

**WTC Health Program Survivors Steering Committee**  
**WTC Scientific/Technical Advisory Committee**  
June 21-22, 2023  
Public Comments

I am Kimberly Flynn and I am making these comments on behalf of the WTC Health Program's Survivors Steering Committee,

We thank the Program for holding a day-long meeting to begin the STAC's deliberation on its recommendations to the Administrator regarding planning for the new cohort. But also, crucially, to begin engaging with young survivors who will make up that cohort, and who will be critical to the success of the endeavor.

For those of you new to the STAC, I want to provide some context.

What we saw and heard at yesterday's STAC meeting has not happened before. Young survivors showed up, in numbers, and spoke for themselves. Five of them delivered a presentation, and before the day is out, young survivors will have comprised the majority of speakers in the public comments sessions.

Yesterday, all of them shared an extraordinary level of ideas, insights and proposals for building the cohort. Some of these are in writing in the recommendations section of yesterday's power point and we strongly advise that all of you read through them.

But my main point is that we older survivors are no longer talking about "WTC pediatric research" as we were in 2008, or "Children's 9/11 Research Needs," as we were in 2011 or 2015. The conversation has shifted. The WTC Health Program is now in dialog with young survivors, who are talking about what needs to happen in order for them to have the answers they (and the whole 9/11 community), are entitled to. In addition, they are holding the Program accountable to address their research needs.

And yesterday afternoon, I got text messages from those who made comments. They want to know what's next.

We of the SSC are proposing that WTCHP set up a meeting with them to continue the unprecedented dialog that was started yesterday. As someone who was recruiting young survivors to speak in the meeting, I can tell you that we gained momentum in the last week. We could easily have doubled the participation. We cannot allow this momentum to go to subside. Time is of the essence.

Now for some corrections / clarifications:

The youth research cohort is on a separate funding stream from the clinical centers in New York/New Jersey, and from the NPN.

The youth research cohort, we think, will cost maybe \$30 to \$40 million over the life of the cohort. Please keep in mind that WTCHP allocates approximate \$16 million per year to research. And that funding has gone overwhelmingly to studies focused on the overwhelmingly male, now middle-aged or older, responder population.

We are in no way opposed to research focused on responders. We're for it. We also benefit from it. But it doesn't tell us what might be happening to 9/11 exposed women and it doesn't give us a view to health issues that may be emerging in people who were exposed at a much younger age.

We have been advised repeatedly over the years by the Program and its researchers that survivor research doesn't get funded because there needs to be a cohort that is not based on a clinic population that is by definition already sick. A good research cohort has to be based on who was exposed, and would include some who have current health impacts and some that do not. That's what this cohort is – it's the research tool that we have lacked all along.

And no one is seeking to enroll 100,000 young survivors. We are looking at 5-10,000. (We have been told by scientists that you need different numbers in order to be able to track different health conditions.) Keep in mind that the Responder Data Center runs a cohort of more than 60,000 responders.

And I want to emphasize again - Because the youth cohort would be 50% female, and followed longitudinally, it would track the emergence of 9/11- related women's reproductive health problems, as well as conditions that are not unique to women. It would also track men's reproductive health problems. We learned yesterday that testicular cancer is emerging for young men in the Survivor Program.

To paraphrase what Armani James said in the Young Survivors Views presentation yesterday, about the importance of research on young survivors – it will make things better for young survivors but it will also make things better for everyone. So for instance, as information flows from this cohort about health impacts emerging in young women in their childbearing years, the Program will gain an understanding of these types of impacts for 9/11-affected women generally.

The rising tide that lifts all boats.

Thank you for your consideration.