

My name is Nancy...

...and I live on Washington street, just South of where the WTC once stood.

When I was 12 years old, my Catholic grade school took us on a field trip to NYC to see the WTC. The Towers seemed to just jut up from the earth like Oz & I had never seen anything so magnificent. Little did I know that 20 years later I would literally be living and working in their shadows, much less running for my life, choking on the ash as they collapsed.

I often shopped there, worked in a neighboring restaurant, & walked my dog around the Deutsche Bank... All of us in this small neighborhood were closely connected to the towers. To say my tiny studio apartment in a tenement building is 2 blocks away from the South Tower, is true, yet misleading. being only about 600 feet away.

I was home on 9/11, along with some of my neighbors. We evacuated on our own, guessing at what we should do and where we should go. Once out the door, we scrambled away, barely able to breathe in the heavy dust cloud, not realizing the South tower had done the impossible, and collapsed.

While inside we had already been engulfed by it, & the sheer force of the collapse penetrated even closed windows and doors, with smoke, ash, papers, and the detritus of modern office towers: plastics, heavy metals, silica, asbestos, & all that comes with freely burning petroleum.

Later, our blanketed building was cleaned by only our Super. The EPA cleanup came a year and a half later, and to put it mildly, did not inspire our confidence. My neighbors and I were already exposed to this all-encompassing toxic brew, and some of us are sick as a result.

Pre 9/11, I used to walk miles around Manhattan, running up and down a dozen subway staircases every day. I tended a 25' packed bar by myself for 10 hours, and managed small restaurants 5-6 days/week -where I would deliver food to tables, clear dishes, run to stockrooms for supplies, cases of wine, racks of glasses, etc. I can't do any of these things, anymore, and feel certain I never will again.

Within 5 years of the attacks, I started getting sporadic unexplainable skin rashes. In 2014, I began experiencing more serious & mysterious symptoms: crippling fatigue, muscle pains, and weakness. I developed such chronic joint and muscle pain, and such debilitating fatigue, that I became unable to work or sustain the activity level I once had.

I continued to live and work in the neighborhood and have met many survivors who struggle with the same types of symptoms. Getting our uncovered conditions diagnosed has been an obstacle course, and for many, an unaffordable one.

When we residents go to our non-WTC doctors telling of our 9/11 exposures, asking if our symptoms, like those of RA or neuropathy, could be related, the doctors brush it off. We can be completely dismissed. The doctors would then cite the EPA – that the air had been safe, so all of our symptoms, even the respiratory ones, were deemed unrelated.

For the many of us who suffer with a variety of problems that are not currently 9/11 certified, such as Fibromyalgia and Undifferentiated Connective Tissue Disease, credibility is paramount.

For example, UCTD, is one of the severely debilitating connective tissue disorders suspected of being autoimmune in nature. If it is linked to 9/11, which is certainly consistent with my experience, there could be protocols for getting the appropriate diagnostic tests and therapies, without having to convince disbelieving doctors to order them. It would be so helpful to be assigned **one** doctor who knows & understands our cases, and provides the continuity of care we need.

In my case, after hobbling around on a chronically painful knee, suspecting an acute injury, I first saw an orthopedist, & when no such injury was found, he then said I needed to see a rheumatologist. Once accepted into the NYU Rheumatology Clinic, which took months, different doctors gave me different diagnoses. After multitudes of tests, I was diagnosed with fibromyalgia by one doctor, while 2 other doctors said it was UCTD. Then yet another believed I had lupus and started me on hydroxychloroquine.

Then, after waking up covered in hives, I tried to reach the doctor. but couldn't according to the clinic's rules. I ended up in the ER, & then hospitalized due to a severe allergic reaction to the medication. I had simply been left to my own devices.

The inclusion of a variety of autoimmune conditions, and of others, would end this runaround, and the dismissiveness, without some ultimately falling through the cracks. It would get us the care we need.

In the last decade new medications have been developed, offering much help, but affording them is a real issue, for so many people do not have Cadillac (or should I say Tesla?) health insurance.

And, how can any new condition be added for coverage, when the WTC Health Program doesn't have a means to keep track of new diagnoses?

I have long thought that new questions on the monitoring exams, and a simple Program-wide database, could reveal these disease patterns, so that the program would be alerted, & then focus research on those emerging illnesses.

It's inconceivable that it's been 10 years since the Program has added a "non-cancer". Responders and survivors were engulfed in an unimaginable environmental disaster. It's not at all surprising so many would now be suffering with a host of chronic diseases. What is surprising, & actually shocking, is that the Program hasn't added a

“non-cancer” in these 10 years. Whatever process is set out in this Policy document must lead the way out of this stalemate.

Finally, I want to say that I am incredibly grateful for the other WTC health care that I have received. I shudder to think where I would be without it. I thank you for all of your considerations, and hope that in the future, many more of us will be able to receive the care we truly need.