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John Howard, MD
Administrator, World Trade Center Health Program
Centers for Disease Control and Prevention (CDC)
National Institute for Occupational Safety and Health (NIOSH)
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Dear Dr. Howard:

Thank you for the opportunity for the STAC to discuss the World Trade Center Health Program's plans for establishing the Youth Cohort, the excellent briefing by Dr. Reibman and the opportunity to learn the perspectives of stakeholders and survivors who will be eligible for inclusion in the cohort. I am writing to provide advice from the STAC regarding each of the four issues you outlined in your Charge and one additional recommendation based on discussions during the meeting.

Advice regarding the four-phase approach and sufficiency of community involvement.

The STAC strongly endorses elements of the four-phase approach with respect to engaging a broad spectrum of stakeholders, community members and organizations, medical and scientific community in developing approaches to establishing the youth cohort as well as ideas regarding outreach, recruitment and retention. We also endorse the concept that alternative options for establishing the cohort should be considered. We are, however, concerned about timeframe in which these activities will be carried out. Given the scope and complexity of the planned work, it will be important to ensure that responsible program staff have the time and expertise to integrate public input from the RFIs (request for information) and other sources to develop and evaluate options for developing the cohort. The STAC suggests that the program develop a timeline for completing the 4 phases with consideration to resources needed. The suggested timeline to complete the four phases is one year.

It is important to engage the survivor cohort and to leverage innovative technologies to conduct outreach, recruitment and retention. Program should do reasonable outreach to promote the availability of the RFIs.

The STAC encourages the program to clarify the amount of funding available for establishing the youth cohort, conducting initial follow-up and future research. As with any research project, the projected budget should be taken account in considering the scope of the work and evaluating the feasibility of different options.

Advice regarding potential partnerships for establishing the youth cohort.

The STAC recognizes that some of the key partners for establishing the youth cohort were represented at the meeting and are well-known to the program. Beyond these specific organizations and individuals, the program may identify potential partners from within the broader WTCHP community of researchers, clinicians and stakeholders. The STAC encourages the Program to involve researchers who have conducted studies of WTC in-utero and childhood exposures, community organizations in the NYC area, as well as national organizations/research programs involving young cohorts which may have experiences to share. To help facilitate outreach, the Program should engage occupational and survivor cohorts that are currently being studied.

Ideas regarding outreach, recruitment, retention and project oversight.

The STAC recognizes that there may be several phases of outreach. Several speakers described the sense of isolation they have experienced as a childhood survivor of 9/11 and others noted a lack of awareness of the World Trade Center Health Program among survivors in younger age groups. Survivors who have left the NYC area and are not otherwise in touch with 9/11 survivors and organizations may be the most difficult group to recruit. The Program may wish to consider a broad outreach campaign to raise public awareness of benefits available to survivors with covered conditions and plans for the Youth cohort study.

The STAC recognizes that at this point it is unclear whether the cohort will be self-identified (with verification) or based on a sampling frame such as NYC Board of Education Records (BOE records), or a combination of both. The STAC believes it is important to use additional sources other than the BOE given that BOE records will include only those in the public school system and not residents in private schools and those who are too young to be in school. To ensure that all these groups are represented in the Youth cohort, it will be critical to conduct multi-faceted national outreach using methods tailored to the communication preferences of the targeted age groups, such as using social media campaigns. In addition, it will be important to identify and utilize existing networks such as alumni associations through which recruitment can be facilitated. To ensure the representativeness of the cohort, it will be important to consider cultural diversity by including community leaders of ethnically and racially diverse groups in outreach and recruitment efforts.

If recruitment is done using a sampling frame such as BOE, experience has shown that it is difficult to get response/participation using traditional recruitment methods. Several options to facilitate recruitment were discussed, including use of communication tools targeted to the relevant age groups (social media, text messaging) and leveraging existing stakeholder partnerships, both local and national. Lessons learned can be derived from experience with COVID and long-Covid affected persons where digital platforms have been leveraged to conduct outreach, education, and recruitment. Since understanding the health effects of 9/11 exposures in this population will require ongoing follow-up, long-term retention will be critical. One suggestion is for the Program to facilitate online opportunities for survivors to communicate with each other, as well as regular communication regarding study findings and activities. This could be

done by partnering with existing stakeholder organizations. The STAC believes that offering compensation for the time and effort of participating will be critical to recruitment and retention.

The STAC discussed the possibility of offering medical screening or testing as an incentive for participation. While we recognize that such an offering might encourage some survivors to participate and offers the possibility of early detection and treatment of WTC-related conditions, it would be premature to make a recommendation without knowing the nature of the screening and careful evaluation of potential risks and benefits.

Anticipated barriers to forming a cohort that can adequately support future research studies, for example, representativeness, insufficient statistical power, information biases, and selection biases, and any potential strategies that address those barriers.

The STAC acknowledges that all of these issues are of concern. If the cohort is self-identified, there will not be a sampling frame from which participation rates can be calculated. If there is, at least in part, a sampling frame such as Board of Education records, it would be possible to determine participation rates among those successfully contacted. In general, when participation rates are low or unknown, there is always concern, from an epidemiologic perspective, as to whether those who agreed to participate did so because they are more likely to have the health condition under study. Given how early it is in the planning for the study, it is difficult for the STAC to suggest strategies to address these barriers, beyond those already mentioned in the context of recruitment and retention.

Inclusion of those with in-utero exposures in the youth cohort.

In addition to the issues outlined in the charge, the STAC supports the inclusion of youth whose 9/11 exposure occurred in utero. Prior research has found evidence of lower birth weight and other adverse outcomes among children of women who lived near the World Trade Center during pregnancy, with a stronger effect among those with first trimester exposure. There is also evidence that environmental contaminants may pass from the mother to the fetus and that maternal traumatic experiences during pregnancy may affect the fetus. Given the level of resources projected to be available for the Youth Cohort, this may be the only opportunity to investigate the impact of in-utero exposure in a large and representative sample.

Sincerely,



Elizabeth Ward, PhD

Chair, World Trade Center Health Program Scientific and Technical Advisory Committee