

April 5, 2016

John Howard, MD
Administrator, World Trade Center Health Program
Patriots Plaza 1
395 E Street, SW, Suite 9200
Washington, DC 20201

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KM

Dear Dr. Howard:

We are writing in response to the World Trade Center (WTC) Health Program's charge to the WTC Scientific Advisory Committee (STAC) to deliberate on the question: "Children exposed to 9/11 are aging. If research is not conducted on this cohort while they are children, to what extent will the opportunity to discover relationships between the 9/11 exposure(s) and developmental milestones or other health effects be lost? What are the most important developmental and health outcomes to target in such a cohort?" At its June 4 meeting, the STAC determined that the most expeditious way to address this question was to form a "Children's Research Workgroup". The charge to the Workgroup was further defined as: "What are the most important physical, psychological, and developmental health outcomes to target and in which groups of children?"

At its first meeting on The Children's Research Workgroup recommended that the STAC plan a full day meeting in which experts on pediatric environmental health and investigators who had conducted studies among WTC-exposed could present their study findings and perspectives on research priorities. The workgroup also nominated the experts who were invited. Based on the presentations and discussions at this meeting, which took place on December 1, 2015, the Children's Research Workgroup drafted a report with 12 recommendations to the WTC Health Program. This report was sent for review to the full STAC on March 10, 2016 and the recommendations were finalized and voted on by the Committee at a STAC meeting on March 22, 2016.

I am enclosing a copy of the twelve recommendations along with a copy of the Children's Research Workgroup Report, which provides the background and rationale for them. We thank you for the opportunity to deliberate and provide recommendations on this important question.

Sincerely,



Elizabeth Ward, PhD
Chair, WTC STAC

STAC Recommendations on Children's Research

March 22, 2016

Recommendation #1

Children and adolescent survivors enrolled in the WTC Health Registry are an extremely important resource for understanding the health effects of WTC exposures. Recommend that the WTCHP:

- Make substantial efforts to sustain and renew participation in surveys and special studies.
- Consider a highly collaborative approach that could examine a broad range of mental and physical health outcomes in the Registry population.
- Develop a funding mechanism that would encourage collaboration between the Registry and a consortium of investigators with diverse expertise.
- Conduct an analysis of the feasibility and usefulness of a standardized health assessment approach, similar to NHANES, that could examine a broad range of mental and physical health outcomes in the Registry population prospectively.

Recommendation #2

Recommend that the WTCHP include the general area of childhood and adolescent physical and mental health in their requests for proposals, and make this a priority for funding.

Recommendation #3

Recommend that the WTCHP create a distinct pediatric study section under the Zadroga research funding mantle so that pediatric proposals can be reviewed by experts with appropriate expertise in environmental health of children, and not compete in the review process, explicitly or implicitly, with responder proposals.

If a distinct pediatric study section is not created, at a minimum, we recommend that the primary and secondary reviewers in the NIOSH review process be pediatricians or other relevant health professionals with research emphasis in childhood environmental health.

Recommendation #4

Recommend that the WTCHP prioritize funding of pediatric research that examines a range of WTC physical health effects, including respiratory illness, cardio-metabolic (including blood pressure), endocrine, neurologic, autoimmune and cancer impacts.

Recommendation #5

Recommend that the WTCHP prioritize, to the extent possible, longitudinal studies of physical and mental health of affected pediatric populations.

Recommendation #6

Recommend that the WTCHP incentivize the creation of consortia for collaborative pediatric research.

Recommendation #7

Recommend that the WTCHP expedite the development of a funding opportunity for limited short-term projects that attempt cohort identification, location, and willingness to participate in studies to answer outstanding questions about whether unexamined opportunities to learn more about childhood effects of 9/11 can be addressed 15 years after the event.

Recommendation #8

Recommend that the WTCHP encourage the use of appropriate incentives to the WTC children cohort to enhance their ongoing participation. Recommend that WTCHP require researchers provide individual study results, where appropriate, and overall study results back to study participants.

Recommendation #9

Recommend that the WTCHP support collection, bio-banking, and preservation of biological samples from WTC-exposed children using state-of-the-art methods so that biological markers of exposure, effects, and long-lasting toxins can be studied now and in the future.

Recommendation #10

Encourage the WTCHP to inform researchers about the WTCHP treatment programs and covered conditions, and to provide this information to study participants.

Recommendation #11

Recommend that the WTCHP communicate to the health care community up-to-date WTC research findings and their implications for practice, such as through updated WTC pediatric care and treatment guidelines.

Recommendation #12

Recommend that the WTCHP conduct a formal study of missed opportunities for childhood study from 9/11, including a roadmap for the post-disaster setting about how to identify and enlist exposed childhood subsets; how to approach exposure measurement; and the nature, range, and tools to use to study health effects.