



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

January 23, 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

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

Dear Dr. Howard:

Re: WTC Health Program Research

We were encouraged to learn that NIOSH plans to issue a new request for proposals (RFP) for research on health conditions resulting from the World Trade Center disaster.

On behalf of the WTC Health Program Survivors Steering Committee, we are writing to reiterate our call for NIOSH to make children's and adolescents' 9/11 environmental health needs a research priority. Moreover, it is urgent that the major gaps in understanding WTC pediatric health impacts be addressed, before the cohort becomes further dispersed.

In addition, we would like to make a number of requests for improvements to the proposal review process.

WTC research on the pediatric population - the most vulnerable, the least studied - should be a federal priority. Tens of thousands of children living or attending school downtown on and in the aftermath of September 11th were subjected to acute and/or prolonged exposures to a complex mixture of hazardous substances. It is well established that by virtue of their development, physiology and behavior, children are more susceptible to harm from environmental pollutants. It is a serious lapse that, of all the populations affected by the WTC disaster, children have been the least studied. The federal government has an obligation to fully support research to understand how the health of those who experienced 9/11 as children has been harmed by their toxic exposures.

Pediatric study proposals should be reviewed by appropriate experts. We have learned that the panel reviewing study proposals responding to NIOSH's August 2011 Broad Agency Announcement did not include anyone with expertise in pediatric environmental health. Whether NIOSH includes appropriate experts on the review panel or refers pediatric proposals to qualified outside reviewers, we ask that the next round of proposals be appropriately peer reviewed.

RFP process should recognize that WTC research is 'disaster science'. All WTC research proposals should be reviewed with the understanding that 9/11-related health effects were, by definition, the result of a disaster. Researchers and doctors are operating in the realm of disaster science, a context that differs in key ways from standard scientific research. Especially with respect to the survivor population, reviewers must take into account that a standardized body of pre-existing medical data for study subjects

does not exist. In addition, the absence of reliable and comprehensive environmental measurements makes quantifying exposures impossible. It is critical that these and other limitations in available data deriving from the unique nature of the disaster or the negligence of the Environmental Protection Agency not become an insurmountable barrier to conducting research required to meet the 9/11 health needs of survivors. We hope that NIOSH would be willing to provide this essential context to the review panel.

We look forward to providing additional comments on research priorities going forward.

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

Sincerely,

Kimberly Flynn

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