

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

From: Rob Spencer <robspencer@osaunion.org>
Sent: Wednesday, February 08, 2012 8:15 PM
To: NIOSH Docket Office (CDC)
Cc: Kimberly Flynn
Subject: NIOSH Docket 248 - Public Comments on WTC HP Research Priorities
Attachments: Ltr_to_Dr_Howard_Re_STAC_Research_Priorities_Feb_8.pdf

Attached please find comments from the WTC HP Survivor Steering Committee in PDF format.

Regards,

**Kimberly Flynn and Robert Spencer
Co-Chairs**



Monitoring and Treatment

c/o Robert Spencer
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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

World Trade Center Health Program Survivors Steering Committee

February 8, 2012

Dr. John Howard, MD, MPH, Director
National Institute of Occupational Safety and Health (NIOSH)
& Administrator, World Trade Center Health Program
Patriots Plaza Building, 395 E Street SW Suite 9200
Washington DC 20201

Dear Dr. Howard:

Re: NIOSH Docket 248 – World Trade Center Health Program Research Priorities

On behalf of the World Trade Center Health Program Survivors Steering Committee, we are writing to summarize the consensus that emerged from a discussion at our last two Survivor Steering Committee meetings in January and February. The comments below focus on NIOSH's World Trade Center research approach and research priorities.

As you know, the Survivors Steering Committee was created to play an advisory role on the administration of the Survivor Health Program and to represent and gain input from the community of affected non-responder World Trade Center stakeholders.

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, epidemiological studies and basic science research. Especially important would be the creation of key resources that can be used by multiple investigators.

Second, NIOSH should solicit and fund proposals that address health effects to survivors as well as responders. Studies of the survivor population should address health effects on those living, working or attending school in the impact zone defined by the Zadroga Act and represent the diverse populations and geographic areas affected. Wherever feasible, cancer incidence studies must include survivors as well as responders.

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 appropriate specialists.

And we have a number of recommendations regarding WTC Health Program 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 move quickly to support in-depth studies of respiratory, developmental and endocrine health impacts for this rapidly dispersing cohort.
2. We recommend that blood samples be collected from WTC-exposed children and preserved 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 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 Survivor Steering Committee.

3. 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 disease mechanisms.
4. Cancer incidence and prevalence must be tracked across all WTC populations.
5. In an analysis of patients enrolled through 2009 at the WTC-EHC, approximately 60% screened positive for a mental health condition, about 40% of whom had co-morbid mental health problems (ie PTSD, anxiety, and /or depression). Those with lower respiratory problems, highly prevalent in the symptomatic WTC-exposed population, seem particularly vulnerable. (manuscript in preparation). There is a growing literature, moreover, about the impact of parental PTSD and depression on children's mood, anxiety and behavior, including one study among 9/11 survivors. (Chemtob, C, et al, Impact of Maternal PTSD and Depression Following Exposure to the September 11 Attacks on Preschool Children's Behavior, Child Development 2010. 81(4):1129-41)

Given this relatively high rate of co-morbid mental health problems among survivors of 9/11, it would be valuable to investigate the impact of parental mental health disorders on their children's mental health and, conversely, the impact of children's behavioral problems on parental functioning. This would provide essential information about intergenerational transmission of mental illness after a terrorist attack that precipitated a concurrent environmental

disaster. It would help identify variables contributing to resilience and vulnerability. And it would serve as a catalyst to develop and inform interventions intended to mitigate the long-term impact of mental illness across generations of an affected population.

On behalf of the Steering Committee, we thank you for your consideration.

Sincerely,

Kimberly Flynn

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