February 10, 2014

Paul J. Middendorf, PhD, CIH
Senior Scientist,
CDC/NIOSH/OD/ADSO
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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 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.

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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,

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