

Public Comment Statement to WTC STAC meeting, June 22nd, 2023

My name is Barbara Caporale.

My child, is now 25, was headed to her first day of PreK on 9/11 when we heard a huge reverberating boom. I assured her it was, probably a truck backfire.

For days our streets and schools were closed; Air thick, cars and playground equip coated with dust, still they played outside,
With little bandanna over her face, my daughter cheered the rescue recovery workers and vehicles headed to & from GZ. *(I began stress-smoking, but not indoors near my child. I had stopped smoking before 9/11).*

We had our windows closed w/ ACs on. She coughed for weeks at night with the atmospheric inversion .

We often visited the active recovery site

Schools and apartments were never cleaned in our area, nor school she later attended in Chinatown, nor the subways where the towers collapse brought debris & fumes .

My child's pre K participated in a New York Academy of Medicine Pediatric respiratory study of 32 daycares/preschools below 14th street, 1 year post 9/11. Snapshot from her E 9th St school study: 32.3% mutually exclusive statistics of increased impacts on children who either had asthma, or never had but were still reporting symptomatic; the entire study of showed over 43% mutually exclusive statistics (The study was to follow up with a 2 years out study, but funding at NYAM for this ended).

Geographically we were not deemed eligible to participate in the WTC registry.

My child has since for years experienced paralyzing migraines especially triggered by environmental & chemical exposures, at school etc
She developed stomach problems, new allergies, n(ot related to family history), and found to have sinusoidal sphenoid polyp, MH issues including PTSD, anxiety, panic attacks, depression, difficulty sleeping...

The NYC Department Of Education did not recognize 9/11 health impacts. Even downtown medical providers didn't link symptoms presenting to the population as 9/11 related, *(many people were told it was all in their heads or that they were crazy).*

I tried figure out what was wrong with my child ; went to countless medical appts, causing school lateness's (we would go to Drs before I had to be at work).
Schools chastised the parents; that we should be more responsible.
Lateness's and absences, impacted her selection to choice schools.

She became a member of the WTC Pediatric Program at EHC Bellevue; now in the 911 Health program, as federally certified survivor with physical & mental health impacts.

After becoming a Federally funded pgm, the boundaries to qualify were changed.
Her peers with similar issues were excluded from applying

Before the program went FEDERAL

The WTC EHC held a conference on 9/11 health
with a panel dedicated to children's health.

One presentation by distinguished developmental expert Dr. Karen Hopkins, told of symptomology
already presenting and of health impacts anticipated in pediatric populations.
This included neuro/developmental issues....(and anticipated behavioral, etc)

My daughter, over time, when we could afford testing by a grad student of a Neuro- psych expert at
Bellevue; was diagnosed w/ ADD & NVLD, & 'Other".
By high school we realized many of her peers had IEPs

And the Federal Program; hardly awarded research \$ to the boots on the ground medical personnel who
had been treating these populations, less so to study pediatric impacts, much of the research dollars
being granted to far away academics, with only WTC registry data.

My daughter attended a selective HS, Bronx High School of Science. Attendance wasn't considered in the
criteria for admission, only the Specialized High Schools test. She missed out on small, closer, preferable
schools with her interests due to 'attendance'.

Such a large school did not give attention to individual learning academic needs, nor understand her
WTC-related health impacts.

Her school was far away; travel time added environmental exposures, further impacting health &
academic issues & curtailed extracurricular participation on the FeMaiden's, (*Iron Maidens, the all-girl
ROBOTICS team*) and sports teams, as those long days were too much, and a dedicated bus service we
paid for would not bring students back to their stops after regular school hours, but dumped them way
uptown to fend for themselves with city busses and subways (*including in a blizzard, and disappearing
being many hours late during Christy-Gate*).

Superstorm Sandy blacked out our neighborhood for almost 2 weeks, triggered MH traumas and
reactions to MOLD, one of her new allergies.

We parents have always been concerned about the endocrine impacts of 9/11

My daughter as well as a male peer developed extra breast tissue.

She shied away from interactions with members of the opposite sex; insurance wouldn't cover
surgery deeming it 'selective surgery'. They did not understand the psychological impact this had on a
teenage girl.

During the pandemic, my child w/ compromised health, stayed away from NYC .

Out of town colleges certainly didn't understand 9/11 health issues.

Quarantining on an pretty empty campus increased MH issues

And with her continued PH issues of her migraines, digestive disorders

her graduate program at RIT suspended her, stating to "come back when she felt better" (*despite the
quality of her work completed being portfolio-worthy*).

She lost campus housing, her on-campus job, her educational career was terminated, possessions and furniture were scattered all over basements & storage upstate, causing such psychological trauma she couldn't focus on applying to another program offered to her; she said, "I just wanted to be hospitalized".

She has not recovered from this trauma.

She bears the graduate school tuition bills, w/o degree to pursue the level of employment she deserves.

Her new PT employment has already suffered from her health issues, as she has frequent urgent care visits and hospitalizations due to respiratory and gastro issues, and still faces anxiety and depression, exacerbated by lack of answers or good health care. And she fears living alone.

I worry about my child; and others her age far from NYC and the 9/11 medical experts from the Center of Excellence Program at Bellevue.

Thank you for recognizing this cohort.

NOTE:

We live in what has become to be known as "The Affected but Neglected Area"; above Houston Street & below 14th Street.

We have argued for years that Lower Manhattan is like one big neighborhood; we frequently walk to, bike to, patronize businesses and events throughout downtown, but this was not considered in the Health Program qualifications, even though it was originally penned as "those who frequented the area", that definition was dropped by far-away politicians in DC, for proven address' of residence, jobs, or classes in the all too narrowly defined "Disaster Area". Also a local elected thought that including all of public housing in this area would cause republicans to think "free healthcare"(which it is not) would be offered to thousands more, and the bill would not pass in a Republican House.

I will add additionally there was a transference of MH conditions as they felt the frustration caused by years of unmet demands of their parents' incessant campaigns to demand recognition of health impacts of workers and residents, and then children, and in their fight for proper cleanup of apartments and common areas in residences and schools.

Another PS, I was diagnosed with adenocarcinoma in my lungs, COPD, and sleep apnea in the years since 9/11. I never did apply to the WTC Health program, even though I was in the fight for its establishment and recognition of health impacts of area workers and residents mirroring what was seen in the NYPD data; and now qualifying boundaries have changed.

I performed outreach for the WTC Health Program under 2 Health & Hospital's grants; first as an "Outreach Specialist" at DC 37, the city's municipal workers union, and then as Pediatric Outreach Coordinator to parents and schools for 9/11 Environmental Action, also on & off later with 9/11 EA as projects were funded by NIOSH.

I continue to serve on the Survivor Program's Steering Committee, (SCC).