The New York City Council Committee on Lower Manhattan Redevelopment Jointly with the Committee on Civil Service and Labor and the Committee on Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services

Oversight Hearing on
Examining the World Trade Center Medical Working Group's
2011 Annual Report on 9/11 Health

Testimony by
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Monday, January 30, 2012, 10:00 AM 250 Broadway, Committee Room, 14th Fl., New York, NY

Good morning. Thank you Chairpersons Chin, Koppell and Sanders for holding this very important hearing on 9/11 Health. I am Catherine McVay Hughes, Vice Chairperson of Manhattan Community Board 1 (CB1) and Chair of the CB1 WTC Redevelopment Committee. Thank you for the opportunity to testify today.

We continue to appreciate the important work done by the 9/11 Medical Working Group that is Chaired by Deputy Mayor Gibbs and Health Commissioner Farley, and includes representation from the WTC Centers of Excellences, the Fire Department of New York (FDNY), NYC Health and Hospitals Corporation, Mount Sinai, the 9/11 Health Registry, as well as other 9/11 health experts. This forth report issued to date summarizes a decade of research, including more than 300 studies, and monitors studies and emerging evidence about health impacts from 9/11. Last month at our WTC Redevelopment Committee, CB1 received a detailed summary about the 2011 Report from Jeffrey Hon, World Trade Center Health Coordinator of the New York City Department of Health and Mental Hygiene.

We are concerned about some of the findings in the report, including the persistence of post-traumatic stress disorder (PTSD), respiratory illness and numerous other conditions among the responder and survivor communities. As the Community Board representing the area surrounding the World Trade Center, we are troubled that children are understudied and that many exposed adults are being treated for persistent multiple conditions. In addition, many Lower Manhattan residents, area workers and passersby with high or moderate exposure had increased risk for all-cause mortality, and cardiac-specific mortality in comparison to those with lower exposure (and no exposure-related differences found among rescue and recovery workers). It will be important for the Medical Working Group to continue to monitor these trends through

the WTC Centers of Excellence and the 9/11 Health Registry and other means, given the evidence linking WTC exposure to such a wide range of conditions including sarcoidosis, gastroesophageal reflux symptoms (GERS), depression, anxiety and substance abuse.

In light of these ongoing indications about significant health impacts in the survivor population, we believe there is a clear need for additional medical studies of the survivor population, and children in particular, who have been studied much less than responders. The James Zadroga 9/11 Health and Compensation Act of 2010 includes funding for this population, and we passed unanimously at our meeting on Tuesday, January 24 a resolution in support of proposals submitted by the WTC Health Program at the World Trade Center Environmental Health Center of Excellence (WTC EHC) at NYC Health and Hospitals Corporation for funding of four studies of the survivor population, including the following:

- 1. **Pediatric** An in-depth evaluation of pediatric effects of exposure, including pulmonary, mental health, developmental and endocrine effects during this vulnerable growth period which has thus far been unstudied.
- 2. **Blood Bank** –Ability to save blood for DNA, RNA and protein analyses so that they can be used by multiple investigators in future studies of susceptibility to diseases including lung and other cancers.
- 3. **Disease Mechanisms -** Studies to understand mechanisms producing symptoms reported by patients in the WTC Health Program.
- 4. **Data Center Analytic Funding -** The Data Centers need additional funding for center-specific analyses on questions such as latency of symptom onset and a case series of cancers in programs with continued cohort recruitment.

When the James Zadroga 9/11 Health and Compensation Act of 2010 (Act) was implemented in 2011, cancer was not included in the list of "WTC-Related Health Conditions" covered under the diseases, although as early as 2009 the first peer-review medical journal study on cancer reported, "... we observed 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..." ¹ Multiple myeloma is when "plasma cells [which normally would help your body fight infection by producing proteins called antibodies] grow out of control in the bone marrow and form tumors in the areas of solid bone. The growth of these bone tumors makes it harder for the bone marrow to make healthy blood cells and platelets." ²

In July 2011, the "First Periodic Review of Scientific and Medical Evidence Related to Cancer for the World Trade Center Health Program" was released by the National Institute for Occupational Safety and Health (NIOSH) of the Centers for Disease Control and Prevention (CDC) finding that "insufficient evidence existed at this time to propose a rule to add cancer, or a certain type of cancer, to the List of WTC Related Health Conditions." However,

¹ Moline, Jacqueline, M., MD, MSc, "Multiple Myeloma in World Trade Center Responders: A Case Series," Journal of Occupational and Environmental Medicine., 2009; 51:896-902

² http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001609/

³ http://www.cdc.gov/niosh/topics/wtc/prc/prc-1.html

"...it is important to point out that the current absence of published scientific and medical findings demonstrating a causal association between the exposures resulting from the September 11, 2001, terrorist attacks and the occurrence of cancer in responders and survivors does not indicate evidence of the absence of a causal association..."

According to NIOSH's 2011 cancer report, "287 chemicals and chemical groups were identified by environmental sampling of the area around the WTC in NYC after 9/11..." Categories of these chemicals include asbestos and glass fibers, crystalline silica, various metals, volatile organic compounds, polychlorinated polycyclic compounds, and polycyclic aromatic hydrocarbons. Some of the chemicals identified through environmental sampling are known to be human carcinogens or are reasonably anticipated to be human carcinogens ... have been associated ... with a number of different types of cancers, such as **lung cancer including** mesothelioma; skin cancer; bladder cancer; hematopoietic cancers; testicular cancer; prostate cancer; and liver and biliary cancer." 5

The November 2011 FDNY presentation based on published medical articles states, "WTC exposure is a known cause of acute and chronic inflammatory illnesses (asthma, COPD, sinusitis, and GERD). Chronic inflammation in turn has been associated with various cancers (non-Hodgkin's lymphoma, prostate, thyroid, melanoma)."

Since cancer is not a covered WTC illness, victims may not report information about cancer or participate in WTC monitoring and treatment programs that do not treat the disease and . . . in addition, the most recent data on the New York State Department of Health (NYSDOH) Cancer Registry website is from 2008-- so there is a several year time lag between disease diagnoses, data collection and release.

As a result, at our meeting on Tuesday, January 24, we also unanimously passed a resolution urging members of the WTC Health Program Scientific Technical Advisory Committee (which was established to review scientific and medical evidence and make recommendations to the WTC Program Administrator -- to strongly consider the emerging medical evidence of cancer among 9/11 responders and survivors and the scientific evidence for a biologically plausible link between cancers and WTC exposure and the experiences of those who responded so selflessly on September 11, 2011 and during the enormous, hazardous clean-up and rebuilding of the WTC. This request was also made on September 7, 2011, by the New York Congressional delegation including our two U.S. Senators and Rep. Nadler who represents our district, when they petitioned Dr. John Howard, NIOSH Director and Administrator of the WTC Health Program, for "... an immediate review of new medical evidence showing increased cancer rates among firefighters who served at ground zero."

I would also like to add a quick update on the impact of The James Zadroga 9/11 Health and Compensation Act of 2010 which was implemented this past year. Due to their different NIOSH

⁴ http://www.cdc.gov/niosh/topics/wtc/prc/prc-1.html; p. 40

⁵ http://www.cdc.gov/niosh/topics/wtc/prc/prc-1.html; p. 39

⁶ Prezant, David, "FDNY: World Trade Center Health Studies," presentation November 9, 2011. http://www.cdc.gov/NIOSH/topics/wtc/stac/meetings/Nov2011.html

grant end dates, the programs for responders and survivors were implemented on different dates, July 1, 2011 and September 29, 2011 respectively. The survivor program had a deadline of contract deliverables on December 31, 2011. The survivors programs at NYC Health and Hospitals Corporation include three clinical sites where care is available, including Bellevue, the first and largest site, and also Gouverneur and Elmhurst.

We understand that it was a challenge to implement brand new bill in such a short space of time. However, since NIOSH started taking a more individual approach with the Centers, it has made it possible to begin to resolve administrative and clinical issues and achieve the best level of care possible. There has been a doubling from about 40-50 new patients per month to 80. Contrary to what people may believe, the survivor population is hard to reach and diverse socially, economically and linguistically and more importantly, psychologically, because some people are in denial. Therefore, anecdotally, although the new patients have the same reported illnesses, their illnesses are more severe, perhaps because they did not seek prior medical care or their other doctors did not have a sufficient background in WTC-related conditions.

For the past eight years, CB1 has continually and vigorously supported health services for residents, children and workers exposed after 9/11. We are grateful to the advocates and allies who have worked tirelessly to address the physical and mental health concerns of all those who were affected by the 9/11 attacks, and we hope this testimony encourages you all to further support and expand these very important studies and services. Thank you for the opportunity to testify today.