

**Dragon, Karen E. (CDC/NIOSH/EID)**

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**From:** Jeffrey Hon [jhon@health.nyc.gov]  
**Sent:** Thursday, April 28, 2011 1:37 PM  
**To:** NIOSH Docket Office (CDC)  
**Subject:** New York City Health Department Submission re NIOSH Docket #227  
**Attachments:** Farley re NIOSH Docket #227 (04.28.11).pdf; 2010 MWG Annual Report (FINAL with Links).pdf

Dear Sir/Madam:

Correspondence from Thomas Farley, MD, MPH, Commissioner of the New York City Department of Health and Mental Hygiene, regarding NIOSH docket # 227 is attached. Hard copies also will be sent via US mail.

Thank you.

Jeffrey Hon  
**World Trade Center Health Coordinator**  
NYC Department of Health and Mental Hygiene  
Gotham Center  
42-09 28th Street, CN10  
Queens, NY 11101-4132

347.396.4067 (desk)  
917.709.6907 (cell)

[www.nyc.gov/9-11healthinfo](http://www.nyc.gov/9-11healthinfo)

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NEW YORK CITY DEPARTMENT OF  
HEALTH AND MENTAL HYGIENE

Thomas Farley, M.D., M.P.H.

Commissioner

Gotham Center  
42-09 28<sup>th</sup> Street  
Queens, NY 11101-4132  
347-396-4100 (t)

April 28, 2011

John Howard, M.D.  
NIOSH Docket Office  
Robert A. Taft Laboratories  
MS-C34  
4676 Columbia Parkway  
Cincinnati, OH 45226  
Via e-mail: [nioshdocket@cdc.gov](mailto:nioshdocket@cdc.gov)

Re: Docket Number NIOSH-227

Dear Dr. Howard:

Attached is a copy of the 2010 annual report from New York City's World Trade Center (WTC) Medical Working Group. This document is in response to the request from the National Institute on Occupational Safety and Health for information on conditions relating to cancer to consider for the WTC Health Program [Docket Number NIOSH-227].

The WTC Medical Working Group was established in 2007 by Mayor Michael R. Bloomberg. Co-chaired by Linda Gibbs, Deputy Mayor for Health and Human Services, and myself, the WTC Medical Working Group includes 13 scientists and 9/11 health experts from inside and outside of City government. It meets regularly to review clinical and research findings on the health effects of WTC exposure and has released three annual reports broadly summarizing more than 250 articles published to date in peer-reviewed journals.

The 2010 WTC Medical Working Group annual report includes research published through July 2010. Regarding cancer, it states:

Whether there is a relationship between WTC exposure and other longer-term illnesses, including cancer, is unknown but this is actively being studied by clinicians, epidemiologists and other researchers.

The WTC Medical Working Group also issued recommendations (*see page 12*) concerning the scientific methods that researchers should consider using when analyzing the number of post-9/11 cancer diagnoses that have been confirmed among the cohorts under study by the Fire Department of New York; the New York/New Jersey WTC Clinical Consortium; the WTC Environmental Health Center; and the WTC Health Registry. These recommendations are based on the



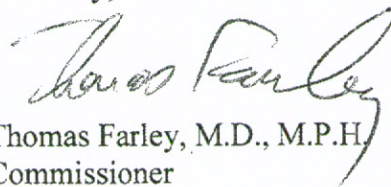
expert advice of nine nationally recognized biostatisticians, environmental health scientists and cancer epidemiologists, including representatives from the American Cancer Society and Harvard University, who attended a June 2010 meeting convened by the Health Department and the Fire Department of New York.

Implementation of the second recommendation is well underway. The cohorts mentioned above have formed a WTC Analytic Methods Workgroup which has been meeting regularly. To date, the workgroup has developed a common WTC exposure matrix so that the degree of exposure within and across responder cohorts can be categorized more consistently. In addition, it has established a WTC Cancer Review Board, which also includes oncologists, so that cancer cases can be categorized more consistently across all cohorts.

It is our expectation that these recommendations will be useful in meeting the considerable scientific challenges WTC researchers face as they continue their ongoing cancer research.

Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read "Thomas Farley".

Thomas Farley, M.D., M.P.H.  
Commissioner

TF/jh





# 2010 Annual Report on 9/11 Health

September 2010

World Trade Center Medical Working Group of New York City

**NYC**  
Michael R. Bloomberg  
Mayor



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## World Trade Center Medical Working Group Membership

Mayor Bloomberg convened the World Trade Center (WTC) Medical Working Group in June 2007. Members meet regularly to review clinical and research findings on the health effects of WTC exposure. In addition to publishing an annual report, they also review the adequacy of physical 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.

### Membership

**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*

*Chair, New York State September 11th Worker Protection Task Force*

**Mitchell Cohen, PhD**

*Associate Professor, Department of Environmental Medicine, NYU School of Medicine*

**Joanne Difede, PhD**

*Director, Program for Anxiety and Traumatic Stress Studies  
Associate Professor of Psychology in Psychiatry, Weill Cornell Medical College*

**Kitty H. Gelberg, PhD, MPH**

*Chief, Epidemiology and Surveillance Section, Bureau of Occupational Health, New York State Department of Health*

**Carolyn Greene, MD**

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

**Eli J. Kleinman, MD, MPH**

*Assistant Professor of Medicine and Hematology, Albert Einstein College of Medicine  
Supervising Chief Surgeon, New York City Police Department*

**Philip J. Landrigan, MD, MSc, DIH**

*Dean for Global Health  
Professor and Chairman, Department of Preventive Medicine  
Professor of Pediatrics, Director, Center for Children's Health and the Environment, Mount Sinai School of Medicine*

**R. Richard Leinhardt, MD, FACS**

*Chief Surgeon, New York City Department of Correction  
Clinical Associate Professor Emeritus of Otorhinolaryngology, New York Medical College*

**David Prezant, MD**

*Chief Medical Officer, Office of Medical Affairs, Co-Director, WTC Medical Monitoring & Treatment Programs, New York City Fire Department  
Professor of Medicine, Albert Einstein College of Medicine*

**Ramanathan Raju, MD**

*Executive Vice President and Corporate Chief Medical Officer, Medical and Professional Affairs, NYC Health and Hospitals Corporation*

**Joan Reibman, MD**

*Medical Director, WTC Environmental Health Center, New York City Health & Hospitals Corporation  
Associate Professor, Medicine and Environmental Medicine, NYU Medical Center Bellevue Hospital Center*

**Pablo Sadler, MD**

*Mental Health Medical Director, New York City Department of Health and Mental Hygiene*

**Michele S. Slone, MD**

*Clinical Assistant Professor, Department of Forensic Medicine, New York University School of Medicine  
City Medical Examiner, Office of Chief Medical Examiner, City of New York*



# WTC Medical Working Group Meeting Highlights

For the first two years of its existence, the Mayor's WTC Medical Working Group (MWG) reviewed the large body of scientific literature about the health impacts of the 2001 terrorist attacks that had accumulated to date. After summarizing the major findings in two comprehensive annual reports (*see page 3*) and sharing them with legislators in city and federal government, as well as other stakeholders, the MWG began addressing specific areas of interest at each of its meetings.

At its September 2009 meeting, the MWG invited nearly a dozen stakeholders, including representatives of the National Institute for Occupational Safety and Health (NIOSH), academia, labor and community, and the New York City Department of Health and Mental Hygiene shared an early draft of the **WTC Health Registry's 2010–2011 survey**. This survey, the third that the Registry will conduct, is especially critical as it will continue to examine the health of up to 70,000 people exposed to the WTC disaster nearly a decade later, not just those who have sought treatment for 9/11-related illness. MWG meeting participants offered many valuable suggestions, including increasing emphasis on development of chronic conditions such as heart disease and cancer; adding more questions about depression, which often develops in people who have post-traumatic stress disorder (PTSD); and continued probing about how enrollees access and utilize health care.

In its December 2009 meeting, the MWG focused on **long-term 9/11-related mental illness sequelae**. In addition to the WTC Centers of Excellence, several providers with experience in service delivery participated in the meeting along with a representative from NIOSH. Together, these providers have treated thousands of New Yorkers for PTSD related to the 2001 terrorist attacks. Access to care, the current capacity for treating what appears to be a high burden of 9/11-related PTSD and mental health comorbidities, and the use of evidence-based practices in treating 9/11-related mental illness were among the topics discussed.

At the April 2010 meeting, representatives from the three WTC Centers of Excellence and the WTC Health Registry each made presentations about the **complex methodological questions associated with preliminary cancer investigations** among their overlapping study cohorts. The Fire Department of New York (FDNY) and the WTC Health Registry, which have both begun determining the number of confirmed cancer diagnoses through 2006 within their cohorts, agreed they would co-chair a conference of outside experts, including biostatisticians and cancer epidemiologists, to help address these analytic questions and to provide invited researchers tracking each of the WTC cohorts with shared guidance for their continued analyses using the best methods available. As a result of this two-day conference, which took place in June 2010, the WTC Medical Working Group endorsed several recommendations (*see page 12*) that have been accepted by the WTC Centers of Excellence and the WTC Health Registry about the methods that they should use in their cancer investigations going forward.

The topic of the August 2010 meeting was **mortality** among people who were exposed to the WTC disaster, which is closely tracked by the New York State Department of Health and the WTC Health Registry. This discussion, which took place after this report went to press, will be summarized in the 2011 MWG annual report.



# Summary of WTC-Related Health Findings

The WTC Medical Working Group has reviewed nearly 250 studies published from 2001 to 2010 that are relevant to its mission. The majority of these studies examined the short-term health effects of people exposed to the WTC disaster 1–4 years later.

Nine years after the attack on 9/11, an increasing number of studies have progressed to the stage where mid-term health effects are now being described and analyzed. These studies indicate that while the majority of people exposed to the WTC disaster are healthy and symptom-free, thousands of individuals—including rescue, recovery and clean-up workers and people who lived, worked or went to school in Lower Manhattan on 9/11—have developed chronic, and often co-occurring, mental and physical health conditions.

New research examining firefighters and emergency medical service workers and published in the *New England Journal of Medicine* this year (*see summary beginning on page 5*) demonstrates that lung damage in this group has persisted for at least 6 years.<sup>1,2</sup> This longitudinal research, however, did not assess the impact of treatment, which may have helped to restore lung function or prevent further deterioration among many of the 13,000 individuals who were studied. Another FDNY study suggests that airway obstruction, not interstitial lung disease, is the predominant lung injury among WTC-exposed rescue workers.<sup>3</sup>

In general, health findings remain remarkably consistent across WTC studies and are summarized below.

## Physical Health

- Numerous studies indicated that respiratory symptoms, sinus problems, asthma, and loss of lung function were diagnosed in or reported by many who were exposed to WTC dust, including nearly 50,000 rescue and recovery workers, residents and office workers in the New York area who have enrolled in 9/11 health programs.
  - Epidemiologic studies indicate that diagnoses of new asthma among exposed groups peaked during the first 16 months after 9/11.
  - Clinical studies demonstrate that the steep declines in pulmonary function first detected among firefighters and EMS workers within a year of 9/11 have largely persisted even among those who never smoked: four times as many firefighters and twice as many EMS workers had below-normal lung function for their ages 6–7 years after 9/11 as they did before 9/11.
- Intense dust cloud exposure on the morning of 9/11 increased the risk for developing respiratory problems across all WTC-exposed groups. Other risk factors among specific WTC-exposed groups included:
  - *Rescue, recovery and clean up workers*: arriving early or working for long periods of time at the WTC site. In addition, lung function declines were slightly greater among the relatively few firefighters and EMS workers who were active cigarette smokers before and after 9/11 than for nonsmokers.
  - *Residents*: not evacuating their homes or experiencing a heavy layer of dust in their homes.
  - *Office workers*: experiencing a heavy layer of dust in their offices.
  - *Both residents and office workers*: living and working in Lower Manhattan.



- Several studies have suggested that WTC exposure is associated with sarcoidosis (an inflammation that can affect any organ, but typically affects the lungs) among rescue, recovery and clean-up workers.
- Many WTC-exposed adults were also diagnosed with or reported having heartburn, acid reflux or other gastroesophageal reflux symptoms, often in conjunction with other respiratory or mental health symptoms. Acid reflux is common among the general population, however; further research is needed to understand the relationship between reflux symptoms, WTC exposure and other WTC-related health conditions.
- 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 this is actively being studied by clinicians, epidemiologists and other researchers. They also are studying the possible relationship between WTC exposure and overall mortality.

### Mental Health

- Results from large epidemiologic studies have consistently shown that posttraumatic stress disorder (PTSD), identified by a positive screening using a standardized psychological assessment tool, is the most common WTC-related health effect among exposed adults.
- Screening positive for PTSD was more likely 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, or knowing someone who was killed or injured in the attacks.
  - Among rescue and recovery workers, early arrival at the WTC site, working there for a long time, or doing tasks outside of their trained area of expertise.
- Trauma before or after 9/11 unrelated to the terrorist attacks, such as losing a job, was also associated with PTSD or with greater symptom severity. Lack of adequate social support was associated with reduced recovery from PTSD.
- Despite widespread evidence of PTSD among exposed groups, suicide rates at the population level in New York City did not increase in the first four years after 9/11.
- Depression, anxiety and substance use disorders have not been as well studied as PTSD among WTC-exposed people.

Sources: 2008, 2009, 2010 Mayor's WTC Medical Working Group annual reports, which can be accessed online at [www.nyc.gov/html/doh/wtc/html/studies/medgroup.shtml](http://www.nyc.gov/html/doh/wtc/html/studies/medgroup.shtml).



## Recent WTC-Related Research

The WTC Medical Working Group identified 64 published papers related to health among the WTC-exposed in the scientific literature since its 2009 annual report. Twenty-two of these papers evaluated the physical health of WTC-exposed individuals; 22 papers looked at mental health; two papers discussed children's health; three papers examined how a stress hormone can affect mental health; and 15 papers addressed other issues, such as WTC exposures, improving diagnostic tools, the impact of 9/11 on dreams and memory, and the role of plastic surgeons in disaster response. New research with the greatest relevance to the work of the MWG is summarized below. Research published by institutions represented on the MWG is noted in boldface type.

### Physical Health

#### Mid-Term Impacts (5-8 Years After 9/11)

A previous study of 12,000 firefighters and EMS workers enrolled in the **FDNY WTC Medical Monitoring and Treatment Program**, whose lung function had been tested prior to 9/11, documented steep and often occupationally disabling declines in lung function among these workers in the first year after 9/11.<sup>1</sup> A new longitudinal study, which includes a thousand additional workers, shows that these declines have largely persisted over time. Among firefighters who never smoked, the percentage with below-normal lung function increased from 3% before 9/11 to nearly 19% at one year after 9/11, and stabilized at 13% six years later. For nonsmoking EMS workers, 12% had below-normal lung function before 9/11, increasing to about 22% at one year and remaining at that level for the subsequent 6 years. Smokers averaged slightly but significantly more severe declines in lung function than did nonsmokers, but WTC exposure remained the predominant effect.<sup>2</sup>

Another **FDNY** study examined lung function in 1,720 firefighters with respiratory symptoms who had been referred for subspecialty evaluation during the seven years following 9/11. The predominant lung injury seen was chronic airways disease; few fighters had interstitial fibrosis. Both types of disease can be mild or severe, and can have varying response to treatment, although airways disease tends to respond much better than does interstitial fibrosis.<sup>3</sup>

Both of the above FDNY studies demonstrated that while the initial intensity of WTC exposure largely determined the degree of acute inflammation and early reductions in lung function, exposure did not predict long-term lung function. These findings suggest complex environmental and genetic interactions that remain to be determined played important roles in lung function changes over time.<sup>2,3</sup>

Between 2002 and 2006, the **New York State Department of Health** (NYSDOH) made multiple comparisons of respiratory health between more than 400 moderately-exposed state responders and a control group of unexposed state employees who worked in similar job titles. The study, which employed a unique WTC exposure tool developed by NYSDOH, found that in comparison to the control group even moderately exposed responders were at higher risk for reporting persistent lower respiratory symptoms (including cough, wheeze, shortness of breath and chest tightness) but not a diagnosis of asthma five years after 9/11. However, the exposed responders with prior histories of asthma and those who were most highly exposed to the dust and smoke were more likely to report greater severity of asthma symptoms than the control group.<sup>4</sup>

More than 2,000 New York City Police Department (NYPD) officers, the majority of whom were under age 60, underwent diagnostic testing to detect the presence of coronary artery calcium (CAC), which correlates with heart disease and is predictive of future heart attacks.



Researchers found that based on CAC scores, the prevalence of premature heart disease was no higher among NYPD officers—including a subset of 75 who were early WTC responders on 9/11—than among the general population.<sup>5</sup>

Two studies investigated obstructive sleep apnea (OSA), a chronic condition in which breathing stops and starts repeatedly during sleep, among WTC rescue, recovery and clean-up workers. In the general population, OSA is associated with male gender, aging and weight gain.

- Based on an analysis of questionnaires answered at least once by 12,000 firefighters and EMS workers from 2005 to 2008, **FDNY** found that more than 36% were at high risk for OSA. An analysis looking only at those firefighters and EMS workers who developed new risk for OSA after 9/11 suggested that earlier arrival time at the WTC site, acid reflux symptoms, upper respiratory symptoms and PTSD symptoms were among the predictors for increased new OSA risk among these workers.<sup>6</sup>
- The **New York/New Jersey WTC Medical Monitoring and Treatment Program Consortium** examined 100 workers who had complained of snoring and had been diagnosed and treated for respiratory disease, acid reflux symptoms or a mental health condition from 2003 to 2006. Sixty-two percent of these workers were diagnosed with obstructive sleep apnea but no associations were found with these conditions or with WTC occupational exposures.<sup>7</sup>

Two small studies conducted at different times compared the sense of smell among WTC rescue and recovery workers and volunteers who sought care at the **New York/New Jersey WTC Medical Monitoring and Treatment Program Consortium** to control groups whose age, gender and smoking status closely matched the WTC workers and which included individuals who worked in similar occupations. They found that:

- WTC workers, especially those who had been exposed to the dust cloud on 9/11, were not able to detect nasal irritation or odors as well as the control group more than two years later.<sup>8</sup>
- WTC workers could not identify odors as well as the control group seven years later, although this impairment was not related to the severity of their upper respiratory illness, which the researchers also assessed.<sup>9</sup>

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

Researchers compared hospital admission data before and after 9/11 in Lower Manhattan to a demographically similar area in Queens. Their analysis, which took into account seasonal and socioeconomic differences, indicates that admissions due to respiratory illness (mainly asthma) increased significantly among residents of Lower Manhattan in the first week after 9/11. It also indicates that admissions for cardiovascular and cerebrovascular diseases increased 2–3 weeks after 9/11, especially among women and the elderly. This is one of the few WTC studies to use hospital admission data, an objective indicator of serious illness.<sup>10</sup>

A longitudinal follow-up of Lower Manhattan residents who were exposed to the WTC disaster and first studied one year later suggests that while self-reported lower respiratory symptoms such as cough and wheeze declined by nearly 8% four years after 9/11, the prevalence of these symptoms among exposed residents in 2005 remained elevated in comparison to a control group of non-exposed NYC residents. Exposed residents who



also worked in Lower Manhattan were at highest risk for persistent symptoms. The sample for this study was small.<sup>11</sup>

Some research suggests that some populations may be more at risk because of underlying conditions. A study at the **New York/New Jersey WTC Medical Monitoring and Treatment Program Consortium** tested 136 workers who had been diagnosed with WTC-related respiratory disease for atopy, or the presence of allergies, from 2003 to 2005. The study indicates that atopic workers may have been at higher risk for upper airway disease such as sinus or nasal congestion than non-atopic workers, and that they experienced greater upper and lower airway disease symptom severity. The prevalence of atopy among this sample (54%) was similar to that found in the general population.<sup>12</sup>

Two population-based studies about the impact of the 2001 terrorist attacks on birth outcomes differ in their conclusions:

- Using a national database of birth and fetal death records from 1996 to 2002, and controlling for seasonality and other factors, researchers demonstrated that fewer male babies were born in the months after 9/11 because male fetuses were more likely to miscarry during this period. Because other studies have indicated that male fetuses are more susceptible to stress, the researchers attribute this decrease to the communal trauma experienced by pregnant women.<sup>13</sup>
- Another study examined U.S. Department of Defense birth records for more than 160,000 infants born to active-duty military families. The authors compared the cohort of infants whose mothers were exposed to the stress of 9/11 during pregnancy with comparable cohorts in 2000 and 2001. The findings suggest that among infants born to women who were pregnant during 9/11, there was no change in the ratio of male to female births or increased risk of adverse infant health outcomes, including birth defects, pre-term birth and growth deficiencies in utero and in infancy.<sup>14</sup>

## Mental Health

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

Two analyses of New York City death records that compared suicide rates before and after 9/11 concluded that suicide rates did not increase in the first four years after the terrorist attacks.<sup>15,16</sup> One of the studies, which also examined suicide rates before and after the 1995 Oklahoma City bombing, concluded that neither event affected suicide rates at the local, state or national levels.<sup>16</sup> Another study, based on national mortality data, showed that suicide rates in New York City declined significantly in the first six months after 9/11.<sup>17</sup>

Although a **WTC Health Registry** study found that police responders were likely to have the lowest overall rates of PTSD among WTC responders two-to-three years after 9/11, a new analysis of more than 4,000 police during the same period suggests that there were vulnerable populations among police, and that female police, especially those who witnessed horrific events or who didn't have a college degree, had a rate of PTSD nearly twice as high as that for male police (14% vs 7%). Older age and 9/11-related injury increased the risk of PTSD among both male and female police.<sup>18,19</sup>

A representative sample of 2,300 New York City adults was interviewed six months after 9/11 and at least once again before November 2005 to assess symptoms of depression. It found that increased and persistent symptoms of depression were associated with lower household income and exposure to ongoing stress and trauma.<sup>20</sup>



A study that sampled 1,000 low-income patients at a primary care clinic in New York City 7–16 months after 9/11 found that:

- Patients who knew someone killed in the WTC attack (9/11-related loss) were twice as likely to screen positive for at least one mental disorder, including depression, anxiety and PTSD, as those who did not.<sup>21</sup>
- 9/11-related loss was associated with an increased level of pain that interfered with daily activities, contributing to functional impairment and work loss.<sup>21</sup>
- Having a loved one in danger or knowing someone involved in WTC rescue also doubled the risk of an anxiety disorder, even after controlling for common co-occurring disorders.<sup>22</sup>

Researchers conducting a longitudinal evaluation of a school-based violence prevention program also examined the mental health impacts of 9/11 on more than 400 New York City adolescents and their mothers from predominantly low-income families who had been recruited for the study. Most reported one or more forms of direct exposure to the attacks. Although researchers found an association between WTC exposure and depression among adolescents, and between WTC exposure and PTSD among mothers 15 months after the terrorist attacks, they identified few enduring associations of 9/11 exposure with the mental health of either group.<sup>23</sup>

### Children

A study that tested the lung function of 200 elementary school children and surveyed their parents in Lower Manhattan's Chinatown suggests that exposure to the WTC disaster may have increased the susceptibility of these children to respiratory illness eight years after 9/11.<sup>24</sup>

Researchers analyzed cord blood specimens of 210 infants whose mothers had been pregnant on 9/11 and delivered in Lower Manhattan hospitals for polybrominated diphenyl ethers (PBDEs), chemicals used in flame retardants. Children whose blood had higher levels of these chemicals scored lower on tests of mental and physical development at 12, 48 and 72 months of age than children with lower levels. Because this study did not find a significant relationship between the level of chemicals and how closely the mothers resided to the World Trade Center, the causal relationship between WTC exposure and the increased blood levels of these chemicals remains unclear. However, this prospective study measures the biologic marker of an environmental contaminant, which has been done rarely in the WTC-related literature.<sup>25</sup>

### Environmental Exposures

The **New York State Department of Health** categorized the stored blood samples of 43 WTC responders as more dust exposed; less dust exposed; more smoke exposed; and less smoke exposed, according to a unique exposure tool. When they analyzed the blood for chemicals that are released into the environment when solid municipal waste is burned, they found that the concentrations were higher in the exposed groups and much higher than those reported for the general population.<sup>26</sup>



# 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:

- Nearly all **FDNY** responders who responded to the disaster. All have pre- and post-9/11 medical records, and the population is restricted to FDNY rescue workers, thus minimizing recruitment bias. The group receives ongoing clinical monitoring with strong participation, indicating limited bias from longitudinal dropout.
- A large cohort of responders enrolled in the **New York/New Jersey WTC Medical Monitoring and Treatment Program Consortium** at the Mount Sinai School of Medicine, 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 for clinical screening, monitoring and treatment. This Consortium collects similar data to FDNY to facilitate comparisons across worker groups.
- A high percentage of **NYPD** members were exposed to the disaster at various locations. The NYPD Medical Division, like FDNY, has pre- and post 9/11 medical records for these individuals. The pre-9/11 exposure of this cohort is similar to that of New York City residents, which makes study findings relevant to the larger population.
- 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 US history, enrolling more than 71,000 exposed individuals to be tracked for an expected period of 20 years. The diverse cohort includes rescue, recovery and clean-up workers; residents; office workers; students; and passers-by.

Several significant challenges also affect the ability to conduct accurate research on 9/11 health effects. It is important to highlight these limitations as they characterize many but not all of the published studies described in this report, and to review these limitations when planning data collection efforts after future disasters:

- With the exception of the FDNY cohort, 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 suffer from recruitment bias with overrepresentation of those who are ill.



# Strengths and Limitations of Published WTC-Related Research

- People with PTSD may be underrepresented 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 for diagnosing a condition. Many studies rely on self-reports of symptoms and conditions to measure the burden of these conditions in exposed populations without verification of diagnoses.
- The high frequency of conditions such as asthma and acid reflux 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 at a clinical level.
- Increased monitoring and diagnostic testing of WTC-exposed populations in comparison to the general public may result in a detection bias for some conditions, such as sarcoidosis.
- Few studies have examined the effects of WTC exposure on children and adolescents.

(April 2009 – March 2010)

## New York City WTC Patient Population Report

WTC Center of Excellence	Individuals Enrolled	Individuals Examined Initially	Individuals Monitored in the Past Year	Individuals Treated in the Past Year
FDNY	15,721	15,307	9,934	4,993
NY/NJ Consortium	32,892	27,682	12,071	7,578
WTC EHC	4,583	4,583	1,208 <sup>a</sup>	2,629
<b>Total NYC Area</b>	<b>53,196</b>	<b>47,572</b>	<b>23,213</b>	<b>15,200</b>

<sup>a</sup> Number of individuals monitored is fewer than the number of individuals treated because it includes only patients who entered the program for the first time or who had a follow-up monitoring exam during this period.

Source: NIOSH website @ <http://www.cdc.gov/niosh/topics/wtc/participants.html>, accessed 8/20/10.

### WTC Centers of Excellence

The New York City area is home to three **WTC Centers of Excellence**. Each of these programs currently monitors eligible individuals for 9/11-related physical and mental health conditions, and offers specialized, integrated care, including medications, with no out-of-pocket costs.

People who participated in WTC rescue, recovery and clean-up operations are eligible for care at one of two centers: the **FDNY WTC Medical Monitoring and Treatment Program** for firefighters and emergency service workers with multiple service locations; and the **New York/New Jersey WTC Medical Monitoring and Treatment Program Consortium**



at the Mount Sinai School of Medicine, 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, for other rescue, recovery and clean-up workers, and volunteers.

Survivors of the WTC collapse—including both adults and children who lived, worked or went to school in the vicinity of the World Trade Center—are eligible for treatment at the **WTC Environmental Health Center** at Bellevue Hospital Center, Gouverneur Health Care Services and Elmhurst Hospital Center. In contrast to the other Centers, this Center does not monitor individuals without physical or mental symptoms, but provides interdisciplinary treatment for individuals with symptoms related to WTC exposure.

All three WTC Centers of Excellence are supported with federal funds appropriated by Congress and awarded through grants by the National Institute for Occupational Safety and Health. Current grant funding for all three Centers ends in 2011.

## NYPD

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 annual monitoring, a full array of treatment options and prescription drugs for all its exposed uniformed members.

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

In the spring of 2008, the New York City Department of Health and Mental Hygiene temporarily extended a privately funded, insurance-like benefit program created by the American Red Cross in 2002. The program, conceived before all three WTC Centers of Excellence were providing specialized and integrated care for both physical and mental health conditions, ensured that individuals and families affected by 9/11 would continue to have access to affordable behavioral health care and substance use services.

In June 2010, the NYC Department of Health and Mental Hygiene sent letters to more than 4,500 people who enrolled in the **NYC 9/11 Benefit Program for Mental Health and Substance Use Services** reminding them of the program’s expiration date in January 2011. Enrollees were encouraged to seek care at the WTC Centers of Excellence if they could not afford to continue care on their own.

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# 2010 Recommendations

The WTC Medical Working Group has made a series of recommendations about 9/11 health treatment and services since its formation in 2007. These recommendations fall into three broad categories: funding; research and evaluation; and education. They can be accessed in full at [www.nyc.gov/html/doh/wtc/html/studies/medgroup.shtml](http://www.nyc.gov/html/doh/wtc/html/studies/medgroup.shtml), along with a report of the progress that has been made on their implementation to date by the City of New York, the WTC Centers of Excellence and other stakeholders. The WTC Medical Working Group remains committed to seeing these recommendations implemented in their entirety.

## New Recommendations: Research and Evaluation

In 2010, nationally recognized biostatisticians, environmental health scientists and cancer epidemiologists made the recommendations below concerning the analytic methods that researchers should consider when analyzing the number of post-9/11 cancer diagnoses that have been confirmed among the various WTC cohorts (*see page 2*). The WTC Centers of Excellence and the WTC Health Registry accepted these recommendations with the understanding that they were not intended to discourage researchers from conducting additional cancer analyses within each of their cohorts. The WTC Centers of Excellence and the WTC Health Registry also cautioned that implementing some of these recommendations will require additional funding.

In turn, these recommendations now have been endorsed by the WTC Medical Working Group with the same understanding:

- 1) Researchers should compare the number of cancer diagnoses among members of their cohorts who were highly exposed to the WTC disaster to the number of diagnoses among less exposed members when possible. Use of internal comparisons is expected to be more meaningful scientifically than external comparisons to other groups because of the difficulty in identifying comparable, non-exposed populations.
- 2) Researchers within the different WTC Centers of Excellence and WTC Health Registry should develop a common WTC exposure matrix where possible, so that the degree of exposure within and across cohorts can be categorized more consistently when analyzing cancer and other late emerging illnesses.
- 3) Researchers should schedule the timing of periodic cancer analyses in advance to ensure that this choice is independent of the results. Researchers also should consider conducting formal analyses no more frequently than every five years because of the length of the induction period between environmental exposures such as the WTC disaster and the development of cancer. However, during the interim, monitoring and tracking of the data can continue so that researchers can detect and share developments of interest.
- 4) Researchers should consider using other New York City data sets (including birth and school records) in addition to the WTC Health Registry in order to conduct cancer analyses of sufficient statistical power among pediatric populations exposed to the WTC disaster.
- 5) Researchers at the WTC Centers of Excellence and the WTC Health Registry should consult with each other on an ongoing basis about the cancer analyses within their cohorts and coordinate the reporting of data and/or research. This kind of collaboration can help reduce confusion among the public when the results of these analyses are published and reported by the media.



## 2010 Recommendations

In making these recommendations, the experts commended the WTC Centers of Excellence and WTC Health Registry for involving labor and community representatives in their cancer analyses, and encouraged continued collaboration in the future.

In July 2010, the WTC Centers of Excellence and the WTC Health Registry formed a WTC Analytic Methods Workgroup, including labor and community advisers, to begin work on Recommendation #2.

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