents. Of those surveyed:



- 88% state their health symptoms may have been caused or worsened by 9/11.
- 81% with 9/11-related symptoms have seen a doctor concerning their symptoms.

Workers and residents report that, despite receiving ongoing treatment, their 9/11-related health symptoms have not improved at all or only some symptoms have improved. Of those surveyed:



- Only 5% state that their symptoms have fully improved.
- 58% state that only some of their symptoms improved.
- · About 1 in 3 state that none of their symptoms have improved.

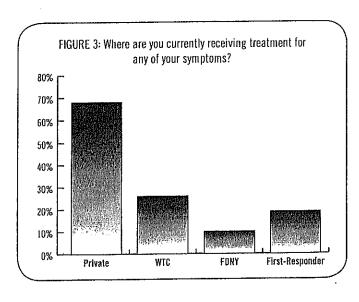
Scientific studies support these WE COUNT! survey findings. For example, a study published in the Journal of American Medicine entitled "Asthma and Posttraumatic Stress Symptoms 5 to 6 Years Following Exposure to the World Trade Center Terrorist Attack," found that people directly exposed to the 9/11 attack were approximately four times more likely than the general population to report post-traumatic stress symptoms. 14 The study also found increased reports of psychological symptoms between 2003 and 2007.15 In addition, researchers found that in the first year after 9/11, asthma was being diagnosed in residents and workers exposed to smoke and dust at six times the normal rate for New York City; while the rate has declined since then, it has still not returned to normal.16 For many, asthma and other respiratory illnesses have become chronic. A study of the residents and workers being treated at the WTC EHC found that they are suffering from new and persistent respiratory symptoms and lung function abnormalities five or more years after 9/11.17

Summary and Analysis of Finding 1

Most workers and residents suffering from 9/11-related health problems are chronically ill, with more than one-third stating that their symptoms have not improved at all after receiving treatment. Patients' symptoms may not be improving for a number of reasons. Chronic illnesses do not go away with treatment, which may only have a stabilizing effect. In addition, as 9/11 toxins and their effects on the human body are not yet fully identified, workers' and residents' health problems appear to be evolving at a faster rate than the medical community's knowledge of how to treat these illnesses.

2. Many 9/11-affected workers and residents are not seeking treatment at the WTC EHC or other 9/11-specific Centers of Excellence.

Although treatment at the WTC EHC is free to patients, a significant percentage of surveyed workers and residents with 9/11-related symptoms choose to see private doctors or seek treatment at clinics that are not part of the Centers of Excellence. 18 At present, the three WTC EHC clinical sites of Bellevue, Gouverneur, and Elmhurst have provided treatment to approximately 4,100 residents and clean-up workers, 19 despite the many thousands who may have been affected. Of those surveyed who have seen a doctor for symptoms related to 9/11, only 39% have exclusively visited WTC EHC doctors, compared to 72% who have seen a private doctor either exclusively or in conjunction with a Center of Excellence.20 Of those surveyed who are currently receiving medical treatment:



- Only 26% are visiting the WTC EHC.
- 68% are visiting private doctors.
- 10% are visiting the FDNY Clinic.
- 19% are visiting Mt. Sinai's World Trade Center Medical Monitoring and Treatment Program.21

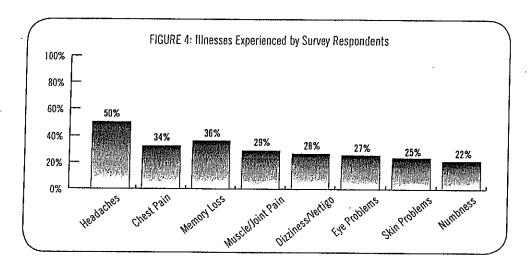
Summary and Analysis of Finding 2

A surprising majority of surveyed workers and residents, many of whom are unaware of the WTC EHC, report going to private doctors either exclusively or in addition to a Center of Excellence for their 9/11-related health problems. This finding has two important ramifications. First, since Congress uses the WTC EHC patient population, not those treated by private doctors, as the basis for determining entitlement to treatment and monitoring in the community program, the affected population is being undercounted. Second, those exclusively seeing private doctors are not being included in the ongoing studies undertaken by the Centers of Excellence and are not receiving specialized 9/11 health treatment and monitoring.²² This finding demands further investigation, as it may reflect patients' frustration with traditional treatment at the WTC EHC or patients' cultural or logistical preferences for their family physicians. As the economic crisis persists and as more workers become so sick they can no longer work, patients with employerbased health insurance will need to seek treatment at the WTC EHC.23 The government must be prepared to adequately support this increased need by expanding services at the WTC EHC. Moreover, recognizing that many people will prefer continuing to see their private doctors in the community, the WTC EHC should establish a network whereby its physicians and psychologists can advise community doctors on 9/11-related illnesses and refer patients for evaluation and collaborative delivery of quality health services.

3. Workers and residents exposed to 9/11 toxins are experiencing a wide range of illnesses, some of which are not recognized as 9/11-related.

Although there has been some recognition of evolving health problems related to 9/11, such as digestive and mental health problems, many other conditions reported by workers and residents are not recognized by the government as such and have not been adequately investigated by the medical community. Many symptoms reported by WE COUNT! respondents—including headaches, memory loss, muscle/joint pain, and cardiac problems—are not listed as 9/11-related in the current 9/11 health legislation.

Workers and residents in the survey report other 9/11-related health problems such as:



Other reported symptoms include gynecological problems, sarcoidosis, and even potentially 9/11-related cancers.²⁴ It is difficult to obtain proper medical care and workers' compensation benefits for symptoms and illnesses not recognized by the government and medical community as connected to 9/11, and private physicians do not have the resources or patient base to investigate these connections. Workers and residents suffering from emerging health problems need specialized care from doctors who have the resources to determine whether these illnesses are in fact 9/11-related.²⁵

Summary and Analysis of Finding 3

Many people exposed to 9/11 toxic air and dust are suffering from illnesses not officially recognized by governments and other bodies. More research must be done to determine if these conditions are linked to 9/11. In the absence of such research, the victims of 9/11 will be underrepresented. In addition, if community members perceive the WTC EHC and other Centers of Excellence as being open to broadened research, they are more likely to seek treatment at those clinics and to contribute to the studies. A long-term response to the 9/11 health crisis demands the "community-health partnership" behind the WTC EHC must continue, with affected workers and residents playing a central role in identifying and implementing new treatments and care for evolving health problems.²⁶ The leadership and participation of directly affected workers and residents must be recognized in the face of imperfect scientific understanding of the disastrous fallout of 9/11.

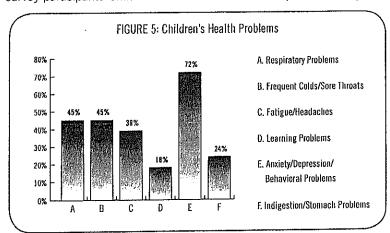
4. Children affected by the WTC health disaster suffer from health symptoms but are not being adequately addressed.

The 9/11 disaster exposed as many as 46,000 schoolchildren to toxic air, dust, furnes, and smoke.²⁷ Even though children are more susceptible to harm from toxic environmental exposures, from the first days following 9/11, the government expressly denied the risks to children who lived or attended school downtown. Though it is now clear from a small number of studies that children have developed respiratory illnesses and other conditions, their 9/11-related medical problems are the least studied of any exposed population.

It was not until 2008 that the WTC Health Registry published a study based on its "child survey," finding that children under five years old who had been attending school or living in lower Manhattan were getting asthma at twice the rates for the northeastern U.S.28 There was no specialized treatment available to children until 2008, when the WTC EHC Pediatric Program opened, and only in 2009 did the City Health Department release its WTC pediatric guidelines. For the last eight years, both parents and pediatricians have lacked both accurate information and appropriate WTC health resources for children.

At this juncture, it is difficult to track and record 9/11-related health symptoms among affected adolescents and young adults, a population that has become more dispersed since 9/11.29 Many parents do not know about the pediatric program at the Bellevue site of the WTC EHC, so outreach is still needed. Moreover, those who utilize the program must continue to push for family-friendly scheduling of appointments—outside of school hours and on the weekends.

To research possible pediatric health effects, WE COUNT! included questions aimed at gathering information about survey participants' children. Of the children of those parents surveyed:



- 27% suffer from health problems possibly related to 9/11.
- 72% suffer from anxiety, depression, or behavioral problems.
- 45% suffer from respiratory problems.
- 45% suffer from frequent colds or sore throats.
- 39% suffer from fatigue or headaches.
- 24% have learning problems.

Like 9/11-affected adults, some children seen by doctors have experienced improvements in their health. Of the children of those parents surveyed:

- 12% have seen all of their symptoms improve.
- 64% have seen some of their symptoms improve.
- 39% have seen none of their symptoms improve.

Summary and Analysis of Finding 4

Children are suffering from serious, persistent 9/11-related health problems. Studies of babies born to mothers in the months after 9/11 show that in-utero exposures resulted in reduced fetal growth, which is associated with cognitive deficits and future health risks.30 A Mount Sinai School of Medicine report observes that the incidence of substance abuse is higher among teens who were exposed to the attacks than those who were not.31 And children whose mothers were depressed or had posttraumatic stress disorder because of the 9/11 attacks were more likely to act out than their peers.32 Even with these studies, the full scope and nature of the pediatric health impact has yet to be accurately documented. Without this base of knowledge, many parents remain unaware of their children's 9/11-related illnesses; and without adequate monitoring, children, youth, and young adults will not receive the attention they need to address evolving 9/11-related health problems.

5. Among surveyed workers and residents who are currently unemployed, most are unable to work due to their 9/11-related health problems.

9/11-related health problems have taken a significant toll on workers' and residents' ability to support themselves and their families. Nearly half (43%) of respondents reported they are not currently working, and a majority of these workers and residents (57%) are not working due to their 9/11-related health problems.33

Unfortunately, many affected workers are ineligible for workers' compensation because they were downtown "area workers," as opposed to cleanup or rescue/recovery workers, in the wake of 9/11. The 9/11-specific section of the New York State Workers' Compensation Law (Article 8-A) does not cover employees who were exposed to dust outside the normal course of their employment; thus, only strictly cleanup, rescue, and recovery workers are eligible—not area workers who breathed in toxic air and may have cleaned dust from their workspaces. Unsurprisingly, then, 66% of workers surveyed have not filed a C-3 claim form (which begins a case) with the New York State Workers' Compensation Board.

Summary and Analysis of Finding 5

There is a close connection between physical/mental health and financial well-being. WE COUNT! survey respondents report the challenges they continue to face in dealing with their 9/11-related illnesses, and their financial need will only increase as workers and residents become sicker.34

While 9/11 cleanup, rescue, and recovery workers are eligible for workers' compensation benefits, downtown office and area workers are not, notwithstanding their participation in cleanup of their workspaces. Nor can area residents, by definition, apply for workers' compensation benefits, even if they were excluded from the Victims Compensation Fund. Some of these community members may have recourse to the social security disability system, but they must fight for benefits in an often impenetrable venue that has little understanding of 9/11-related health problems.

The economic needs of residents and downtown workers have been shockingly absent from discussion of the 9/11 health crisis. For injured 9/11 cleanup workers eligible for workers' compensation, it has not been easy to secure compensation. An unprecedented 76% of injury claims have been "controverted" (challenged) by workers' compensation insurance companies, a rate more than triple the average.35 Moreover, the median number of days from filling to receipt of benefits in a case of permanent partial disability is 309, nearly one year, 36 and appeals in 9/11 workers' compensation cases take an average of 133 days, during which time the worker receives no benefits.37 Shamefully, the employers from the 9/11 cleanup, large contractors and small subcontractors alike, were contracted by the government to clean WTC debris from commercial, residential, and government buildings, as well as schools and churches. While profiting from the labor of exploited workers, these companies and their insurance carriers relentlessly fight the workers' claims for minimal compensation.

V. POLITICAL CONTEXT: THIS LEGISLATIVE MOMENT

In February 2009, Congresspersons Carolyn Maloney (D-NY 14) and Jerrold Nadler (D-NY 8), together with 68 other sponsors, introduced the James Zadroga 9/11 Health and Compensation Act of 2009 (HR 847) in the House of Representatives.38 This is the first bill that would provide extensive federal funding to treat the 9/11-related health problems of affected first responders, clean-up workers, students, and residents.

In the U.S. Senate, New York Senators Gillibrand and Schumer, with New Jersey Senators Lautenberg and Menendez, introduced the James Zadroga 9/11 Health and Compensation Act of 2009 (S 1334).39 As the companion and virtual twin to HR 847, this Act would also provide federal funding for 9/11 clinics serving community members as well as first responders.

Although these bills are overdue and welcome, HR 847 and S 1334 are inadequate to meet the needs of all those whose health has been negatively affected by 9/11. The bills do not encompass all potentially related medical symptoms or illnesses, nor do they provide for all workers, residents, and students who have been affected. 40 Below is a chart summarizing the current provisions and shortcomings of the House and Senate bills:

FIGURE 6

BGZ and 9/11 EA demand that:	HR 847 and S 1334 provide that:	How the bills should be amended	
Arbitrary geographic boundaries do not limit healthcare access.	Residents, clean-up workers, and area workers are only eligible if they lived/worked south of Houston or in Brooklyn within a 1.5 mile of the WTC towers.	At the very least, extend the northern eligibility boundary to 14th Street, which is in line with medical data and does not exclude communities of color from the Lower East Side.	
Community members must be involved in decision-making about their health.	The Administrator of the program must consult the WTC Community Program Steering Committee, which includes representation of, among others, "hard-to-reach populations," but only has 11 spots.	Clarify to ensure that directly affected community members and WTC EHC patients, not just large "community" groups, participate on the Steering Committee.	
Community members contribute to defining "WTC-related health condition."	The definition of causally related physical or mental illness is broadly defined but then narrowed by a restrictive list of "aerodigestive disorders" and "mental health conditions." "Musculoskeletal conditions" are not considered 9/11-related for persons who were not first-responders.	Expand the list and provide for accommodation of evolving health conditions.	
Community members should receive their fair share of funding and resources.	The first-responder program is allocated hundreds of millions more in funding than are community programs.	Funding must be justly distributed for all those suffering from medical conditions caused by the attacks, first-responders and workers/residents alike.	

While BGZ and 9/11 EA support these bills and the hard work of residents, workers, responders, and elected officials who have fought for a federal program to track and treat 9/11 illnesses, it is clear that the legislation does not provide for the current or future burdens of the affected population. Even if these bills are passed, it will be up to the workers and residents affected by 9/11 to stand up for their rights to quality healthcare, to take advantage of the treatment available at the WTC EHC, and to push for studies and medical decisions that speak to the causality of their 9/11 diseases. It is the hope of BGZ and 9/11 EA that the WE COUNT! community survey can contribute to these ongoing efforts.

VI. RECOMMENDATIONS

Findings from the WE COUNT! survey confirm that workers and residents still suffer from severe 9/11-related health problems, that their symptoms are not improving, that many health problems go unrecognized as 9/11-related, and that children are affected as well. Increasing numbers of workers and residents can no longer work because of the severity of their illnesses.

Congress and President Obama must bring justice to 9/11-affected workers, residents, students, and their communities. After eight years of neglect, they must finally investigate the full extent and scope of the 9/11 health crisis and respond to the health and economic needs of workers, residents, students, and first-responders. Based on the WE COUNT! survey findings, and understanding that federal leadership is needed in response to the 9/11 health crisis, BGZ and 9/11 EA make the following recommendations:

Fashion a Holistic Public Health and Economic Response to the 9/11 Health Crisis.

- 1. The WTC EHC and other Centers of Excellence should create a network to enable 9/11-specialist physicians, psychologists, and staff to educate doctors in the community as to diagnosis and treatment of 9/11-related conditions and to establish a referral path to the WTC EHC. The Centers of Excellence should work with local private doctors to ensure that all those affected by 9/11 are included in ongoing studies and continue to receive the highest quality care possible, and to explain the importance of doctors' sending their patients to the WTC EHC for long-term monitoring, an essential epidemiological tool for recognizing new patterns of disease,
- 2. Recognizing that many 9/11-affected workers and residents can no longer work due to their 9/11-related health problems, Congress and President Obama must guarantee all those unable to work due to their 9/11-related health problems—whether past, present, or future—compensation for lost income as well as medical and other support services, including home-healthcare services.
- 3. Recognizing workers' and residents' chronic, worsening 9/11-related health problems, Congress and President Obama must instruct and fund the Centers of Excellence to explore alternative therapies and treatments for 9/11-affected workers and residents.
- 4. Congress and President Obama should recognize the critical role played by the "community-health partnership" between the WTC EHC, the current or former workers and residents who are its patients, and community stakeholders, including BGZ and 9/11 EA. Affected workers and residents seeking treatment in federally funded 9/11 health programs should be regarded as non-medical experts in assessment and monitoring of 9/11-related conditions, and funding should be provided for continued outreach to affected populations.

Guarantee Treatment for and Expand Knowledge of Emerging Illnesses, Conditions, and Health Problems Reported by 9/11-Affected Workers and Residents.

- 1. Congress and President Obama must direct the Centers of Excellence and provide resources to screen, treat, document, describe, and track the progress of all 9/11-related illnesses, including emerging illnesses, conditions, and health problems not currently recognized as 9/11-related but reported by 9/11-affected workers and residents.
- 2. Barring timely additions to the list of illnesses and WTC-related conditions in the proposed 9/11 legislation, Congress and President Obama should guarantee retroactive reimbursement for the treatment of emerging illnesses, conditions, and health problems not covered by the legislation but later found to be WTC-related.
- 3. Congress and President Obama must increase federal funding for further long-term research into WTC-related conditions and mandate that a significant portion of that research focus on emerging conditions (i.e., symptoms and illnesses not currently recognized as 9/11-related) reported by 9/11-affected workers and residents.
- 4. Congress and President Obama must provide incentives for academics and medical professionals to engage in longitudinal research in partnership with 9/11-affected communities, the Centers of Excellence, and local governments and agencies (e.g., the NYC Department of Education) on the connections between 9/11-related toxic exposures and the health problems of workers, residents, students, and first-responders.

ENDNOTES

- ¹ Nordgren, Megan D., Eric A. Goldstein, and Mark A. Izeman. The Environmental Impact of the World Trade Center Attacks: A Preliminary Assestment. The Earth's Best Defense, Feb. 2002. Web. 11 Sept. 2009. http://www.nrdc.org/air/pollution/wtc/wtc.pdf>.
- ² See Urban Justice Center. "The Ripple Effect: The Crisis in NYC's Low-income Communities After September 11th." www.beyondgroundzero.org. N.p., Sept. 2002. Web. 8 Sept. 2009. <www.beyondgroundzero.org/files/RippleEffect.pdf>.
- 3 "HHC WTC Environmental Health Center." Web. 11 Sept. 2009. http://www.nyc.gov/html/hhc/html/services/wtc-cac.shtml.
- ⁴ See, e.g., NYC government. 9/11 Health. N.p., n.d. Web. 8 Sept. 2009. <www.nyc.gov/html/doh/wtc/html/ home/home.shtml>. Pallarito, Karen. "Dust exposure after 9/11 linked to high asthma rates." CNN.com. CNN, 5 Aug. 2009. Web. 8 Sept. 2009. http://www.cnn.com/2009/ HEALTH/08/05/dust.exposure.asthma/>.
- ⁵ DePalma, Anthony. "Whitman Defends Air Quality Assurances Made After 9/11." The New York Times. June 26, 2007.
- 6 "9/11 Health WTC Health Registry." Web. 11 Sept. 2009. http://nyc.gov/html/doh/wtc/html/registry/registry.shtml. The Registry reports "tracking the health of 71, 437 people directly exposed to the WTC disaster." ("World Trade Center Health Registry 2008 Annual Report." NYC Health, Apr. 2009.)
- ⁷ "[Community and labor] representatives have noted that the geographic boundaries used by the registry exclude office workers below Chambers Street who were not at work on September 11 but returned to work in the following weeks; office workers, including several groups of city employees, working between Chambers and Canal Streets; and Brooklyn residents who may have been exposed to the cloud of dust and smoke." United States. U.S. Government Accountability Office. September 11: Health Effects in the Aftermath of the World Trade Center Attack. www.GAO.gov. U.S. Government Accountability Office, n.d. Web. 8 Sept. 2009. http://www.gao.gov/htext/d041068t.html,
- ⁸ See, e.g., Szema, Anthony M., et al. "Clinical deterioration in pediatric asthmatic patients after September 11, 2001." Journal of Allegery and Clinical Immunology 113:3 (Mar. 2004): 420-426.
- 9 See Open Congress. "H.R.847 James Zadroga 9/11 Health and Compensation Act of 2009." OpenCongress.com. N.p., n.d. Web. 8 Sept. 2009. http://www.opencongress.org/bill/111-h847/show.
- ¹⁰ United States. Cong. House. Summary of H.R. 847, the 9/11 Health and Compensation Act in the 111th Congress. maloney.house.gov. Rep. Carolyn B. Maloney, 24 Feb. 2009. Web. 8 Sept. 2009. http://rnaloney.house.gov/documents/911recovery/20090224_Summary%20of%20 911%20HC%20Act.pdf>.
- 11 Representative Carolyn Maloney stated, "The 9/11 Health and Compensation Act, which Congressmen Nadler, King, McMahon and Lintroduced with the support of the entire New York Congressional delegation, would reopen the federal Victim Compensation Fund to help those who lost their livelihoods as a result of the 9/11 attacks." "Maloney Statement on Today's 9/11 Health and Compensation Hearing ." maloney.house.gov. Rep. Carolyn B. Maloney, 31 Mar. 2009. Web. 8 Sept. 2009. <a href="http://maloney.house.gov/index.php?option=com_content&task=view&id=1822
- ¹² Paul, Ari. "PBA Bucks Other Unions in Opposing Zadroga Bill." www.thechief-leader.com. Civil Service Leader, 4 Sept. 2009. Web. 8 Sept. 2009. http://www.thechief-leader.com/news/2009/0904/news/005.html>.
- ¹³ See Moline, Jacqueline M., et al. "Multiple Myeloma in World Trade Center Responders: A Case Series." Journal of Environmental Medicine 51(8) (Aug. 2009): 896-902.
- ¹⁴ HealthDay News. "For Many, 9/11-Linked Trauma Emerged Years Later." www.AJC.com, N.p., 4 Aug. 2009.Web. 8 Sept. 2009. http://www.ajc. com/health/content/shared-auto/healthnews/asth/629697.html>.
- 15 Ibid.
- 16 Brackbill, R.M., et al. "Asthma and posttraumatic stress symptoms 5 to 6 years following exposure to the World Trade Center terrorist attack." Journal of the American Medical Association 302(5): 502-516 (Aug. 2009).
- ¹⁷ Reibman, J., et al. "Characteristics of a residential and working community with diverse exposure to World Trade Center dust, gas, and furnes." Journal of Occupational and Environmental Medicine 51(5): 534-541 (May 2009).
- ¹⁸ Recognized by Congress as representing the authority on 9/11 health screening, monitoring, and treatment, the Centers of Excellence provide specialized testing and treatment for 911-related health conditions. The Centers of Excellence include the WTC EHC, the NY Fire Department's WTC Medical Monitoring and Treatment Program, and Mount Stnai's WTC Medical Monitoring and Treatment Program.
- 19 Miles, Terry. "World Trade Center Environmental Health Center Update." Presentation to HHC Strategic Planning Committee. 15 Sept. 2009.
- 20 Wagner, Victoria, Marleen Radigan, Patrick Roohan, Joesph Annarella, and Foster Gesten. "Asthma in Medicaid Managed Care Enrollees Residing in New York City: Results From a Post World Trade Center Disaster Survey." Journal of Urban Health 82.1 (2005): 76-89. Print.
- ²¹ "Mount Sinai World Trade Center Programs FPA." Mount Sinai Home. Web. 11 Sept. 2009. http://www.mountsinai.org/Education/ School%20of%20Medicine/Faculty%20Practice%20Associates/Practices/World%20Trade%20Center%20Programs%20FPA>.
- ²² One respondent admitted as much, saying, "My private doctors are not trained to recognize the connection (to 9/11)." -Respondent #192.

- As survey respondent #206 stated, "My COBRA runs out in 6 months and I don't know what I'll do after that." While some are losing their healthcare, others are paying high out-of-pocket costs on their 9/11-related health problems. In fact, 16% of people surveyed have spent more the \$5000 total on 9/11 related health costs.
- ²⁴ See supra, on myeloma (Moline). The sponsors of the House bill released a statement in response to the myeloma study, stating, "The fact that the authors of this cancer study say the results are inconclusive only reinforces the urgent need for an established, long-term monitoring program for 9/11 responders and treatment for illnesses that result from exposure to toxins at Ground Zero." ("Media Center." Online Office of Congressman Michael E. McMahon. Web. 11 Sept. 2009. <a href="http://mcmahon.house.gov/index.php?option=com_content&view=section&layout=blog&id=16<emid=160&limitstart=10>.)">http://mcmahon.house.gov/index.php?option=com_content&view=section&layout=blog&id=16<emid=160&limitstart=10>.)
- 25 The need for better research was echoed by survey respondent #184: "Some illnesses are acknowledged as 9-11[-related], others are denied."
- ²⁶ See Kim, E. Tammy and Jei Fong. "The Beyond Ground Zero Network: A model for grassroots public health responses following an urban environmental disaster." Advancing Climate Justice: Transforming the Economy, Public Health & Our Environment conference (Jan. 2009). On file with authors.
- ²⁷ Landrigan, Philip J. "Impacts on the Health of Children of the September 11 Attacks on the World Trade Center." Testimony before the Subcommittee on Clear Air, Wetlands, and Climate Change, Committee on Environment and Public Works; United States Senate. 11 Feb. 2002. http://epw.senate.gov/107th/Landrigan_021102.htm.
- ²⁸ Thomas, Pauline, Robert Brackbill, Lisa Thalji, Laura DiGrande, Sharon Campolucci, Lorna Thrope, and Kelly Horning. "Respiratory and Other Health Effects Reported in Children Exposed." *Environmental Health Perspectives* 116.10 (2008): 1383-390. Web. 11 Sept. 2009. http://www.ehponline.org/members/2008/11205/11205.pdf>.
- ²⁹ Some parents reported in the survey that their children suffer from *in utero* 9/11 effects: "(My) wife became pregnant during my time working there during 9/11 . . . our child was born with a growth disorder which was not related to genetics." (Survey respondent #113.)
- ³⁰ See Perera, FP, et al. "Prenatal airborne polycyclic aromatic hydrocarbon exposure and child IQ at age 5 years." *Pediatrics* 124(2): 195-202 (Aug. 2009). Choi, H., et al. "Prenatal exposure to airborne polycyclic aromatic hydrocarbons and risk of intrauterine growth restriction." *Environmental Health Perspectives* 116(5): 658-665 (May 2008). Perera, FP, et al. "Relationship between polycyclic aromatic hydrocarbon-DNA adducts, environmental tobacco smoke, and child development in the World Trade Center cohort." *Environmental Health Perspectives* 115(10): 1497-1502 (Oct. 2007). Perera, FP, et al. "Relationships among polycyclic aromatic hydrocarbon-DNA adducts, proximity to the World Trade Center, and effects on fetal growth." *Environmental Health Perspectives* 113(8): 1062-1067 (Aug. 2005).
- ³¹ Mt. Sinai School of Medicine. "Substance use and functional impairment among adolescents directly exposed to the 2001 World Trade Center attacks." www.ncbi.nlm.nih.gov, N.p., 31 Oct. 2008. Web. 9 Sept. 2009. http://www.ncbi.nlm.nih.gov/pubmed/19178553.
- ³² Mt. Sinai School of Medicine. "Effect of Maternal Psychopathology on Behavorial Problems in Preschool Children Exposed to Terrorism: Use of Generalized Estimating Equations to Integrate Multiple Informant Reports." www.ncbi.nlm.nih.gov, N.p., June 2009. Web. 9 Sept. 2009. http://www.ncbi.nlm.nih.gov/pubmed/19487609?dopt=abstractplus.
- ³³ Survey respondent #84 stated, "(My) health is worsening and I cannot hold a job." Survey respondent #189 commented on the need for economic support: "I was let go from my job and told due to my health issues since 9/11 and continued absence from work I was no longer effective in my position. I am now on social security disability due to my numerous health issues."
- 34 The WTC Registry has also found event-related loss of spouse or job to be associated with PTSD five to six years after 9/11.
- 35 New York State Workers' Compensation Board. "World Trade Center Cases in the New York Workers' Compensation System." Pp. 7, 33, 34. Sept. 2009. http://www.wcb.state.ny.us/content/main/TheBoard/WCBWTCReport2009.pdf.
- ³⁵ Ibid. p. 43.
- 37 Ibid. p. 38.
- ³⁸ Open Congress. "H.R.847 James Zadroga 9/11 Health and Compensation Act of 2009." *OpenCongress.com.* N.p., n.d. Web. 8 Sept. 2009. http://www.opencongress.org/bill/111-h847/show.
- ³⁹ United States. Cong. House Committee on the Judiciary. Joint Hearing on: H.R. 847, the "James Zadroga 9/11 Health and Compensation Act of 2009." judiciary.house.com. U.S. House of Representatives Committee on the Judiciary, n.d. Web. 8 Sept. 2009. http://judiciary.house.gov/hearings/hear_090331.html.
- 40 "HR 847." THOMAS (Library of Congress). Web. 11 Sept. 2009. http://thomas.loc.gov/cgi-bin/bdquery/z?d111:h.r.00847. "S 1334." THOMAS (Library of Congress). Web. 11 Sept. 2009. http://thomas.loc.gov/cgi-bin/bdquery/z?d111:SN01334.

9/11 Environmental Action

www.911ea.org



www.beyondgroundzero.org

BGZ GROUPS INCLUDE:

Commission on the Public Health's System
National Mobilization Against Sweatshops
Chinese Staff and Workers' Association
Community Development Project of the Urban Justice Center
Asian American Legal Defense and Education Fund



email: concerned@concernedstuy.org; loripandolfo@gmail.com

Dear Council Representatives,

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NYC Council Oversight - Examining the NYC World Trade Center Medical Working Group 2009 Annual Report on 9/11 Health.

Meeting date/time: Monday, December 7, 2009 at 1:00 PM

Meeting location: Council Chambers - City Hall

I am Lori Pandolfo, parent of affected Stuyvesant alum, and former PA Co-President along with Linda Lam.

Although I speak on behalf of Concerned Stuyvesant Community today, I believe I can presume to speak on behalf of the rest of the parents and students affected, such as those who attended BMCC and the other high schools, since I have remained active by attending community advisory meetings on studies and activities of the DOHMH. With that participation, I gained knowledge of the current state of the programs and the needs of affected students, residents and workers.

Regarding requesting that NYC Council consult with the U.S. Congress with respect to provisions for monitoring and healthcare of 9/11 affected workers, residents and students currently contained in the proposed James Zadroga 9/11 Health and Compensation Act (HR 847 and S 1334)- to broaden the scope of the bill to better meet unmet health needs arising from 9/11 exposures by students, residents and workers.

Reminder that as Students – They had no option but to return to their school after as short as a 3 week stay elsewhere- after false reassurances of safety, due to inaccurate reports on the cleanup. A toxic brew of materials both in their school through the ventilation system and outside with a hazardous debris barge dumping operation of the discarded material right next to the schools continued the dust and debris exposures through nearly the end of that school year.

Surveillance Should be Expanded:

We want to emphasize the needs not addressed sufficiently in the current version-chiefly the continuing lack of a real monitoring program for residents, students and area workers only those who have signed up for the registry are included in any surveillance while those not enrolled in the registry and those not attending the limited sized WTC EHC programs currently underway, are not accounted for in a systematic or scientific way. No data is collected or tracked beyond those who have *opted-in* for either the limited surveillance through surveys every 3 years or treatment so far. Also, the diseases being studied and included in the care at WTC EHC are limited to the few that are known to be "proven to be connected" to exposures. Therefore, it is likely to remain a very limited treatment option for anyone of the students who are sick now or become sick in the future with anything else.

Broaden List of Disorders Beyond Aerodigestive and Mental

There should be a way of predicting the probable expected diseases based upon the mix of the various chemicals our students lived in daily over those years during and after this horrific event. The placement of the collection site for debris containing asbestos was illegal — can't do that next to a school. And asbestos and lead were found in the school after so-called clean-up, so young people were exposed. Possible consequences of such exposure IS known and do go beyond aerodigestive, so other illnesses that asbestos, lead, benzene, etc. cause, should be included.

Anecdotally, for example, we have already been aware of illnesses that mimic the unexpected cancers that have been studied in the responders group, but there is no formalized method in any of the current or proposed provisions to include those for either study or treatment. There is no way of tracking this currently and there seems to be a catch-22 in setting up a method, since the included conditions are severely restricted due to lack of monitoring.

The community program could be provided adequate funding to follow the lead of the responders' program at Mt. Sinai which more effectively monoitors the illnesses in general by not only administering questionnaires, but also performing examinations on each participant to ensure that self-reporting is not relied upon as the sole means of gathering the important information that will lead the care for this entire group in the near and future term. This is the only way that "other than respiratory and mental diseases" such as cancers will be revealed as incontext and not assumed to be normally occurring for this group.

Expand Capacity and Coordinate Treatment-Educate and Outreach to this Population As far as capacity, of course we believe the increase of treatment slots provided to the community program under the Zadroga bill is too limited. As the outreach efforts are being improved and expanded, more people are likely to want to take advantage of the community program so the number 15,000 seems quite modest to cover this population fully.

Attention to the Adolescent to Adult Transition of former Students

This group is especially vulnerable to being overlooked as they were adolescents and are now young adults. While their exposures should be considered within the pediatric guidelines, their care and monitoring happen as young adults — without specialized attention to this group, the link to 9/11 can easily be lost over even the short 8 years already passed. It bears repeating that "they don't know what they don't know?". If these students have used denial as an effective healthy tool to move forward from this experience, they may not/ and most importantly/ their doctors will not know about associating illnesses that crop up over a lifetime with their exposures in this event if there is no real data gathered or disseminated.

Adults are more likely to continue care under the original/same practitioners they were seeing at the time of the event, while these students will be sure NOT TO since they age/aged out of the care of their original pediatricians. This loss of coordination may lead to misdiagnoses and improper care in our population, especially over the longer term. Some program must be devised to capture this transition and account for it at every point of change in these programs.



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December 7, 2009

Committee on Mental Health & Mental Retardation Committee on Lower Manhattan Redevelopment Committee on Civil Service and Labor The City Council of New York New York, NY 10007

Re: Oversight Hearing on the NYC World Trade Center Medical Working Group 2009 Annual Report on 9/11 Health
December 7, 2009

Dear Chairs G. Oliver Koppell and Alan Jay Gerson and Committee Members:

I am writing to ask your committee to support the residents of Manhattan Community Board Two. It is very important the Council request that the language in the Zadroga Bill placing the boundary for 9/11 healthcare not be drawn across Houston Street, which would divide our district between 9/11 healthcare haves and have not's. There is extensive empirical evidence that those who lived or worked up to and beyond 14th Street need treatment for the health effects of 9/11.

Furthermore, it is imperative that there be a uniform standard of care for all those who were impacted by the WTC attack. We ask that you ensure the firefighters, school teachers, students, police, clean-up workers, residents, first-responders, etc., all be given the same access to medical and mental health care regardless of what role they played.

Ten of thousands of people are still living with often unbearable consequences and they should not be discriminated against simply because they were above Houston Street or because they were a student, a resident or a cleanup worker, and not a first responder.

Thank you for your continued hard work to provide excellent health services to those affected by 9/11.

Sincerely,

Jason Mansfield

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Chair: Environment, Public Health, Public Safety Committee

World Trade Center Medical Working Group of New York City

2009 Annual Report on 9/11 Health

September 2009



Michael R. Bloomberg,

LETTER TO MAYOR BLOOMBERG

September 2009

Dear Mayor Bloomberg:

The World Trade Center (WTC) Medical Working Group is pleased to submit its second annual report on the state of 9/11 health. We were charged two years ago with advising you about health issues that are related—or potentially related—to the September 11, 2001 terrorist attacks on the World Trade Center, and have continued to meet regularly to review and report on the evolving research in this field. In our first report, we reviewed seven years of published research about health effects resulting from the attacks and WTC collapse. This body of research described short-term health effects occurring one to three years after the event, and findings are summarized on page 2.

In the past 12 months, additional findings have been published, including some that address midterm health effects among adults, five to seven years after 9/11. This newer research suggests that, while the vast majority of people exposed to the attacks on 9/11 and its immediate aftermath are healthy and symptom-free, thousands of exposed individuals continue to suffer from WTC-related mental and physical health conditions, and some of these conditions are likely to be chronic.

Of particular note are new epidemiological findings by the WTC Health Registry, which has been tracking the health of a large, voluntary sample of 71,000 exposed individuals since 2003 through periodic surveys. The results are published this year in the *Journal of the American Medical Association* (JAMA), and they indicate reports of high levels of new asthma diagnoses since the attacks, especially during the first 16 months after 9/11, and sustained and late-emerging posttraumatic stress symptoms. At the time of the second survey, five to six years after 9/11, one in ten adult enrollees reported having been diagnosed with new asthma. New onset symptoms of asthma five to six years after 9/11, however, were comparable to expected levels and were not linked to the degree/intensity of WTC exposure. In the same survey, nearly one in five enrollees reported experiencing symptoms of posttraumatic stress. Many of those developing symptoms years after 9/11 also had experienced other life stressors subsequent to the attack, such as losing a job or inadequate social support.

Several newly published studies suggest that WTC-related mental and physical health conditions often can occur together, and in fact, 10-25% of people currently being treated by the WTC Centers of Excellence (see WTC Patient Population Report beginning on page 10) are being treated for both mental and physical health conditions. Fortunately, monitoring and treatment continues to be available in the New York City area for those whose health has been affected by 9/11 thanks to a combination of federal and City funding.

Our state of knowledge about the short-term health effects of 9/11 has come into sharper focus since the formation of the WTC Medical Working Group in June 2007. With this report, we better understand the longer-term health care needs of exposed individuals, in particular those who may have developed chronic conditions that can seriously affect quality of life.

Linda Gibbs, Co-Chair New York City Deputy Mayor for Health and Human Services Thomas Farley, MD, MPH/Co-Chair New York City Health

Commissioner

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WORLD TRADE CENTER MEDICAL WORKING GROUP MEMBERSHIP

Mayor Bloomberg appointed the WTC Medical Working Group in June 2007. Members meet quarterly to review clinical and research findings on the health effects of WTC exposure and publish an annual report. They also review the adequacy of health and mental health services available to WTC-exposed persons, and they advise city government on approaches to communicating health risk information related to WTC exposure.

Linda Gibbs, Co-Chair

New York City Deputy Mayor for Health and Human Services

Thomas Farley, MD, MPH, Co-Chair New York City Health Commissioner

Thomas K. Aldrich, MD

Professor of Medicine, Pulmonary Division, Montefiore Medical Center and Albert Einstein College of Medicine, Bronx, NY

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Eli J. Kleinman, MD, MPH

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Lorna Thorpe, PhD, MPH

Deputy Commissioner, Division of Epidemiology, New York City Department of Health and Mental Hygiene

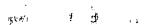
WTC Medical Working Group • 1

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SUMMARY OF PRIOR 9/11 HEALTH FINDINGS (2001-2007)

For our first annual report on 9/11 health in 2008, the WTC Medical Working Group reviewed nearly 100 studies published from 2001-2007. Most of these studies examined the health of rescue and recovery workers one to three years after their exposure to the WTC disaster, although some studies also included residents and building evacuees. Physical and mental health findings were remarkably consistent across studies and can be summarized as follows:

- Results from large epidemiologic studies suggest that probable posttraumatic stress disorder (PTSD) is the most common WTC-related health condition among exposed adults. Probable PTSD means that individuals scored above a certain threshold when responding to a mental health screening questionnaire but have not undergone the psychiatric interview necessary to confirm the diagnosis.
- 國 The risk for developing probable PTSD was higher among those who were:
 - Caught in the dust cloud released by the buildings as they collapsed
 - · Injured as a result of the attacks
 - Directly exposed to the events of 9/11, including proximity to the WTC site, witnessing horrific events and knowing someone who was killed or injured in the attacks
 - Among rescue and recovery workers, working at the WTC site for a long time or doing tasks outside of their trained area of expertise.
- Several studies indicated that respiratory symptoms, sinus problems, asthma, and loss of lung function were found in people or reported by some who were exposed to WTC dust, including rescue and recovery workers, residents and evacuees. Other studies have suggested that risk of developing sarcoidosis (an inflammation that usually affects the lungs) was elevated in the first few years after the event. Many exposed adults were also diagnosed with or reported having heartburn, acid reflux or gastroesophageal reflux disease (GERD), often in conjunction with other respiratory or mental health symptoms. GERD is a common condition among the general population, however; further research is needed to understand the association between GERD, WTC exposure and other WTC-related health conditions.
- The risk for developing respiratory problems has been examined most thoroughly among rescue, recovery and clean-up workers, and was increased among those who:
 - Arrived early at the WTC site
 - Worked at the WTC site for long periods of time.
- Few studies addressed the impact of WTC exposure on child and adolescent health, especially physical health.
- Whether there is a relationship between WTC exposure and other longer-term illnesses, including cancer, is unknown but clinicians, epidemiologists and other researchers are actively studying this. They also are studying the relationship between WTC exposure and mortality.
- At the time of the report's publication last year, treatment for WTC-related conditions was available for exposed groups, including children and adolescents, in the New York City area.



Source: World Trade Center Medical Working Group, 2008 Annual Report, September 2008 (accessible on line at www.nvc.uoz.html-om-per 2008:2908 mwg_annual report pdf)

NEW 9/11 HEALTH FINDINGS

Since the release of its first annual report in September 2008, the WTC Medical Working Group has identified 75 new studies published about WTC-related issues in peer-reviewed literature. Forty-eight examined health impacts or exposures and were relevant to the purpose of this report. Among relevant studies, the majority (36) examined mental health and 13 studies addressed physical health.

The new research findings, summarized below, largely support previously published research. Most studies continued to focus on the short-term health of adults one to three years after the disaster, although a few studies now have examined the mid-term health of adults five to seven years after 9/11.

Continued research is needed to better understand mid-term health impacts on adults, but a broad picture has begun to emerge. A large epidemiologic study conducted in 2006-2007 by the World Trade Center Health Registry provides the most recent information on mid-term health impacts of 9/11. The burden of probable posttraumatic stress disorder (PTSD) among enrollees (19%) was slightly higher than previously published estimates (16%) from 1-3 years after the event, and post-9/11 risk factors such as job loss or lack of social support were strong predictors of posttraumatic stress symptoms at the time of the survey. These findings from the WTC Health Registry highlight the effects of compounded stresses and traumas on this exposed population. In terms of physical health findings, 10% of adult enrollees reported receiving a new diagnosis of asthma after 9/11. While the bulk of asthma symptoms developed soon after 9/11, many symptomatic adults appear to have delayed seeking care for these symptoms.

These mid-term health findings from the WTC Health Registry, described in more detail below, as well as the WTC Patient Population Report on page 10, indicate that mental and physical health problems persist among thousands of adults who were exposed to the WTC collapse. They also indicate that many have not yet sought care, particularly for PTSD. The persistence of both mental and physical health problems suggests that some of the symptoms have become chronic and may require care for the foreseeable future.

Estimates of Health Impacts

Based on its 2006-2007 survey findings of physical and mental health impacts, the **WTC Health Registry** has estimated that among the 409,000 people who were most heavily exposed to the disaster on 9/11:1

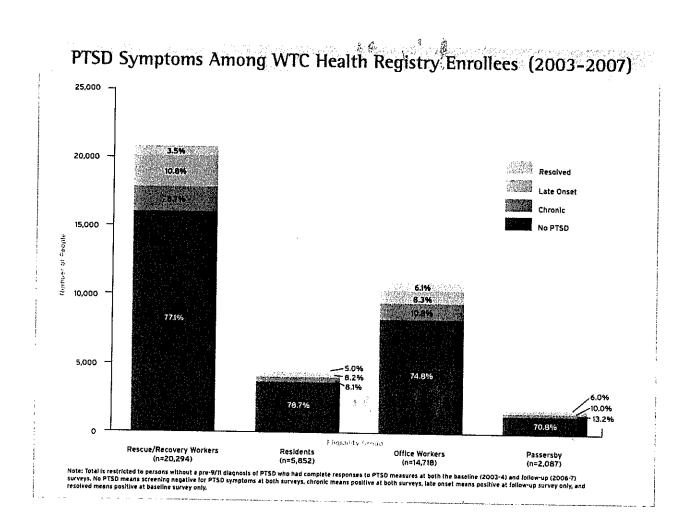
- Between 17,400-40,000 adults may have been newly diagnosed with asthma five to six years later.
- Between 43,000-88,600 adults may have experienced symptoms indicative of PTSD five to six years later.

The WTC Health Registry derived these estimates by taking rates of self-reported new diagnoses of asthma and posttraumatic stress symptoms five to six years after 9/11, and applying these rates to an estimated population of people who were most heavily exposed to the WTC disaster. Ranges were used to take into account the potential for self-selection that is inherent in a voluntary registry.

Mental Health

Mid-Term Impacts Among Adults (5-6 Years After 9/11)

- 19% of adults enrolled in the WTC Health Registry—more than 8,200 adults—showed symptoms of probable PTSD in 2006-2007, including rescue and recovery workers and volunteers, residents, office workers and passersby. Since 2001, 10% of all enrollees showed symptoms of probable chronic PTSD, meaning that they reported current symptoms on both surveys (2003-2004 and 2006-2007).²
 - Passersby had the highest rates overall (23%) at the time of second survey but rescue and recovery workers and volunteers experienced the greatest increase in the rate of people experiencing symptoms between the first survey and the second (from 12% to 19%).
 - Among nearly 5,000 enrollees with probable PTSD who had not seen a mental health provider in the year before the second survey, approximately half are residents, office workers or persons other than rescue and recovery workers who were in the vicinity of the WTC site on the morning of 9/11.
- Over a five-year period from 2002 to 2007, 11% of more than 10,000 rescue, recovery and clean-up workers being monitored at the **New York/New Jersey WTC Clinical Consortium** met the criteria for probable PTSD in the month prior to their initial clinical examination. Half of the workers with probable PTSD also had either probable depression, panic disorder or both. Workers with probable PTSD also were twice as likely as those without to have an alcohol problem.³



Short-Term Impacts (1-4 Years After 9/11)

- Among 8,487 firefighters who enrolled in the FDNY WTC Medical Monitoring and Treatment Program, 12% screened positive for probable PTSD symptoms in the first six months after 9/11. More than one-quarter (28%) of those who screened positive self-referred for counseling over the first 2.5 years after 9/11, a fivefold increase in the number of persons referred from pre-WTC rates. Elevated PTSD risk was significantly associated with counseling use, functional job impairment and mental-health related medical leave during this period.4
- Several studies of people, including children, exposed to the 9/11 terrorist attacks, have found that trauma either before or after the event increased their vulnerability to PTSD or resulted in greater symptom severity:
 - Among 842 utility workers who were deployed to the WTC site and who participated in a
 voluntary psychological screening 17 to 27 months later, those with PTSD were more likely
 to have a history of trauma, depression and panic disorder prior to 9/11. In addition, the study
 found that the ability to function at work, or in family and social situations decreased with
 PTSD symptom severity.⁵
 - A clinical study of 124 ironworkers who worked at the WTC site and who sought mental health treatment 14 to 17 months after 9/11 at the **New York/New Jersey WTC Clinical Consortium** found significantly elevated rates of alcohol misuse (39%); anxiety (6.5%); and PTSD (18.5%), in comparison to the general population. Psychiatric symptoms were correlated with excessive alcohol use since 9/11, injury to and/or death of a friend, family member or coworker on 9/11, and at least one adverse life event in the six months after 9/11.6
 - Findings from a study of 200 volunteer middle school children in a Lower Manhattan immigrant community near the WTC collapse suggest that children exposed to additional trauma, either before or after 9/11, were more likely to have higher PTSD symptom severity than those with exposure to 9/11 events alone, regardless of high directly they were exposed.7 This supports a previous finding among pre-school children.8
- Page 20 A convenience sample of 1,040 adolescents attending the five schools closest to the WTC responded to a survey and 10% reported an increase in their post-9/11 alcohol or substance use 18 months after the attacks. Although the study didn't include a general population comparison group to adjust for time or age trends, the likelihood of increased substance use rose with the degree of reported 9/11 exposure, even after controlling for depression and PTSD. For example, substance use among adolescents with three or more exposure risk factors was nearly 20 times higher compared to adolescents with no exposure risk factors. Increased substance use was associated with impaired schoolwork, school behavior and grades.
- A small study of 102 pairs of mothers and their pre-school children in Lower Manhattan who were exposed to the terrorist attacks found that three years after 9/11, children, especially boys, whose mothers had depression and PTSD were at greater risk for aggressive behavior, emotionally reactive behavior and complaints about physical health problems that had no medical basis.¹⁰
- One small study compared mental health outcomes before and after the attacks among 18 young New York City adults with generalized anxiety disorder (GAD). This group had been assessed the day before 9/11 and one-year post event findings were compared to 25 controls that also were assessed prior to 9/11. Findings suggest increased levels of functional impairment among those with GAD but not higher levels of posttraumatic stress symptoms.¹¹

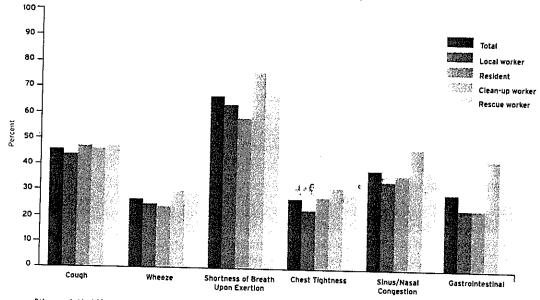
- A representative sample of more than 2,300 adult New York City residents who were interviewed about their mental health one, two and three years after 9/11 indicates:
 - People who received early, brief interventions at their worksites reported better mental health outcomes than those who received more extensive post 9/11 interventions such as formal psychotherapy sessions lasting 30 minutes or longer, adjusting for extent of 9/11 exposure, although the study did not control for severity of illness. Informal support seeking from friends, neighbors and from spiritual communities also appeared beneficial.¹²
 - Problem drinking and alcohol abuse were associated with psychological trauma up to four years after exposure, and these outcomes tend to be associated with other adverse mental health outcomes post-exposure.¹³
- A growing body of literature about people who were indirectly exposed to the WTC collapse (i.e. through media reports) supports previous findings that measurable trauma impacts were found:
 - Pre- and post-9/11 psychological screening of nearly 5,500 students who were attending college in California at the time of the attacks indicate that 44% of women and 32% of men experienced at least one symptom of posttraumatic stress disorder (PTSD) 6-17 days after 9/11,14
 - A retrospective study of 143 Canadian students two years after the attacks found a correlation between watching television coverage and two hallmark symptoms of PTSD: re-experiencing and hyper arousal.¹⁵

Physical Health

Mid-Term Impacts (5-7 Years After 9/11)

- A clinical study of nearly 2,000 Lower Manhattan area workers, clean-up workers and residents who reported being exposed to WTC dust and who sought care from the WTC Environmental Health Center five to seven years after the attacks documented a range of continuing respiratory symptoms, including persistent (two or more times per week) shortness of breath upon exertion, cough and sinus or nasal problems in each patient category. Although pulmonary function was normal for the total clinical sample, among those reporting persistent respiratory symptoms that arose after 9/11, nearly one third (31%) had below-normal pulmonary function similar to that found in studies of rescue, recovery and clean up workers.¹⁶
- 10% of adults enrolled in the WTC Health Registry have reported a new diagnosis of asthma at some point since 2001, with the highest rates reported during the first 16 months after 9/11. This is three times as many adults as would be expected in the general population over a six-year period.¹⁷
 - Although elevated rates of new asthma were reported across all eligibility groups, rescue and recovery workers who arrived at the WTC site on 9/11 had the greatest risk, and residents had the lowest.
 - Intense dust cloud exposure on 9/11 was a major contributor to new asthma diagnoses across
 all eligibility groups; other more lingering risks included working longer at the WTC site, not
 evacuating homes and experiencing a heavy layer of dust in homes or offices.
 - New onset symptoms of asthma five to six years after 9/11, however, were comparable to expected levels and were not linked to the degree/intensity of WTC exposure.
- A clinical study of more than 3,000 workers examined twice at least 18 months apart between 2002 and 2007 at the New York/New Jersey WTC Clinical Consortium found that weight gain between exams but not degree of WTC exposure was associated with continued loss of pulmonary function. An additional risk factor for continued loss of pulmonary function was abnormal bronchodilator response, which can be indicative of asthma, on the first exam. The majority continued to have pulmonary function within the normal range but the prevalence of reduced pulmonary function at the time of the second exam remained higher than in the general population.¹⁸

Respiratory Symptoms in a WTC-Exposed Population at the WTC Environmental Health Center (2005-2008)



Date presented for 1.852 symptomatic patients who sought care at the World Trade Center Environmental Health Center (WTC EHC) from 2005-2008. Symptoms were defined new onset (occurring after September II, 2001 for the first time and still occurring upon entry into the WTC EHC) and persistent (experienced by patients more than twice each week in the month prior to entry into the WTC EHC).

Short-Term Impacts (1-4 Years After 9/11)

- Among 10,378 firefighters who enrolled in the FDNY WTC Medical Monitoring and Treatment Program after 9/11 and were evaluated at yearly intervals over the first four years, cough and sore throat declined significantly from 54% to 16% and 62% to 36%, respectively. In contrast, the prevalence of other respiratory symptoms (dyspnea, wheeze, nasal congestion or GERD) remained relatively stable, between 45% to 35% over this time period. Initial arrival time at WTC site was linked with higher risk of respiratory symptoms at every exam, and in those evaluated at both year one and year four after 9/11, symptoms were linked to both earlier arrival time and longer work duration at WTC each additional month of work increased the likelihood of symptoms by 8% to 11%.
- Clinical studies of WTC rescue, recovery and clean-up workers who had voluntarily enrolled in a monitoring program at the **New York/New Jersey WTC Clinical Consortium** support earlier findings that respiratory problems have persisted for some, and that respiratory problems often co-occur with other diagnoses:
 - A small study of 42 sequentially-selected patients with gastroesophageal reflux disease (GERD) suggests that it may be related to abnormal lung function.²⁰
 - Among 172 randomly selected workers, ten were diagnosed with vocal cord dysfunction (VCD), which can cause hoarseness or pain while breathing. The workers also all had GERD and chronic rhinitis. Although the study was not designed to determine whether VCD was directly associated with WTC exposure, these preliminary findings suggest that VCD may be part of a spectrum of WTC-related respiratory disorders.²¹

WTC Medical Working Group • 7

- One study of 750 office workers compared those in close proximity to the WTC on 9/11 to those who were not and found that more directly exposed workers—half of whom had experienced a personal loss as a result of the attacks—were more likely to report headache and cough two years after the attacks. This is one of the first studies to examine headache as a physical health outcome.²²
- A retrospective study correlated results from models of the path of the smoke plume released in the first five days after the WTC collapse with results from a random telephone health survey of nearly 3,000 New York City residents conducted six months after 9/11. For respondents residing beyond the immediate vicinity of Lower Manhattan, the study found no association between the five-day estimated cumulative intensity of the smoke and either new onset of respiratory symptoms or worsening symptoms in asthmatics. However, the smoke plume which circulated through the greater metropolitan area is different from the dust cloud which immediately resulted from the collapse of the towers.²³

Physical Exposures

An analysis of blood samples from nearly 500 New York State employees and members of the National Guard who worked at the WTC site sometime between the attacks and December 2001 found concentrations of perfluorochemicals—manufactured chemicals used to make products that resist heat, oil, stains, grease and water—that were twice as high as those found in the general population. Levels of chemicals in the blood were similar between those who did and did not report symptoms, but were higher among those reporting higher levels of dust or smoke exposure. The blood samples were taken from May 2002 through November 2003 and the



Strengths and Limitations of Published WTC-Related Research

Much of the data presented in this report were gathered and analyzed by scientists and clinicians associated with a select number of institutions that recognized the need to monitor the health of individuals affected by the WTC collapse early after the disaster.

Particular strengths of this body of research include the fact that many different studies have found similar physical and mental health effects across exposed groups, and that research findings are gleaned from several large longitudinal cohorts, in addition to numerous one-time surveys.

Some of the largest study groups include:

- Mearly all FDNY responders who responded to the disaster. All have pre- and post-9/11 medical records and the group receives ongoing clinical monitoring.
- A large cohort of responders enrolled in the **New York/New Jersey WTC Clinical Consortium** for clinical screening, monitoring and treatment. This Consortium collects similar data to FDNY to facilitate comparisons across worker groups.
- A growing cohort of symptomatic patients who include residents, area workers and clean-up workers at the WTC Environmental Health Center at Bellevue Hospital Center, Gouverneur Health Care Services and Elmhurst Hospital Center.
- The WTC Health Registry, the largest post-disaster exposure registry in U.S. history, enrolling more than 71,000 exposed individuals to be tracked for an expected period of 20 years.

Several significant challenges also affect the ability conduct accurate research on 9/11 health effects. It is important to highlight these limitations that characterize most of the published studies described in this report, and to review these limitations when planning data collection efforts after future disasters:

- The exact size and composition of the population affected by the disaster remains unknown, although estimates have been developed and published.
- It is difficult to measure how much and what type of exposure different people had to traumatic or environmental impacts of 9/11. All exposure measurements remain imprecise.
- Many studies are conducted on volunteer or clinic-based samples, which may not be representative of the true population of exposed people. Depending on the enrollment criteria of specific studies, they may over-represent those who are ill. People with PTSD may be under-represented in studies because avoidance of anything that reminds them of 9/11 can be symptomatic of the condition.
- It is difficult to determine the incidence and prevalence rates for many potentially WTC-related conditions, including persistent cough, dyspnea, sinusitis, gastrointestinal symptoms, PTSD and depression because confirmatory laboratory or diagnostic testing is either not available or because an acknowledged "gold standard" does not exist. In addition, the high frequency of conditions such as asthma and GERD in the general population, as well as the absence of pre-9/11 data in most WTC- exposed populations, make it difficult to draw firm conclusions about whether or not post 9/11 diagnoses can be attributed definitively to WTC exposure.
- Many studies rely on self-reports of symptoms and conditions to measure the burden of these conditions in exposed populations without verification of diagnoses.

New York City WTC Patient Population Report

In the New York City area, three WTC Centers of Excellence offer physical and mental health monitoring and treatment, including medications and social support services, with no out-of-pocket costs to eligible individuals. In addition, any resident of New York City who continues to experience psychological distress related to 2001 terrorist attacks can seek cost reimbursement for out-of-pocket expenses through the New York City 9/11 Benefit Program for Mental Health and Substance Use Services. These programs are described briefly below.

The utilization of these four programs, which are made possible through a combination of funding from the federal government and New York City, offers the most concrete measure of the continuing demand for health services among people who were exposed to the WTC collapse. A fifth program, the federally funded WTC National Responder Health Program, monitors and treats rescue, recovery and clean-up workers who live outside of the New York area. It is important to remember, however, that there may be many other persons under care of their own physicians for WTC-related conditions.

Total Patients¹ in the New York City Area Receiving Publicly Funded WTC Monitoring and Treatment Services (FY 2009)

	July 2008 – June 2009	Since WTC Programs Began
Number of Patients Screened/Monitored ²	19,760	42,410
Patients Treated For Physical Health ³	12,230	N/A
Patients Treated For Mental Health4	5,680	N/A
Total Number of Patients Treated ⁵	15,688	N/A

- 1 Includes patients enrolled in the New York/New Jersey WTC Clinical Consortium, FDNY and the WTC Environmental Health Center, and individuals reimbursed by the NYC 9/11 Benefit Program for Mental Health and Substance Use Services, Specific details about each program follow on pages 11-14.
- 2 Shortly after the 2001 terrorist attacks, the federal government recognized that there might be health risks associated with rescue, recovery and clean-up work at the WTC site. It began funding services to screen workers for 9/11-related health problems and monitor their health on a regular basis through 2009.
- 3 WTC patients may have multiple physical health diagnoses. Upper respiratory symptoms include sinus or nasal congestion; lower respiratory symptoms include cough, shortness of breath, wheeze and chest tightness; gastrointestinal conditions include gastroesophageal reflux disease (GERD) and acid reflux-like symptoms; musculoskeletal symptoms include pain in the back, neck, shoulders and upper limbs.
- 4 WTC patients may have multiple mental health diagnoses. Diagnoses include posttraumatic stress disorder (PTSD), depression, generalized anxiety disorder and substance use disorders.
- 5 This reflects the actual number of individual patients treated. Some of these patients may appear in both of the rows above.

Patients Receiving Services at the WTC Medical Monitoring and Treatment Program: New York/New Jersey Clinical Consortium (FY 2009)

er for the first of the first of The first of the first o	July 2008 June 2009	Since Program Began
Total Number of Patients Screened/Monitored	10,121	27,250¹
Number of Patients Treated For Physical Health	6,436	N/A
Number of Patients Treated For Mental Health	2,207	N/A
Total Number of Patients Treated	6,990	9,9492

The WTC Medical Monitoring and Treatment Program, coordinated by the Mount Sinai School of Medicine and formally known as the New York/New Jersey WTC Clinical Consortium, is currently funded by the National Institute for Occupational Safety and Health (NIOSH). Begun in 2002, it screens, monitors and treats workers and volunteers who participated in the rescue, recovery and clean-up operations at the WTC site and three other locations. Services are provided in 10 clinical centers throughout the greater New York area.

- Since its inception in 2002, the New York/New Jersey WTC Consortium has provided screening examinations to 27,250 WTC rescue and recovery workers from all 50 states.
- In this same time period, the program has provided over 48,000 medical monitoring exams to WTC rescue and recovery workers. Monitoring exams now are conducted annually.
- Since NIOSH began funding treatment services in September 2006, the New York/New Jersey WTC Consortium has provided over 58,000 treatment services to approximately 10,000 responders.

Between July 1, 2008 and June 30, 2009, 39% of 10,121 responders who had a monitoring examination were referred into the NIOSH-funded WTC treatment program. The rate of referral was highest for those responders entering the program for their initial visit and declined for those seen for Visits 2 and 3.

NY/NJ WTC Consortium Treatment Facts in FY 2009:

- 25% of patients received treatment for both mental and physical health conditions.
- 71% of patients received treatment for an upper respiratory condition, 46% received treatment for a lower respiratory condition, 52% received treatment for a gastrointestinal condition, and 15% received treatment for a musculoskeletal condition.
- 32% of patients received treatment for a mental health condition.3
- 19% of patients were uninsured for at least one point during the year.
- 5% of patients were covered by Medicaid at least one point during the year.
- 10% of patients were served in a language other than English.



¹ Includes National Program (NP) numbers that were coordinated through the WTC Medical Monitoring and Treatment Data and Coordination Center at Mount Sinai through June 30, 2008. Effective July 1, Logistics Health Incorporated is the NP clinical center with coordination provided by NIOSH.

² Reflects the period from January 1, 2007 through June 30, 2009

³ Patients included in each respective category may have multiple diagnoses.

Patients Receiving Services at the WTC Medical Monitoring and Treatment Program: FDNY (FY 2009)

	July 2008 – June 2009	Since Program Began
Total Number of Patients Screened/Monitored	9,639	15,160
Number of Patients Treated For Physical Health	3,517	8,280
Number of Patients Treated For Mental Health ¹	1,457	9,350
Total Number of Patients Treated ¹	4,794	N/A

The WTC Medical Monitoring and Treatment Program at the Fire Department of New York (FDNY) is currently funded by NIOSH. Begun in 2001, it screens, monitors and treats active and retired members of FDNY [firefighters, emergency service workers (EMS) and officers] who responded to the WTC disaster. Services are provided at six clinics throughout the greater New York area. WTC-related mental health treatment services are also available to family members of FDNY-WTC patients but they are not included in the "Number of Patients Treated for Mental Health" above.

After initial screenings, workers were asked to return at 18-month intervals for monitoring exams. Annual monitoring exams began in 2009. 13,965 workers (92%) have been examined at least twice since 2001; 12,238 workers (81%) have been examined at least three times since 2001; 9,940 workers (66%) have been examined at least four times.

FDNY Treatment Facts in FY 2009:

- Approximately 10% of patients received treatment for both mental and physical health conditions.
- Lower respiratory symptoms were the leading diagnoses among patients treated (77%) followed by gastrointestinal symptoms (46%) and upper respiratory symptoms (32%). Many patients have at least two of these diagnoses.



¹ FY 2009 numbers for mental health are only through March 31, 2009 due to a change in reporting mechanisms in final quarter of FY 2009. Final numbers will be available by the end of the 2009 calendar year.

Patients Receiving Services at the WTC Environmental Health Center (FY 2009)

	July 2008-	Since Program
Number (Dec)	June 2009	Began
Number of Patients Treated For Physical Health	2,277	3.915
Number of Patients Treated For Mental Health	389	389
Total Number of Patients Treated	2 275	
The second section of the section of		3,915

The WTC Environmental Health Center (EHC) at Bellevue Hospital Center, Gouverneur Health Care Services and Elmhurst Hospital Center, began in the Bellevue Hospital Clinic asthma clinic in 2005. It became a separate program in 2006 when the American Red Cross provided funds to treat both residents and responders. New York City subsequently expanded the program to three locations in 2007 when the WTC EHC began focusing primarily on local residents, area workers (including commuters living outside of New York City), students and others who report exposure to WTC dust and fumes and are currently experiencing physical or mental health symptoms.

Unlike the other WTC Centers of Excellence, the WTC EHC did not receive funding from the federal government to provide screening exams for asymptomatic people who lived and worked in Lower Manhattan on 9/11 and in the months afterward. In September 2008, the WTC EHC received its first NIOSH funding to expand its program. The WTC EHC is now beginning a monitoring program that offers follow-up exams and evaluations for patients once they have begun treatment.

Initially, the WTC EHC accepted only patients with physical health symptoms. Patients were then screened for mental health symptoms and treated for both conditions if present. In late 2007, the WTC EHC established a formal mental health program, which includes individual and group counseling in several languages, and began treating patients with mental health symptoms only.

The WTC EHC developed a pediatric program in 2007 that offers medical and mental health treatment. With NIOSH funding, program staff has been expanded to include specialists in pulmonary medicine and child development.

WTC EHC Treatment Facts in FY 2009:

- More than 40% of all patients treated at Bellevue scored positive for PTSD.
- 17% of patients received treatment for both mental and physical health conditions.
- 19% of patients were treated in a language other than English.
- 50% of patients were uninsured for at least one point during the year.
- 35% had some form of commercial insurance; 7% of patients were covered by Medicaid at least one point during the year.
- Lower respiratory symptoms were the leading diagnoses among new patients treated at Bellevue (55%) followed by upper respiratory (40%) and gastrointestinal symptoms (32%). Many patients have at least two of these diagnoses.



Patients Reimbursed by the NYC 9/11 Benefit Program for Mental Health and Substance Use Services (FY 2009)

The state of the s	July 2008 – June 2009	Since Program Began
Patients Reimbursed	1,627	1,637¹
Patients Enrolled	2,575	3,130²

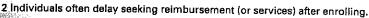
The New York City Department of Health and Mental Hygiene (DOHMH) launched the NYC 9/11 Benefit Program for Mental Health and Substance Use Services in April 2008. This insurance-like program serves as a payer of last resort for two groups of New York City residents who are experiencing psychological distress as a result of the 2001 terrorist attacks:

- Residents who were directly affected by the WTC disaster (Group A). These individuals also met the eligibility criteria established by a privately funded program that offered a similar benefit from 2002-2007. They include rescue, recovery and clean-up workers and their family members, and Lower Manhattan residents and area workers.
- Residents who do not meet the criteria of the privately funded program but who screen positive for a WTC-related mental health condition and whose providers will attest that this condition is related to 9/11 (Group B).

The extent of reimbursement for the two groups differs over the life of the program which covers outpatient services received through January 7, 2011. Medication reimbursement for both groups is capped at \$1,500.

The NYC 9/11 Benefit Program provides coverage retroactive to January 2007, when coverage under the privately funded program expired. Retroactive coverage was offered to help ensure continuity of care for 9/11-affected New York City residents who had been enrolled in the privately funded program.

1 Most individuals who were reimbursed when the program began in FY 08 also were reimbursed in FY 2009.





Recommendations

The WTC Medical Working Group made a series of recommendations about 9/11 health treatment and services in its 2008 annual report. These were grouped into three broad categories and can be accessed in their entirety at www.nyc.gov/9-11HealthInfo.

The WTC Medical Working Group remains committed to seeing its 2008 recommendations implemented in their entirety. The City of New York, the WTC Centers of Excellence and other stakeholders have made significant progress on many of these recommendations during the past year. The WTC Medical Working Group also identified a small number of new recommendations. These are both described below.

New Recommendations

- Advocate for federal funding to increase scientific knowledge about WTC-related health impacts including:
 - Research at the WTC Centers of Excellence, including the development of population-specific mental health screening tools.
 - Investigations to identify how environmental conditions such as the WTC collapse can cause illness, specifically through laboratory experiments using stored or generated environmental dust samples.
 - Research to identify biologic indicators of specific 9/11 exposures.
 - Other research as needed to identify people at higher risk for illness due to WTC exposure.
- Gather and publish lessons learned after 2001 terrorist attacks on the World Trade Center about preventing and treating disaster-related health conditions.

Progress Report on Implementation of 2008 Recommendations

I. Funding

These recommendations emphasized advocacy for long-term funding of 9/11 health programs so that all WTC- exposed populations could be tracked, monitored and treated.

Since the publication of the 2008 report, the WTC Environmental Health Center (WTC EHC) successfully applied for grant funding from the Centers for Disease Control and Prevention to provide monitoring and treatment services to Lower Manhattan residents, area workers and students. In September 2008, the National Institute for Occupational Safety and Health (NIOSH) awarded \$30 million to the WTC EHC over the next three years. This is the first time that the federal government has funded WTC-related services for community residents, area workers and students.

As part of the NIOSH grant, the WTC EHC and the WTC Health Registry have begun reaching out to Registry enrollees who are eligible for services at the WTC EHC by phone and by mail to refer them to care. Preliminary results from the 2006-2007 adult follow-up survey conducted by the WTC Health Registry indicate that 15% of 46,000 survey respondents had unmet health care needs.

The WTC EHC is now seeking a modification of the grant so that it can offer this population other options for mental health care through the NYC 9/11 Benefit Program for Mental Health and Substance Use Services. If NIOSH approves the modification, people eligible for services at the WTC EHC also will be able to seek outpatient care through licensed providers of their own choice in New York State.

In June, NIOSH awarded a \$12 million grant over the next three years to the WTC Health Registry, which had been supported by the Agency for Toxic Substances and Disease Registry since 2002. The new funding will permit the Registry to survey the health of more than 71,000 people who were directly exposed to the WTC disaster a third time, nearly a decade after 9/11.

In July 2009, NIOSH awarded a \$1.8 million research grant over four years to the **Department of Environmental Medicine**, **NYU School of Medicine** to investigate the toxicities of WTC dusts. Specifically, researchers will study how select physico-chemical properties of the dusts may have contributed to the respiratory illness and sarcoid-like granulomatous pulmonary disease development that has been documented in WTC-exposed responders.

The continued success of these programs and the WTC Medical Monitoring and Treatment Programs at FDNY and the New York/New Jersey Consortium requires dependable, long-term funding. In April, Mayor Bloomberg identified long-term federal funding for WTC medical monitoring and treatment programs as one of five legislative priorities. Representatives of the Mayor's Office and the Centers of Excellence have been consistent and persistent in their testimony concerning the critical need for this funding before the Senate Committee on Health, Education, Labor and Pensions; the House Committee on Energy and Commerce, Subcommittee on Health; and the City Council.

In response to the documented persistence of WTC-related illnesses, similar bills were introduced in both the House (H.R. 847) and Senate (S. 1334) during the 111th Congress that would permanently fund monitoring and treatment services at all three Centers of Excellence, as well as epidemiologic research through the WTC Health Registry. If this legislation becomes law, an estimated 55,000 responders and 17,500 community members will have long-term access to the specialized care and medications with no out-of-pocket costs at the WTC Centers of Excellence.

In the meantime, the 2009 fiscal year omnibus appropriations bill, signed into law by President Obama in March, included \$70 million in new funding "to provide screening and treatment for first response emergency services personnel, residents, students, and others related to the September 11, 2001 terrorist attacks on the World Trade Center. "President Obama also proposed an additional \$70 million in funding in his 2010 fiscal year budget. In July, the House approved adding nearly \$930,000 to the President's request, bringing the total for FY 10 to nearly \$71 million. This funding, along with unspent appropriations from previous years, continues to sustain screening, monitoring and treatment services at the New York/New Jersey WTC Clinical Consortium and the FDNY on a temporary basis.

II. Research and Evaluation

These recommendations focused on continuing research about 9/11 health issues, particularly in the areas of mental health and any potential late emerging conditions such as cancer, and evaluating treatment effectiveness.

Many institutions who are represented on the WTC Medical Working Group actively continue to investigate health impacts related to 9/11 exposures. In addition to recent published research that is included in the **New Findings** section, several of these institutions have important research initiatives underway to advance research and evaluation. Examples of this progress are summarized below.

Fire Department of New York (FDNY)

Over the last year, FDNY has expanded its medical monitoring and treatment of WTC-related physical health diseases beyond its main center in Brooklyn to satellite locations in Queens, Staten Island, Long Island and Orange County, NY that previously were used only for mental health treatment.

FDNY also is verifying self-reported cancer diagnoses among enrollees with medical records and NYS cancer registry data. Analysis is ongoing with results expected in the next year. Similar work is ongoing for autoimmune diseases such as sarcoidosis, polymyositis, rheumatoid arthritis and other systemic inflammatory illnesses.

In previously published research, FDNY demonstrated that the average decline in lung function in the first year after 9/11 was nearly 12 times the normal annual decline observed in this population before the WTC terrorist attacks. The study also indicated that further monitoring would be required to ascertain whether the elevated rate reflected long-term effects. In December 2008, FDNY finished collecting data for over 96,000 pulmonary function tests done between 1997 and 2008 in FDNY firefighters and EMS rescue workers. Analysis that would extend first-year findings to an eight-year longitudinal study of pulmonary function among these workers after 9/11/01 is nearly complete.

Preliminary results have been published in abstract form by the American Thoracic Society on a study of 1,720 FDNY rescue workers (13% of the total FDNY cohort) with respiratory symptoms or reduced lung function who received extensive pulmonary testing at the FDNY WTC Medical Monitoring and Treatment Program. Evidence for airways obstruction was found in the majority of patients. Interstitial lung disease was rare.

FDNY has just completed and had accepted for publication mental health studies of nearly 2,000 retired firefighters. One study validates the use of self-administered mental health screening tools in comparison to structured diagnostic interviews; another demonstrates nearly equal rates of PTSD (22%) and depression (23%) in this group during 2005-2007. Co-morbidity studies are now underway.

New York City Department of Health and Mental Hygiene (NYC DOHMH)

In December 2008, the WTC Health Registry's follow-up pediatric survey ended, and analyses on this important, understudied population six to seven years after 9/11 have begun. Surveys were completed for 50% of the 2,000 children currently under the age of 18 enrolled in the Registry. This is the only cohort of WTC-exposed children whose health is being tracked prospectively, and external researchers are encouraged to propose collaborative studies.

The WTC Health Registry is verifying self-reported cancer diagnoses among enrollees with cancer registries in twelve states. Cancer data linkage is nearly complete with all state cancer registries (except Missouri and Massachusetts); the NYC DOHMH Institutional Review Board has approved a protocol for contacting enrollees whose diagnoses cannot be verified through the state registries.

The WTC Health Registry is also comparing mortality rates among enrollees, as well as rates for specific causes of death, to local and national rates over time. This comparison will be critical in determining whether or not people exposed to the WTC disaster are at an increased risk for premature death. Three rounds of matching to the NewYork City Bureau of Vital Statistics and two rounds of matching to the National Death Index (NDI) have been completed using social security numbers provided by enrollees. A preliminary analysis of death rates through 2006 is underway.

In addition, the WTC Health Registry encourages external researchers to analyze existing survey data for enrollees and to recruit enrollees for new studies. The physical and mental health effects of the 2001 WTC disaster on police responders; the impact of parental exposure to mass violence on child mental health; the combination of exposure therapy and medication in treating PTSD; and how maternal PTSD may affect pregnancy outcomes are among the nine studies that have been initiated with a number of institutions, including Columbia University, the New York State Department of Health and the Yale School of Medicine.

New York City Police Department

The New York Police Department (NYPD) —whose members comprise the City's largest WTC responder group—has evaluated, tracked and referred for treatment all its exposed members since 2001. The NYPD Medical Division continues to offer an uniform, a full array of treatment options and prescription drugs for all its exposed uniformed members. It also recently completed an analysis of a five-year follow-up study of pre- and post-9/11 data of the NYPD Emergency Services Unit personnel. Results are forthcoming.

New York/New Jersey WTC Clinical Consortium

This consortium, coordinated by the Mount Sinai School of Medicine and also including the State University of New York at Stony Brook, New York University/Bellevue Hospital, Queens College and the University of Medicine and Dentistry of New Jersey, continues its long-term medical monitoring and treatment programs for WTC rescue, recovery and clean-up workers not covered by the FDNY program. Many of these workers are first-generation immigrant male laborers, a population that has limited access to appropriate health care.²⁵ In December 2008, Mount Sinai, in partnership with Richmond University, expanded to include a fourth Mount Sinai-operated clinical center located on Staten Island.

During the past year, the New York/New Jersey WTC Clinical Consortium has conducted investigations of sarcoidosis and anosmia (loss of sense of smell) among patients who have sought treatment in the WTC Medical Monitoring and Treatment Program.

The New York/New Jersey WTC Clinical Consortium also has documented eight confirmed cases of multiple myeloma, the second most commonly diagnosed blood cancer in the United States, among 28,252 responders who sought treatment in the WTC Medical Monitoring and Treatment Program in the first six years after 9/11. While four of these responders were younger than 45 years of age, this was not a statistically significant elevation above the background estimate of one. It is still too early to tell whether WTC exposures caused these cases of multiple myeloma among rescue and recovery workers, and continuing medical follow-up is therefore necessary. The New York/New Jersey WTC Clinical Consortium published this case series in the August 2009 issue of the Journal of Occupational and Environmental Health.²⁶

The Mount Sinai School of Medicine conducted a semi-structured clinical evaluation of 416 responders in the New York/New Jersey WTC Clinical Consortium. Results of the evaluation, published in the summer 2009 issue of the *Psychiatric Quarterly*,²⁷ personalized the 9/11 symptom reports and mental health diagnoses among rescue, recovery and clean-up workers. It also provides useful information for addressing the psychological dimensions of disasters, particularly in the areas of occupational roles and exposures.

The Mount Sinai School of Medicine also published a special issue of the *Mount Sinai Journal* of *Medicine* ²⁸ devoted to the WTC Medical Monitoring and Treatment Program. It summarizes key physical and mental health findings among WTC rescue, recovery and clean-up workers.

New York State Department of Health

Using a variety of source materials, including employment information, death certificates, and medical and autopsy records, the New York State Department of Health identifies and tracks all deaths among WTC responders so that science-based investigations of root causes can be explored. As of July 2009, the WTC Responder Fatality Investigation Program had confirmed the causes of death for 614 people who worked at the WTC site. 74% of these responders died as a result of illness; the remainder died as a result of traumatic injury. Researchers are beginning to compare mortality rates for the responders to local and national rates. These comparisons will assist in determining whether WTC responders may be at increased risk for specific causes of death. Until these or similar analyses are completed, there is insufficient information available to assess whether or not mortality rates may be elevated.

WTC Environmental Health Center

The WTC Environmental Health Center (EHC) serves local workers, residents, students and children, as well as a population of clean-up workers. The number of area workers seeking care continues to increase the most, particularly at Bellevue Hospital, with the Gouverneur program serving more residents. Elmhurst Hospital, the smallest of the three programs, provides services predominantly for clean-up workers. At Bellevue Hospital, an increasing number of patients are seeking second opinions after having previously sought care elsewhere, a trend in keeping with the potentially chronic nature of the symptoms.

Several ongoing projects at the WTC EHC include those to better understand disease mechanisms in the WTC-exposed community, as well as the high prevalence of PTSD, depression and anxiety among patients who have been referred primarily for physical symptoms.

These projects include: correlating clinical, radiographic and pathologic findings among patients who have undergone open lung biopsies because of abnormal CT scans or because they have restrictive lung disease; using methacholine challenge tests to evaluate patients with lower respiratory symptoms and normal lung function to evaluate airway hyperreactivity; evaluating CT scans of patients with persistent sinus complaints; and using endoscopy to examine the esophagus and stomach in patients who have persistent GERD-like symptoms.

III. Education

These recommendations sought to increase awareness of 9/11-related health conditions among the general public and within the medical community, and to increase awareness of the services available to affected individuals.

The New York City Health and Hospitals Corporation (HHC) launched a \$5 million advertising and grass roots marketing campaign in September 2008 to promote the services available at the WTC Environmental Health Center. Multilingual subway advertisements using the tag line "Lived There? Worked There? You Deserve Care" were particularly effective in increasing awareness among Lower Manhattan residents, area workers and students who were exposed to the WTC disaster but who may not have been aware that treatment is available at no out-of-pocket cost for various common physical and emotional symptoms that may be related to 9/11. Ads also ran in newspapers and on radio and television, urging people to call 311 for more information.

Recognizing that a broad-based advertising campaign was likely to reach people eligible for services at the New York/New Jersey WTC Clinical Consortium, information about this program was incorporated into the City's **311 referral system**. This made it possible for hundreds of callers to be directly transferred to the WTC EHC or to the toll-free number operated by the Consortium for the first time.

As part of the HHC campaign, ten community-based and other organizations also received grants to conduct grass roots outreach to hard-to-reach groups, host educational forums, conduct health fairs, and provide patient navigation services to improve access to care. The following groups received up to two year grants that together total \$2.1 million: Beyond Ground Zero (BGZ) Network; Henry Street Settlement; Lin Sing Association; United Jewish Council; Ecuadorian International Center, Inc.; Communications Workers of America; DC 37 Safety & Health; NY Committee for Occupational Safety & Health (NYCOSH); and the Organization of Staff Analysts. These groups also were provided with informational brochures in English, Spanish, Chinese and Polish as well as premiums to promote the WTC Environmental Health Center.

In June 2009, DOHMH published Clinical Guidelines for Children and Adolescents Exposed to the WTC Disaster for distribution to pediatricians in the New York City area. The guidelines were developed to raise awareness among pediatricians about the potential health effects of WTC exposure among children; to provide evidence-based recommendations about the treatment of WTC-exposed children; and to encourage referral to the specialized services available through the pediatric program at the WTC Environmental Health Center. Pediatricians and other clinical experts from the WTC Environmental Health Center, Children's Hospital at Montefiore, Columbia University, Mount Sinai Medical Center, New Jersey Medical School, New York-Presbyterian Medical Center, New York University and the University of Oklahoma participated in the process, in addition to parent and community representatives from Lower Manhattan.

Many adolescents who were exposed to the WTC disaster have entered college since the terrorist attacks. DOHMH expanded the distribution of the *Clinical Guidelines for Adults Exposed to the WTC Disaster* in 2008 to more than 200 college health clinics in the northeastern United States, with a letter encouraging physicians to consider the potential impact of WTC exposure on student health. The clinical guidelines for adults, children and adolescents are also accessible from New York City's **9/11 health website**, which receives an average of 5,000 unique visitors per month.

As part of its overall effort in June to increase awareness of WTC-related problems and services, DOHMH used its flagship publication, **Health Bulletin**, to educate the general public about WTC-related health effects and to urge individuals who may have been affected to seek specialized treatment for posttraumatic stress disorder and asthma. More than 65,000 subscribers received the *Health Bulletin* called "Is 9/11 Affecting Your Health?" electronically. Printed copies may be obtained in English, Spanish or Chinese by calling 311.

Although the number of programs specifically serving the various needs of people who were affected by the terrorist attacks decreased with the end of American Red Cross funding in 2008, DOHMH also published a **9/11 Resource Guide** that categorized all remaining programs and included all publicly funded WTC services. Publication of the guide coincided with the 7th anniversary of the 2001 terrorist attacks, the time of the year when demand for services typically is greatest. Copies of the *9/11 Resource Guide* are available in English, Spanish, Chinese and Polish, and were widely distributed by WTC Health Liaisons at New York City agencies whose employees participated in WTC rescue and recovery operations.

Appendix A: How WTC-Related Deaths Are Evaluated by New York City's Office of the Chief Medical Examiner

New York City's Office of Chief Medical Examiner (OCME) evaluates possible WTC-related causes of death on an individual, case-by-case basis.

After a request has been made by a physician or family member, OCME applies the same objective rules and definitions in determining causes of death related to the WorldTrade Center as it does for other cases. This includes, but is not limited to, the evaluation of autopsy reports, microscopic tissue examination, case history, medical records, medical and legal investigation and a review of current scientific literature. In some cases, additional testing or external consultation may be necessary. The information is then evaluated by a committee composed of the Chief Medical Examiner along with Senior Medical Examiners who make a determination about both the cause and manner of death.

According to a March 23, 2009 letter from Charles S. Hirsch, MD, the Chief Medical Examiner, "The underlying cause of death is the disease or injury responsible for initiating the lethal sequence of events. The manner of death explains how the cause arose: natural or violent. Natural deaths are caused exclusively by disease. The way in which an injury was sustained determines the sub-classification of violent deaths: accident, homicide or suicide."

Dr. Hirsch further explains that "the criterion used to determine whether or not a WTC-related death is *homicide* is objective and non-arbitrary; the injury responsible for death must have been caused by burns, trauma from collision of an airplane or collapse of the one of the buildings on 9/11/01, inhalation of the dust cloud created by the collapse of a building on 9/11/01, or acute stress directly related to the disaster."

Because OCME takes into consideration the circumstances of a particular injury when determining the manner of death, not all WTC-related deaths are classified as homicide. In order for OCME to classify a WTC-related death as a homicide, the precipitating injury must have occurred on September 11, 2001. Dr. Hirsch offers the following example to illustrate why the manner of death may differ in WTC-related cases: "if a person at the WTC was crushed by a falling steel beam on 9/11/01, this is homicide. Two weeks later, if a recovery worker at the WTC was crushed by a steel beam falling from a crane, the death would have been an accident not homicide." Similarly, if a person who participated in WTC rescue and recovery operations eventually died as a result of inhaling dust at the site, but didn't begin working until sometime after September 11, 2001 the manner of death would be classified as natural. Nevertheless, Dr. Hirsch adds, "In instances when exposure to WTC dust after 9/11/01 contributed to the development of the fatal disease, the cause of death will be noted as 'WTC-related' on the death certificate."

Using these standards, OCME has determined that "other than the terrorists on the airplanes, all persons killed at the World Trade Center on 9/11/01 are victims of homicide. Three persons who sustained physical injuries at the WTC on 9/11/01 were treated in hospitals until they died, 11-112 days later. Those three persons are victims of homicide. Two persons who died from heart disease, either fleeing from a falling building or shortly following exposure to the dust cloud created by a falling building, were both victims of homicide. One woman died in February, 2002, and one man died in October, 2008, from sarcoidosis or related complications; since their disease either was caused or aggravated by exposure to the dust cloud created by the collapse of a building, their deaths ultimately were classified as homicide. No other death has been classified as a WTC-related homicide by the OCME."

Dr. Hirsch also notes that its classification of the manner of death "does not preclude formal recognition by New York City of the rescue and recovery personnel believed to have suffered harmful effects of their exceptional and dedicated service."

Appendix B: Impact of 9/11 on New York City Disability Pensions

New York City employees who are disabled as a result of an accidental injury that occurred while they were doing their jobs are eligible to file for an accidental disability pension through their retirement system. If the accidental disability pension is granted, they receive a tax-free pension that is equal to three quarters of their final annual salary if they are uniformed personnel or 60% of their final annual salary if they are civilian personnel.

A disability determination requires that an injury or illness result in a permanent level of functional impairment that reasonably prevents the worker from safely performing his or heressential job tasks. This means that the same level of functional impairment may be disabling for one type of job but not for another.

Under New York State law, each City retirement system has one or more independent medical boards whose sole responsibility is reviewing disability applications. They determine whether or not the applicant is disabled and advise the retirement systems' Board of Trustees if the disability occurred as a result of job-related duties, or if the injury was caused by circumstances unrelated to work duties.

A variety of state laws direct the pension system to presume certain injuries and illness are work-related. For example, if members of NYPD and FDNY develop certain kinds of heart diseases or suffer from a stroke, the "Heart Bill" presumes that these conditions were caused by job-related stress or other occupational strains on the heart. There also are presumption laws for lung diseases (FDNY only), many cancers (FDNY only) and certain communicable diseases (FDNY, EMS and NYPD).

World Trade Center (WTC) Disability Law

In 2005, New York State enacted the World Trade Center (WTC) Disability Law which establishes a presumption that certain disabilities for certain New York City employees were caused by their participation in WTC rescue, recovery or clean-up operations. This presumption law entitles employees with a range of medical conditions who meet certain requirements (including the kind of work that they did, and where, when and how long they worked) to collect accidental disability retirement benefits, unless evidence proves otherwise.

Three important factors make the WTC Disability Law different from other presumption laws (e.g., the "Heart Bill"): 1) it is based on participation in an event; 2) it includes employees in the New York City Employees Retirement System (NYCERS) who work for agencies that typically are not covered by other presumption laws; and 3) it includes a large number of qualifying conditions that may be physical or psychological.

In October 2008, New York State amended the WTC Disability Law following unanimous recommendations by the New York State September 11th Workers Protection Task Force, which includes representatives of City and State governments, unions and physicians with expertise in occupational medicine and/or WTC-related illness. The amendment broadened the definition of eligible workers, and extended to September 11, 2010 the filing deadline for a Notice of Participation. These Notices protect employees who haven't shown any signs of illness to date or when they retire(d). If they get sick with illnesses covered under the WTC Disability Law after retiring, these employees can apply to have their pensions reclassified and benefits increased to reflect this disability.

Of the 1584 New York City employees who have retired with WTC-related accidental disability through December 2008, (see WTC Disability Approvals By NYC Retirement System below), 62% of these employees retired prior to the enactment of the WTC Disability Law on June 14, 2005. The vast majority of these retirees worked at FDNY.

WTC Disability Law, Cancer and Treatment

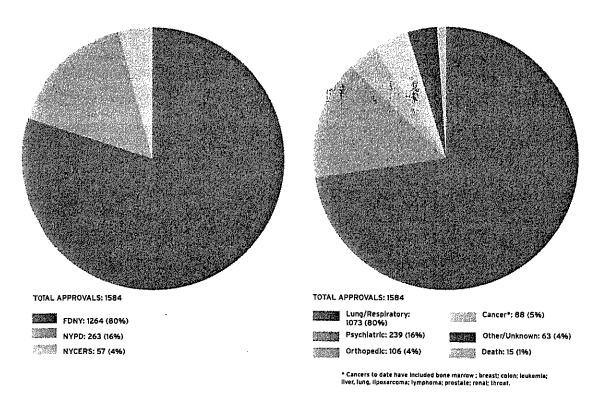
Cancer is among the diseases covered by the WTC Disability Law. However, the federally funded WTC Centers of Excellence, which provide treatment for most of the conditions covered by the WTC Disability Law, do not provide free care for any kind of cancer. This means that a disabled WTC rescue worker employed by New York City or New York State may be able to collect a WTC disability pension but will not be eligible for cancer treatment through a WTC Center of Excellence. Instead, the worker will have to rely on private insurance for cancer treatment which, depending on the extent of coverage offered by a particular plan, may not cover all the costs.

Given these differences between federal policy and state disability law, an important function of the WTC Medical Working Group, which includes representation from the WTC Centers of Excellence, is to offer policymakers advice based on current scientific knowledge. In its 2008 annual report, the WTC Medical Working Group concluded "to date, there is no evidence for or against a causal connection between WTC exposure and any form of cancer." A year later, this is still the case.

Multiple studies have begun to evaluate whether there are such associations, but conclusive results are not yet available. The WTC Medical Working Group will continue to monitor results of those and other studies regarding possible latent or late-emerging illnesses with the goal of determining if these illnesses are occurring in higher proportions among persons with WTC exposure than among persons of similar age and gender without this exposure.

WTC Disability Approvals by NYC Retirement System 2001–2008

WTC Disability Approvals by Health Conditions 2001–2008



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