World Trade Center Health Program
Youth Research Cohort

Young Survivors' Views

A presentation by Young
World Trade Center Survivors

with Kimberly Flynn, WTCHP Survivors
Steering Committee Chair

SPONSORED BY THE WTCHP SURVIVORS STEERING COMMITTEE

WEDNESDAY

JUNE 21, 2023

12:45PM – 1:15PM

WTC SCIENTIFIC & TECHNICAL ADVISORY COMMITTEE MEETING

JUNE 21 - 22, 2023

TODAY, WE HEAR FROM YOUNG SURVIVORS

Today is the beginning of a long process - the effort to imagine, plan, build, shape and ultimately sustain the new Youth Research Cohort.

This effort will succeed or fail based on the quality of the WTC Health Program's engagement with young survivors as equal, active and valued partners.

Young survivors are ready to engage– listen to the quality of their ideas and the insights only they can bring to this endeavor.

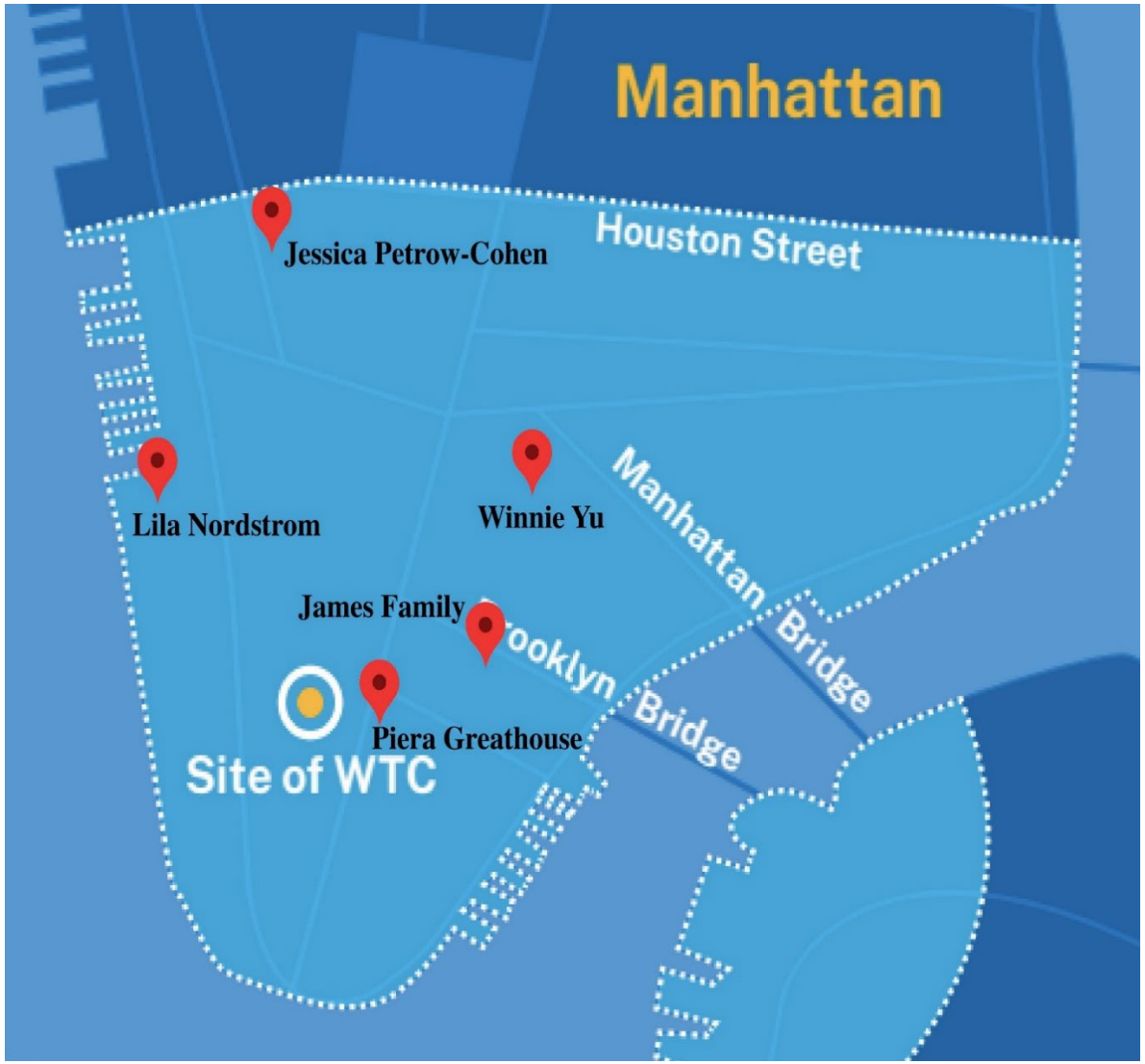
The 9/11 Environmental Disaster

In Lower Manhattan, the plane crashes resulted in the collapse of the Twin Towers—and created massive dust clouds that filled the air and left hundreds of highly populated city blocks covered with ash, debris, and harmful particles, including asbestos, silica, metals, concrete, and glass. Smaller particles penetrated into homes, schools and workplaces.

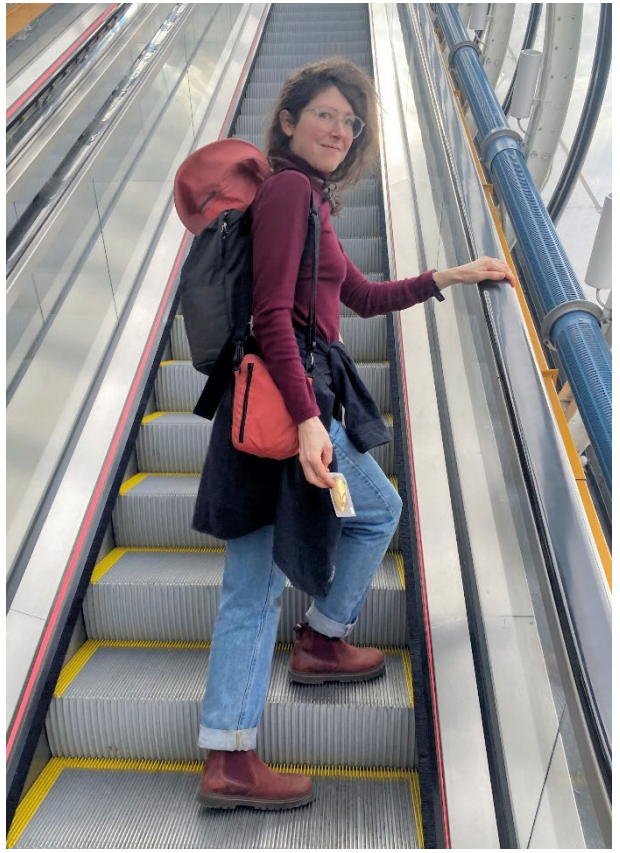
Fires within the debris pile burned into early 2002, releasing carcinogenic combustion by-products. These contaminants were released throughout Lower Manhattan and beyond. In the weeks after 9/11, the plume moved with the wind direction and sat over every neighborhood, sometimes very close to the ground.

Dust and smoke contaminants remained in Lower Manhattan and parts of Brooklyn for an undetermined amount of time after 9/11. Residents, local workers and students, including more than 35,000 children, had potential for acute exposures and continuing exposures from residual materials—indoors and outside—as well as exposure to toxic gases, smoke, vapors, and combustion by-products from continuing fires.

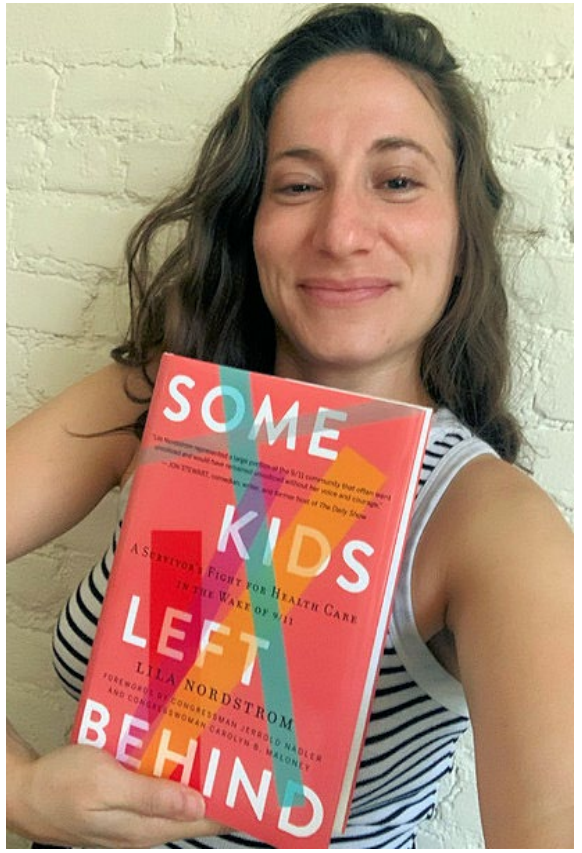
Where our presenters lived or attended school.



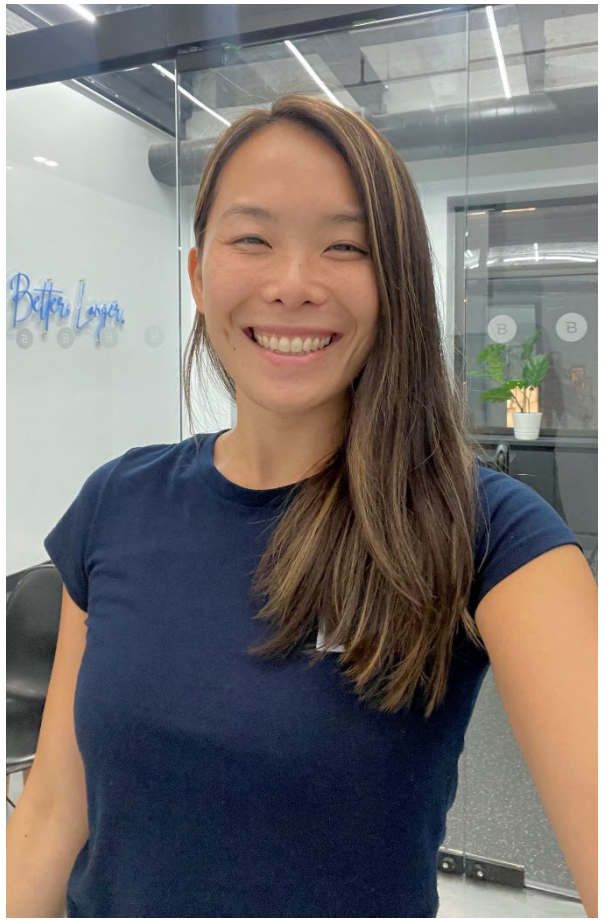
Piera Greathouse-Cox



Lila Nordstrom



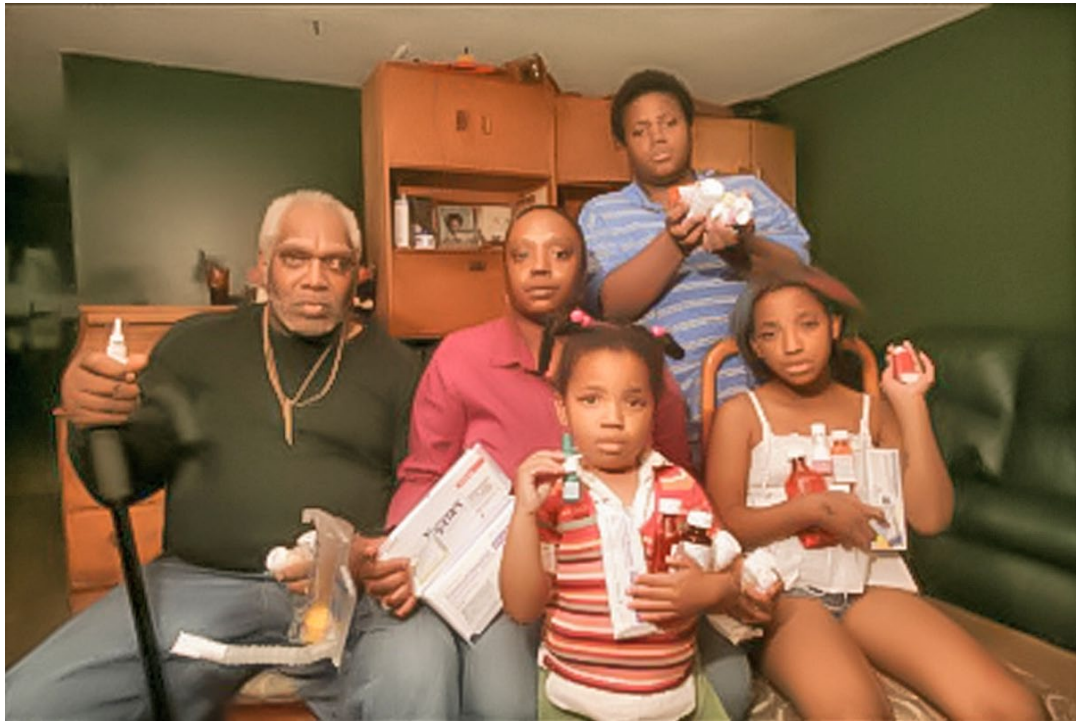
Winnie Yu



Unfortunately, due to her work schedule, Winnie Yu is unable to attend today's STAC meeting.

Her statement will be read by Kimberly Flynn.

Abishai, Alijah, and Armani James



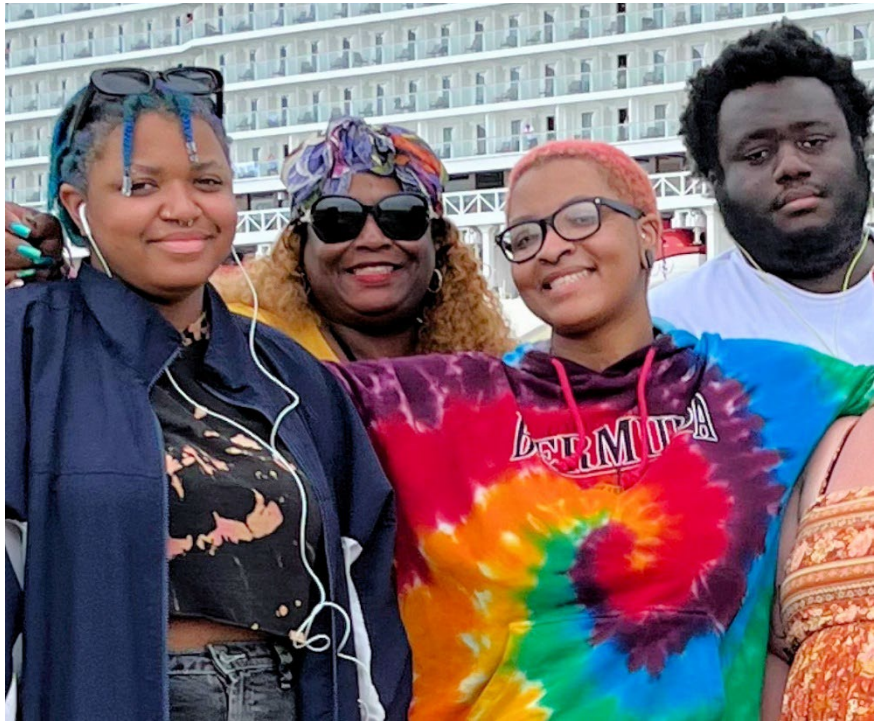


Photo by Alan Tannenbaum

Jessica Petrow-Cohen

Recommendations

COHORT COMPOSITION

Who should be included in the Youth Research Cohort?

- There must be a representative cohort of people exposed as children. It should include a representative sample of New Yorkers under 21 at the time of the attack including those who lived, attended school or worked below Houston Street across gender, age, race, and ethnicity.
- The cohort must be 50% female and studied longitudinally to track the emergence of 9/11-related health problems that disproportionately impact younger people and women (such as women's cancers). Historically, WTCHP research has disproportionately focused on a largely older, male, population of responders.

Recommendations

- The cohort must be used to study the physical health impacts to children, the population most vulnerable to environmental toxins, and currently the most understudied. People born to women who were pregnant well into 2002 should be included. Their vulnerability to exposures is well established.

- The cohort must include survivors before they become sick. Coverage must be provided to the population being studied, through science that meets people's needs in their time of need. Reaching young survivors when they are well means they learn about the WTCHP before they need it, so when they do, they know how to get help.

Recommendations

COHORT STRATEGIES

How can we effectively build and utilize the Youth Research Cohort?

- Adequate financial resources and qualified experts with relevant experience are a must.
- Planning should include the input of stakeholders. The WTCHP must solicit the active participation of young survivors. Their insights and opinions need to be included now and at every step of the process.
- To reach a diverse, representative cohort, there must be survey outreach across multiple communication channels, especially email and text message as these are the channels most frequently used by this demographic.

Recommendations

- To increase engagement, there must be development of a web portal and mobile app.
- The portal and app should host all relevant information on the research cohort and provide participants easy access to additional surveys, health data, and research findings.
- The long-term benefits of the study, for cohort members and for the community, must be made clear to participants upfront.
- The research cohort should receive ongoing updates on the findings of studies and additional diagnoses receiving coverage as a result of this work.

Recommendations

- Ongoing engagement requires an understanding by participants of the imperative nature of the cohort.
- One way to secure engagement, in light of shrinking insurance coverage and fragmentary heath care, would be for the WTCHP to provide free screenings to all those participating in the research cohort.
- Incentives, including money incentives, should be considered for participants to encourage commitment of time and energy. Young adults should have cohort-related employment opportunities.

Recommendations

SOME THINGS TO REMEMBER

- Medical and research biases have tended to privilege the older, male responder populations, In the uterine cancer conversation, we discovered that these biases meant there was not much pre-existing, high-quality data on conditions affecting women and research cohorts did not include sufficient women to obtain good data. In addition, the responder cohorts are largely racially, ethnically, demographically homogeneous. The Youth Cohort must look like the population of children exposed to 9/11.
- In attending to the physiological impacts on people who were under 21, half of whom are female, we create a significant opportunity for improved outcomes among long-neglected survivor groups. This will maximize our ability to identify long-term trends among diverse populations and ensure that research keeps pace with the emergence of 9/11-related conditions. This will allow us to better identify who is at risk and develop targeted treatments.

Recommendations

- For example, non-cancer reproductive health problems in younger survivors are presently excluded from the data because those with these problems but without a certified condition, are not subject to pro-active monitoring - and younger people, especially women, are not well-represented in existing research.
- As the WTCHP adds new conditions and develops more robust medical screenings, it will better provide potentially life-saving interventions for everyone whose health was harmed by the World Trade Center disaster.

We would like to thank:

- All our Young Survivor presenters
- The Survivors Steering Committee, especially Rob Spencer, Mariama James, Hannah Silverman, Piera Greathouse, Barbara Reich, Lila Nordstrom, and all who supported this effort, including Tyler Pell
- Dr. Joan Reibman, NYC H+H Survivor Program Medical Director
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- Dr. Tania Carreon-Valencia
- Mia Wallace
- Jessica Bilics
- Ben Chevat, 9/11 Health Watch
- Micki Siegel deHernandez, Chair, Responders Steering Committee
- Matthew Baione
- Christopher Baione
- JoAnn Lum
- Tosh Anderson
- Cora Fung
- Matt McCauley
- Abishai James
- Julie Petrow-Cohen
- Wai Wah Chin
- Senators Gillibrand and Schumer, and current & former Congressmembers Maloney, Nadler, and Garbarino for the authorization of the Youth Research Cohort.