

Young Survivors' Presentation to WTCHP-STAC, June 21st, 2023

Hello, everyone. My name is Piera Greathouse-Cox. I'm enrolled in the World Trade Center Health Program and I sit on the Survivors Steering Committee.

On 9/11, I was 16 years old and living in an apartment with my father in the Financial District, two blocks from Ground Zero. When the planes hit the towers, I was in class at Hunter College High School on the Upper East Side. I didn't go home that afternoon or the next. My father and I stayed with a family friend in Queens for a week, but returned home briefly a couple of days after 9/11. We walked south from Union Square through three miles of police checkpoints, the air growing increasingly acrid and chemical. Arriving at our building, we stood outside the front door and stared at the massive pile of smoking rubble. Fourteen flights up, our apartment was blanketed in a thick layer of dust and tattered office documents.

Within the next few days, our apartment was cleaned by a FEMA-contractor, but we would continue to find pockets of dust and debris in unexpected places for months. We were also given a FEMA voucher for a HEPA vacuum, which we redeemed. That was the extent of our involvement with any federal remediation efforts.

Eighteen years later, In 2019, I was diagnosed with adrenal cancer. I have been living on the West Coast for the past two decades and was not aware of the World Trade Center Health Program. My mother, who still lives in New York, had seen ads for the Victims Compensation Fund and encouraged me to do some research. As I'd had what appeared to be a successful adrenalectomy and was symptom free, I did not. I was ready to move on with my life. When my cancer recurred in 2021, I finally took my mother's advice and enrolled in the World Trade Center Health Program. I've since undergone chemotherapy, immunotherapy, and two additional surgeries (the most recent just last month), but the cancer has spread to my ovaries and various other spots in my abdominal cavity.

When I was approved for enrollment in the World Trade Center Health Program, I felt extremely relieved and grateful to have access to the care. But I'm just one of many 9/11 affected young survivors who need and deserve answers in the form of more research. The recently authorized cohort is incredibly important because it allows us to track the long-term health impacts of exposure to WTC toxins on the tens of thousands of children who lived or attended school in the Disaster Area. This is a population whose physical illnesses, which could look quite different from responder illnesses, are currently understudied by the WTC Health Program. We need better information about conditions emerging in this population. The new cohort can help us meet this need through more equitable inclusion in studies that satisfy the WTCHP's evidentiary requirements for demonstrating causal association between health conditions and 9/11 exposure.

I'm here today to advocate for the government's full support of this cohort. Adequate financial resources and qualified experts with relevant experience are a must. It's also imperative that the

WTCHP solicit the active participation of young survivors and the *personal* expertise only we can offer. Our insights and opinions need to be included now and at every step throughout the process. A process which should have begun years ago--but much better late than never.

Tracking people down and persuading them to participate twenty plus years after the fact will be challenging. Especially if, like me, these people have moved out-of-state, weren't affiliated with a neighborhood or a neighborhood school, or didn't have any early onset symptoms. It shouldn't have taken Stage IV cancer to alert me to the health impacts of exposure to 9/11's toxic chemical compounds. I didn't know about the WTCHP, but I should have. This cohort is an opportunity to ensure that other young survivors are familiar with the resources available to them. Reaching young survivors when they are well means they learn about the Program *before* they need it, *before* googling "9/11 health" on a laptop becomes their best next step.

Finally, we look to the new cohort to remedy the research inequity you will be hearing all of us address. The bodies the science *has* been attending to--primarily male, primarily middle-aged--are only some of the bodies that were present on 9/11 and during the many months of cleanup. In attending to the physiological impacts on people who were under 18, half of whom are female, we create a significant opportunity for improved outcomes among long-neglected survivor groups like women. In maximizing our ability to identify long-term trends among diverse populations, we can ensure that research keeps pace with the emergence of 9/11 related conditions, allowing us to better identify who is at risk and develop targeted treatments. Quality longitudinal research won't just benefit young survivors like me. As the WTCHP adds new conditions and develops more robust medical screenings, this research will better provide potentially life-saving interventions for *everyone* whose health was harmed by the World Trade Center disaster.

As someone with a rare cancer, I'm fortunate to have my medical expenses covered. There are people who need and deserve access to the World Trade Center Health Program resources that I have. People who may be facing mountains of medical debt because they don't know about the government's programs or because their conditions cannot be certified due to inadequate research. Enrollment might just save their lives. We now have the authorization to pursue this research. Let's give it everything we've got.

My thanks to the STAC for all your work and to everyone present for listening to my thoughts today. I'll end here.