World Trade Center Health Program

Survivors Steering Committee

c/o Robert Spencer
Director of Media Services
Organization of Staff Analysts
220 East 23rd Street, Suite 707
New York, NY 10010

Steering Committee Members

105 Duane Street Residents
125 Cedar Street Residents
9/11 Environmental Action
Beyond Ground Zero Network
Civil Service Employees Association
Communication Workers of America, District 1
Concerned Stuyvesant Community
District Council 37, AFSCME
Ecuadorian International Center, Inc.
Good Old Lower East Side (GOLES)
Henry Street Settlement
Independence Plaza North Tenants' Association
Manhattan Community Board 1
Manhattan Community Board 2
Manhattan Community Board 3
New York City
New York City Health & Hospitals Corporation WTC Environmental Health Ctr
New York Committee for Occupational Safety and Health
New York From the Ground Up
New York State Laborers' Union
New York State Public Employees Federation
The Organization of Staff Analysts
Rebuild.Downtown.Our.Town
Rebuild with a Spotlight on the Poor
Southbridge Parent and Youth Association
StuyHealth
United Jewish Council of the East Side
University Settlement
WTC Community Labor Coalition
World Trade Center Residents Coalition

February 10, 2014

Paul J. Middendorf, PhD, CIH
Senior Scientist,
CDC/NIOSH/OD/ADSO
2400 Century Parkway NE
4501.03
Atlanta, GA 30345

Dear Dr. Middendorf:

On behalf of the World Trade Center Health Program Survivors Steering Committee (SSC), I am writing to provide comments about NIOSH's World Trade Center Health Program research approach and priorities that emerged from discussions of the Survivor Steering Committee. Members of the committee hope that these can help inform the deliberations of the WTC Scientific and Technical Advisory Committee (STAC) at its February 14, 2014 meeting.

As you know, the SSC was created to play an advisory role on the administration of the Survivor Program and to represent and provide input from WTC survivor stakeholders. The comments below include input from both survivor representatives and WTC Environmental Health Center clinicians..

A few recommendations regarding NIOSH's research approach:

First, there are a wide range of knowledge gaps with respect to the science, biology and treatment of WTC-related illnesses. Therefore, NIOSH should approach closing these gaps by supporting a diverse portfolio of studies at different levels of funding, including pilot studies, clinical trials, studies of disease mechanisms, and epidemiological studies. It is especially important that the STAC recognize that input from the WTC Centers of Excellence is critical to developing the WTCHP's research agenda, since clinicians likely have the best sense of which conditions may be emerging, as well as crucial perspectives on resolving diagnostic and treatment uncertainty.

Second, NIOSH should solicit and fund proposals that address survivor as well as responder health effects. Studies of the survivor population should address health effects on those living, working or attending school in Lower Manhattan and western Brooklyn and should represent the diverse populations and geographic areas affected.

Third, NIOSH should recognize that World Trade Center research is "disaster science." An understanding that 9/11-related health impacts were the result of a disaster should inform RFPs and the proposal review process. Especially with respect to populations in the survivor community, researchers and clinicians are operating in the absence of pre-existing baseline data or a comprehensive set of environmental measurements from which to assess exposures. These limitations should not become an insurmountable barrier to conducting the research required to meet the 9/11-related health needs of survivors.

Fourth, NIOSH should encourage researchers who will commit to engaging in collaboration with affected communities using a Community Based Participatory Research (CBPR) model for all phases of their studies. According to the Harvard Clinical Translational & Science Center, CBPR is an emerging approach to scientific inquiry that equitably includes community members in all aspects of research including the conception, design, analysis and dissemination of the research." The benefits of the CBPR model are well established. In our experience, an extremely productive dialogue can emerge where a sharing of perspectives, information and expertise has the effect of strengthening the quality of the research. Information about CBPR can be found at catalyst.harvard.edu/programs/communityengagement/cbpr.html.

Fifth, NIOSH must strengthen the critical surveillance function of the WTC Health Program's Data Centers to gather and analyze data in a timely fashion. Otherwise, there is little chance that important trends, including the emergence of new conditions, will be recognized..

Sixth, NIOSH should ensure that all research proposals receive proper peer review by including specialists with appropriate expertise.

Going forward, the SSC has a number of recommendations regarding WTCH P research priorities for the survivor population.

1. Given children's increased susceptibility to harm, especially in critical periods of development, it is imperative that NIOSH support research into 9/11 physical and mental health impacts to those who were exposed to the disaster as children. Especially important are in-depth studies of respiratory, developmental and endocrine health impacts for this rapidly dispersing cohort.

2. Longitudinal clinical research into the long term physical and mental health impacts of 9/11 on those who were children at the time of the disaster., as well as long term studies that explore the progression of disease and the effect of treatment In the survivor population.

3. Because of the known difficulties of performing epidemiologic studies on small populations with ongoing recruitment, we would like to suggest that alternate approaches to studying cancer in diverse populations be explored. These populations include: children at the time of 9/11, local workers, residents, clean-up workers, and other non-responders. Possible approaches include nested studies, as well as a case series approach to understand the possible role of exposures, differences in presentation, the effects of co-morbid conditions or additional risks..

4. We recommend that blood samples be collected from WTC-exposed survivors, including children at the time of 9/11. Samples should be banked for later analysis -- including the freezing of live cells from which DNA, RNA and proteins can be recovered. We anticipate that
these samples will prove useful in at least three ways:

-- As a potential source of long-lived biomarkers of exposure to WTC toxics, useful in analyzing exposure-related health conditions in this population.

-- As a source of protein markers of disease, with potential use in diagnosing and understanding WTC-related disease.

--As a source of genetic material which can be analyzed for evidence of enduring genetic and epigenetic alterations relevant to disease that may still be detected many years after exposure.
Strong protocols to protect privacy, including anonymization of all data, must be developed in consultation with the SSC.

5. Because so little is known with respect to inflammation and other underlying mechanisms for WTC illnesses, such as sarcoidosis, cancer and even asthma, it is critical that NIOSH support studies of underlying disease mechanisms. This would include both physical and mental health disorders, with potential final common pathways.

6. NIOSH should support studies of co-morbidity of mental and physical health impacts.An important research focus would be the evolving clinical understanding of treating respiratory and
anxiety conditions simultaneously,

There are few treatment algorithms that explicitly address coordination of anxiety and respiratory symptoms, particularly in a post-disaster setting. This would be more of a systems/treatment-services study to identify or develop a collaborative care model that demonstrates efficacy (with regard to symptom reduction, improved functioning/quality of life) and efficiency (with regard to overall program costs).

7. Studies that seek to characterize cognitive issues such as memory, learning and attention problems, experienced by affected survivors and responders should be undertaken.

8. The SSC believes that it is essential that NIOSH support research into the physical and mental health impacts to people exposed between Houston and 14th streets. This population had been eligible for treatment at the WTC EHC prior to passage of the Zadroga Act. Clinicians observed the same physical and mental health conditions in those who lived, worked or attended school in this geographic area as in those in the current Zadroga catchment.

9. Studies that look at the effects of exposures to other disasters -- such as Hurricane Sandy --after individuals were exposed on 9/11. There is solid evidence that prior trauma is a risk factor for more morbidity upon re-traumatization.

We appreciate the opportunity to offer input and ask that you please provide the SSC's recommendations to the STAC prior to its February 14th meeting. The SSC thanks you for your consideration.

Sincerely,

Robert Spencer

Robert Spencer
Member & Former Labor Co-Chair
robspencer@osaunion.org
212-686-1229