



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
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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

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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 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 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). 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.