

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

### **Statement by Jessica Petrow-Cohen**

My name is Jessica Petrow-Cohen and on 9/11 I was in my third day of kindergarten at P.S.3, a New York City public school in lower Manhattan. I had just turned five.

The first sign that this was not a standard third day of kindergarten was the presence of parents. My two moms, who just hours before had kissed me goodbye and promised to pick me up when school ended at 3PM, came rushing back into the building that morning.

From the window of my kindergarten classroom, we could see the towers fall, the fire and smoke that cloaked the city just south of us. As the school grew overcrowded, we were brought up to the roof where the air smelled of ash and burnt plastic. "What's that?" We asked, pointing at the monument in flames.

In the days that followed, I asked my moms incessantly if another plane was coming, if the building we lived in, a mere 10 minutes from the twin towers, was safe. I remember using crayons to write thank you cards to the firefighters at the station on our block. Outside the station's red garage door, memorials littered the sidewalk. So many of our heroes had died.

Twenty-two years later I am still a proud New Yorker. I live in Brooklyn and work as the Chief of Staff at a social impact tech start up and as a writer. In the past six years both of my moms have been diagnosed with cancer. One of my mothers, Julie, was diagnosed with stage four ovarian cancer in 2017 and has recently transitioned to hospice care. My other mother, Maddy, was diagnosed with head and neck cancer in 2019 and is currently in remission. Both of my mothers' care is covered by the World Trade Center Health Program.

To say that this program has been monumental to my family is an understatement. The ability to access lifesaving drugs, treatments, and in the end stages of Julie's disease, palliative care measures, without concerns over their cost has made managing her terminal illness more bearable. It is the extent of the impact that the World Trade Center Health Program has had on my family so far that brings me here today. It is this impact that makes me fiercely passionate about the necessity of the new Youth Research Cohort.

As the daughter of two moms, one of whom has ovarian cancer, a women's cancer, the new Youth Research Cohort's necessity is particularly prescient. Up until this point, there has been an over reliance on occupational cohorts, such as 9/11 responder cohorts, that are primarily male. In fact, 87% of 9/11 responders were adult males, a biased sample population when used to draft policy that impact women and children alike.

It is imperative that there is a representative cohort of people exposed as children studied. This cohort must be 50% female and studied longitudinally to track the emergence of 9/11 related health problems that disproportionately impact women (such as women's cancers). Further,

this cohort must be used to study the physical health impacts to children, the population most vulnerable to environmental toxins, and currently the most understudied.

The cohort should include a representative sample of New Yorkers under the age of 21 at the time of the attack, those who lived, worked, and attended school below Houston Street across gender, age, race, and ethnicity. Critically, the cohort must include survivors before they become sick. While epidemiological studies have been relied on heavily until this point, in this case epidemiology is the science of “too late.” While relying on data from previously exposed populations to determine what diagnoses will and will not be covered by the World Trade Center Health Program has resulted in 50+ cancers being covered, it still leaves other survivors who are sick to suffer. — Sick survivors waiting for research that isn’t ripe for decades will be left to find and afford treatment on their own accord. Research must be sped up so that coverage can meet the 9/11 related health needs of survivors closer to emergence, instead of after the fact.

Reaching a diverse and representative cohort of young survivors will require several key strategies be put in place. First, survey outreach across multiple channels, including social media, traditional media, email, and text message as these are the channels most frequently used by this demographic. The use of a web portal or mobile app to host all relevant information on the research cohort and provide participants to easy access to additional surveys, health data, and research findings will also serve to increase engagement of participants. Finally, it is critical that the long-term benefits of the study be made clear to participants, the research cohort should receive ongoing updates on the findings of the studies and additional diagnoses receiving coverage as a result of this work. Ongoing engagement is dependent on a widespread and diverse population understanding the imperative nature of the youth research cohort.

On 9/11 I was in my third day of Kindergarten at PS3. I’d spend the next several years afraid of the planes in the sky and fearful that my moms had been caught in a burning building if and when they did not answer their phone on the first ring. As it turns out, my fear was valid but misplaced. It was instead the silent killer, the environmental toxins released during the attack, that threatened my family’s safety. With two moms that have been diagnosed and one mom who is currently dying from a 9/11 related illness, I say with the deepest conviction that accurate, representative research to inform the care and support of future survivors is critical. The new youth research cohort is an opportunity to collect exactly that.

Thank you for having me today.