

Comments to WTC STAC

Lila Nordstrom (Executive Director, StuyHealth)

February 2023

As a former member of this committee, a member of the Survivor Steering Committee, and the founder of StuyHealth, which helps young adults in the survivor community, I've been present for a large number of conversations about the conditions that are missing from the WTC Health Program's list. And I've noted that a frequent reason petitions get denied is insufficient data.

So to begin with, as we discuss the best way to add non-cancer conditions, I want us all to be mindful of what we came up against in the uterine cancer conversation, where previous medical biases meant there was not much pre-existing high-quality data on the condition AND the WTCHP's research cohorts didn't include enough women to get good data on the condition either. So, though via common sense, we could all see that it was unlikely that uterine cancer would be the only cancer not affected by WTC exposures, women with uterine cancer had to wait a full decade longer for access to care than other WTC cancer victims.

As we consider the process by which we will add new conditions, we should remember that requiring high-quality data to add conditions cannot be an excuse for ignoring institutional biases either in the program's data or the medical community more broadly.

In fact, it is critical that we think about how we will discuss and add conditions that have not been researched adequately and are prevalent in populations like my cohort. We have, for example, lots of reports from StuyHealth members of complaining of non-cancer reproductive health problems. You're not going to find those complaints in the program's data because many of these complaints are from people who don't actually qualify for the program and are from demographics that are not well represented in any program research cohorts. We find the same with autoimmune disorders, which are startlingly common among my classmates, especially the women, and are significantly more common in women overall. We can assume that there are other conditions like these – conditions that are more common or only present in younger subsets of the population and women. As I frequently reminded the members of this committee, though your mission here is to discuss the scientific rationale for adding new conditions to the WTC Health Program's list, real people are sick with 9/11-related conditions right now. There has to be a timely and appropriate way to support their needs that isn't solely reliant on a 20 year research plan that never actually gets underway.

However, we also need to do our part to research the 9/11 community in an equitable manner. As part of addressing the data disparities that put younger and female program patients at a disadvantage, we also have to actually start studying these long-ignored populations. We all know that the program's research has, to date, primarily been focused on first responders. We know that responders are 90% male and significantly older than many of the survivors now seeking care in the program. And to that end – and I know you've heard me say this before - it's critical that we establish a new research cohort of people exposed as children. This time is

different because the creation of a WTC Young Adult cohort was AUTHORIZED by Congress in 2022.

StuyHealth also supports the SSC's call for the Administrator to request that the STAC hold a meeting to discuss the Program's plans for the creation of this new WTC cohort. There has to be ample opportunity for stakeholders, including survivors like myself who were exposed as children, to play a meaningful role in shaping any plans for building this cohort prior its implementation. We've been waiting for decades, even as we continue to get sick, for this youth cohort to be a reality. STAC is the right forum for this kind of dialog between experts, stakeholders and the Program and should do everything it can to ensure we have the space and expertise to establish this new cohort in a way that is effective and inclusive.

Thank You.