

# WTC Health Program Survivors Steering Committee

## Public Comments

### WTC Scientific/Technical Advisory Committee

September 18, 2019

I am Kimberly Flynn and I chair the World Trade Center Health Program's Survivors Steering Committee (SSC).

I make these comments on the SSC's behalf. I will start by stating the obvious: you cannot integrate research that does not exist.

I am referring to disparities between the amount of NIOSH support for research on the largely male population of responders and research on the much more diverse population of survivors. We think it's fair to say that for many years, the NIOSH's approach to research has in effect been women and children last.

We are not arguing that this is deliberate. We understand that in general, responders got sickest fastest. We understand that the responder population includes a large number of people whose health the program has been monitoring over time. We understand that there is baseline data for the 9/11-affected FDNY cohort, and we deeply appreciate the research leadership of Dr. David Prezant, from which the entire 9/11 community benefits.

Nonetheless, research gaps have persisted over many years that undermine the program's ability to meet the 9/11 health needs of its female and young adult members. This is both unjust and bad science.

Through the years, key research proposals are passed over. I will cite a study of breast cancers in the survivor program clinical population. I will note the fact that there is no survivor blood bank. And I will once again remind the program about the urgent need for research on those who experienced 9/11 as children, by reading from comments I made to the STAC in 2015.

“Although children are especially susceptible to harm from environmental exposures, eighteen years after 9/11, we still know very little about the physical health effects of the WTC disaster on the more than 35,000 children living or attending school or daycare in the NYC Disaster Area.”

SSC has urged NIOSH to move quickly to fill these major knowledge gaps by supporting a portfolio of studies that would investigate a range of biologically plausible health effects.” SSC recommended research examining a range of WTC physical health effects especially cardio-metabolic, endocrine, reproductive, developmental, autoimmune and cancer impacts.

In addition, over many years, the SSC has been calling on the WTCHP to fund a critical effort to create a sufficiently large and representative research cohort of the WTC -exposed child population. The cohort would be drawn from the more than 19,000 NYC public school children attending disaster area schools in the 2001-2002 academic year.

This is a high stakes effort. Why? Because creating this cohort is key for meeting what the program (and the STAC) call “Children’s 9/11 Research Needs.” In fact, this cohort is the necessary foundation for the WTC Health Program to define and meet young adults 9/11 health needs into the future.

This critical project, called the 9/11 Millennial Study, would create and follow a large cohort longitudinally. It is now in a feasibility phase to work out the logistics of reaching former students.

Unfortunately, at this time, this project is at risk.

The WTC Health Registry which is leading the project has moved too slowly. The Registry gained the agreement of the New York City Department of Education in 2017, to transfer contact information for the 19,000 WTC exposed students, along with a group of less exposed students. Under instructions from its IRB, the Registry has accepted 1000 contacts for a feasibility phase, and worked with SSC and others to develop a mailer. Our issue is that it has taken more than 2 years for that mailer to go out to a small sample of students.

In addition, the Registry has not been appropriately transparent with the SSC. One example, we have requested the protocols for the feasibility phase, most recently in a September 5<sup>th</sup> SSC letter. We have yet to receive them.

The SSC believes that this uniquely valuable effort should be a program priority, and protected from anything detrimental to recruitment for the study.

Today, we call on the STAC to issue the following resolution: The WTC STAC urges the WTC Health Program to urge the WTC Health Registry to move with deliberate speed to assemble the 9/11 Millennial Study cohort. Furthermore, everything needed should be done to protect the 9/11 Millennial Study and ensure its moving forward.

This means that the WTCHP must make a full commitment to the 9/11 Millennial Study. It means a faster timetable toward a full launch, with funding available now to enable the next steps to prepare for the study to be taken now.

The SSC also calls on NIOSH to organize a Disaster Science conference, similar to the cancer conference called by Dr. Prezant some years ago. This conference should bring together WTCHP experts and outside experts to discuss key research challenges for study of disaster populations. Pediatric environmental medicine experts must be at the table.

One outcome of the conference should be new instructions to study panels evaluating WTCHP research proposals. Another should be a set of guidelines for research on the 9/11 Millennial Study cohort.

We know that NIOSH has hired Rand to do an evaluation of its research portfolio, an effort we support. But the program must take immediate steps to address imbalances and inequities in its research portfolio. The disparities are glaring and we do not need to wait for Rand to uncover them.

As the STAC will understand, the WTCHP can only add new conditions for care when there is sufficient research evidence. Lacking the research evidence, this next generation of survivors will be blocked from accessing Zadroga benefits that they need and deserve. That would be a grave injustice that we must do everything we can to prevent.

Thank you for your consideration.