

RE: CDC–2023–0040; NIOSH 248–K Additional Comments by Barbara Caporale  
In Support of Establishment of Youth Cohort (Survivors, formerly Pediatric (or in utero) when exposed); a prior underfunded research category, many who do no longer live in NYC but were affected. The establishment of & proper outreach to these individuals will also inform & set precedent to design and implementation of future disaster relief , treatment, and research studies.

The foundational outreach for identifying and studying this Cohort should spring from the Survivor Steering Committee, who have long standing engagement with this population, and includes many who either represent essential organizations in this population, who have worked on prior WTC-health population outreach grants, have treated the health of potential cohort members, and are parents of such "affected & neglected" population. Additionally many members of the SSC (formerly the Community Advisory Committee (CAC )when a NYC H&H program)), were instrumental gathering testimony on exposures and health impacts in the community, when advocating for the establishment of and funding for the WTC Health Program, fighting for the recognition of WTC impacts on area workers and residents (now "Survivors") & then the Pediatric component of that program (at Bellevue/NYU Center of Excellence), several who participated the small group, along with DOHMH epidemiologists in the creation of the CHI, Adult Clinical Guidelines for Treatment of WTC-impacted persons, as well as later, the Pediatric Guidelines.

A member of the SCC served on the USEPA WTC Expert Technical Panel series of hearings, created by Senator Clinton, to determine the geographic extent of WTC contaminants, the health impacts of, and recommend revisions to the Test & Clean Program. Many of the SSC participated in the 12 month hearing process, testified at, and drew out testimony of residents, workers, clean-up workers and first responders,  
As now-State Assemblywoman, then-Chief of Staff to Congressman Jerrold Nadler stated, "never have victims of a terrorist attack had to go through such a steep learning curve to advocate for their own safety and health". One SCC member (myself), served as Assistant Outreach Liaison the EPA's subcontractor in the related Community-Based Participatory Research amongst WTC-impacted populations. They are members of and represent many downtown organizations, several serving on the Community Boards in District 1,2,and 3 Manhattan, or now elected representatives of their population.  
This is where outreach is formulated.

It is exciting that you're creating this essential Youth (Young Adult) Cohort to find and study exposed members of this population, guide them to healthcare for their WTC-related impacts, get to them before they develop new health conditions; let them know that they are not alone and are supported.

We have NEVER studied female reproductive or other health impacts, nor the Endocrine Impacts of the WTC event, male reproductive issues, Neuro Cognitive impacts and impacts of this event on the lives and careers of this population.

Additionally, we have not gathered clear data on synergistic effects of all the toxins, nor completely understood co-morbidities.

The outreach to & research of this cohort will help us all more fully understand what happened to us on 9/11, and may very well reveal health impacts that are not yet but may need to become covered for treatment by the program.

The community will guide the research modalities and organizations which should be tapped. Many of these have been utilized by the Pediatric Outreach program of 9/11 EA under the prior H&H grant. Known members of this cohort will help shape the outreach, use word of mouth & their own knowledge of persons & methods to support identifying others.

You all should understand, that much of this population (and their parents) was discounted /told they were not a part of programs set up to aide in NYC's recovery; which made individuals feel they did not qualify for the WTC Health Program (many were confused by difference of WTC Registry, WTC Health Program & now Victim's Comp, with different qualifiers & geographical boundaries)

.

I am thrilled you'll include up to 14th Street as an area of population study which was the original frozen zone (on 9/11 the smoke alarms went off at Bellevue; on 28<sup>th</sup> St. which is why MDs there included this population who presented WTC health impacts (others on a case by case basis) until DC dropped their new boundary line despite US Geological Survey aerial imagery, medical studies of Anthony Szema and others, eyewitness testimony & anecdotal surveys.

I am however, surprised that all of Brooklyn was included (must be political), yes WTC papers were found as far out as Breezy Point (actually is Queens), it would be more sensible to include Staten Island & parts of New Jersey as we witnessed (and they complained of) the smoke & fumes & health issues.