

## **Young Survivors' Presentation to WTCHP-STAC, June 21<sup>st</sup>, 2023**

### **Statement by Lila Nordstrom**

My name is Lila Nordstrom, and I'm a 9/11 survivor and member of the WTC Health Program. I'm also a former member of the STAC, a member of the Survivor Steering Committee, and the founder of StuyHealth, which assists and advocates for the 19,000 public school students impacted by the WTC clean-up.

On 9/11, I was at school at Stuyvesant High School, three blocks from the WTC, and my classmates and I fled just as the second building collapsed. Our building was converted into a command center during the rescue efforts, but our 3000-person student body was sent back to that location less than a month after the attacks.

In 2006 I founded StuyHealth because the young adults of the 9/11 survivor community, who were exposed to the WTC clean-up as minors and did not have the agency to make decisions about our health and well-being, have unique needs and face unique health risks. It's frustrating that so little of the WTC Health Program's data is focused on this quite large cohort, and that, as a result, our 9/11 health needs are frequently overlooked or deprioritized.

As a former member of the STAC, I've been present for a large number of conversations about the conditions that are missing from the WTC Health Program's list. And, as I noted in my comments a few months ago, a frequent reason new petitions get denied is insufficient data.

So, as I've mentioned a few times to this committee, when we discuss the best way to add new conditions, we need to remain 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 how our community was being impacted by it. We also need to remain mindful of what we continue to come up against in the autoimmune conversation, which is continually deferred because of lack of data.

Alongside autoimmune issues, I see a lot of StuyHealth members complain of non-cancerous reproductive health problems as well, and like with many of those who autoimmune conditions, you're not going to find those complaints in the program's data because a lot of these complaints are from people who don't actually qualify for the program – remember there is no pro-active monitoring of survivors that don't have a qualifying condition - and of course young people are not well represented in the WTC Health Registry either so they're absent from the major research cohorts that include survivors. I am one of the only people I know from Stuyvesant who is actually in the WTC Registry.

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, especially one that never actually gets underway.

Overall, we need to ensure that research the 9/11 community is collected and considered in an equitable manner. We all know that the program's research has, to date, primarily been focused on first responders, who are nearly 90% male and significantly older than many of the survivors now looking to the program for health information and for care.

And as part of addressing the data disparities that put younger and female program patients at a disadvantage, we have to actually start studying these long-ignored populations. This is why it's so critical that we establish a new research cohort of people exposed as children.

It's also critical that we think about how to best reach these populations realistically. We've already seen outreach efforts to this cohort stall because researchers refused to use accessible methods of contact like social media and traditional media, and instead were relying on out-of-date parental contact information and cold calls. Young people are mobile, they don't like to answer the phone, so any plan regarding how to build this cohort should include stakeholders from it.

Young people are also working full time so if you are asking them to spend time filling in surveys and participating in more in-depth studies, there need to be incentives. Monetary incentives that respect their commitment of time and energy would be appropriate.

And, especially in light of ever shrinking insurance coverage and increasingly fragmentary health care, it would be appropriate for all those participating in the cohort to receive free screenings from the WTC Health Program, that are currently offered only to those enrolled in the WTC Health Program.

Thank You.