



The City of New York

Manhattan Community Board 1

Julie Menin CHAIRPERSON | **Noah Pfefferblit** DISTRICT MANAGER

**National Institute for Occupational Safety and Health
Public Meeting on
Implementing the Provisions of the
James Zadroga 9/11 Health and Compensation Act of 2010**

**Testimony by Catherine McVay Hughes, Vice Chairperson
Manhattan Community Board 1**

Thursday, March 3, 2011 at 9:00am

Jacob K. Javits Federal Building, 26 Federal Plaza, 6th Floor Conference Room A/B

Good morning. I am Catherine McVay Hughes, the Vice Chairperson of Community Board 1. On behalf of Community Board 1, I would like to thank Representatives Carolyn B. Maloney, Jerrold Nadler and Peter T. King, the primary sponsors of the James Zadroga 9/11 Health and Compensation Act of 2010 (Public Law 111-347) in the U.S. House of Representatives, for requesting that the National Institute for Occupational Safety and Health (NIOSH) host today's public meeting to receive comments on implementing the provisions of the Act. In addition, we would like to thank NIOSH for its prior support of the 9/11 health issues for both the responder and survivor communities, and for being here today.

The World Trade Center (WTC) lies at the heart of Manhattan Community Board 1 (CB1) – and many of us who were here when the towers were attacked are still living and working here. Some of us volunteered as first responders and many of us continued to work or attend school downtown in the aftermath of the September 11, 2001 terrorist attacks.

CB1 has strongly supported the James Zadroga 9/11 Health and Compensation Act for many years, and we were very glad when the bill finally passed at the very end of the federal legislative session at the end of 2010. Today we would like to raise some concerns about how the bill will be implemented, including the WTC Medical Program Administrator who will be appointed, and other issues regarding medical monitoring and treatment for survivors, education and outreach, clinical data collection and analysis, research on health conditions, and expansion of the diseases and conditions covered.

Under the 9/11 Health & Compensation Act, a WTC Medical Program Administrator will be appointed to run the WTC Health program to be established within the Department of Health and Human services beginning July 1, 2011. I believe that the appointment of Dr. John Howard would ensure continuity of leadership in the implementation of the legislation. Dr. Howard is currently the Director of NIOSH and Coordinator of the World Trade Center Health Programs (appointed in 2006 as the first federal WTC Health Coordinator), and over the years, Dr. Howard has met with and carefully listened to the concerns of diverse coalition members of the survivor community.

In the short term, an important part of the medical monitoring and treatment of survivors is the continuity of funding for the WTC Environmental Health Centers (EHC) while the legislation is being implemented. Continuity is important to the wellbeing of the patients and the need to retain specially trained, dedicated doctors and staff, especially funding for the pediatric program including keeping a pediatrician, pulmonologist, child psychologist, and development doctor. It is important to continue the healthy dialogue that the WTC EHC Community Advisory Committee (CAC) has had with NIOSH for several years.

The education and outreach component of the WTC EHC for the survivor community will be a critical component of the delivery of health care for the next five years. Although the legislation does not go into effect until July 1, 2011, money spent on outreach would be much more effective if some funding were available prior to the upcoming ten year anniversary of the terrorist attacks. Only now are some members of the survivor community beginning to understand the correlation between their exposure to WTC contamination and its health impacts.

Community-based education and outreach is the key to success, especially to a diverse community that is somewhat cynical after all that it has been through during the past 9 ½ years. We request that there be a special emphasis on outreach to children that have become adolescents or young adults. On September 11, 2001, about 25,000 children were living or attending school in Lower Manhattan in close proximity to the WTC, but they comprise only a very small portion of the WTC Health Registry (HR). Besides the WTC HR baseline survey findings, there has been not as much research as we would like about the impact of 9/11 on children, a particularly vulnerable population.

The limited studies that have been performed, such as those cited by the NYC World Trade Center Medical Working Group 2010 Annual Report on 9/11 Health, suggest that elementary school children could be more at risk of respiratory illnesses. We are also concerned about conditions that may affect survivors more because of gender, and we are worried that both gender and age may not be adequately represented in the responder population that has been studied. Therefore, we urge that the Science Advisory Committee take steps to address the unique needs of children, adolescents, and women.

To date, most studies have focused on first responders and not others who continued to live and work downtown in the aftermath of the September 11, 2001 attacks. There is no monitoring program for survivors, and the enrollment in the WTC Health Registry was voluntary for people who lived, worked, or went to school in the area of the WTC disaster. Therefore, any disease that is included for responders should be included for survivors as well.

How the data collection and analysis portion of the survivor program will be implemented is important. The WTC EHC based at the Health and Hospitals Corporation's Bellevue Medical Center has had diverse community input from the beginning. In order to ensure continuity of data collection and analysis, the WTC EHCs should continue to oversee survivor programs at all satellite locations. This way the information collected will be uniform and can be analyzed by a staff which has years of scientific expertise and insight.

The diseases and conditions covered in the recent legislation need to be expanded. At this time, the 9/11 Health & Compensation Act does not include cancer in its list of "WTC-Related Health

Conditions Defined” diseases. The addition of cancer to the list of approved diseases needs to be expedited, especially those cancers that are most strongly correlated to environmental exposure through the inhalation, ingestion, and other exposure to carcinogens. We are concerned with the long lag between disease diagnoses, data collection, research, and approval. For example, the most recent data on the New York State Department of Health (NYSDOH) Cancer Registry website is from 2007. A three year delay in information relating to cancer is not acceptable since such a gap in medical knowledge could be the difference between life and death.

It is clear that there is a lot of work ahead. We look forward to continue working with NIOSH and Dr. John Howard. Thank you.