

I welcome this opportunity to share my thoughts on the matter of changes in the **Policies & Procedures for Adding Non-Cancer Health Conditions to the List of WTC-Related Health Conditions.**

The most obvious change is increasing the length of time from 90 days to 180 days for determining whether a condition is certifiable. This is a double-edged sword because patients would have to wait 6 months, possibly without treatment if they have no private insurance to cover them. On the other hand, the additional 3 months proposed, would hopefully give NIOSH more time to do due diligence in researching evidence-based studies to support that a yet-to-be-certified condition is in fact WTC-related.

However, if the evaluation of the scientific evidence is conducted solely using data specific to the WTC community, I foresee a problem. Though very appreciative these programs existed...from early on, both the Bear Stearns/Mt. Sinai Health for Heroes Program, & the WTC Medical Monitoring & Treatment Program...in place prior to the WTC Health Program coverage being implemented in July 2011...did not adequately track emerging conditions to determine if they were linked to 9/11. I personally experienced this during my quarterly office visits & annual monitoring exams. Neither the intake nurse nor the treating physician would note on my record any reference to symptoms or diagnoses I manifested that were not at that time considered linked to the WTC.

Mine was not an isolated case. From my involvement in various 9/11 health-related activities, as well as long rides to & from Washington DC with FealGood Foundation busloads of responders & survivors...I learned this was happening in most of the WTC clinics within the tri-state area. Upon learning this, I organized a group representing various sectors of the 9/11 community to at least meet with the leadership of my particular WTC clinic, hoping to address our concerns. Though I'd been communicating this issue to the leadership of the facility early on when my sister & I were experiencing it ourselves, it wasn't until after hearing how widespread this was that I began gathering a consensus list of issues needing to be raised, & in 2009, began planning a formal meeting.

For a number of reasons, it took longer than expected & we didn't meet until April 2010, though I individually continued to communicate with the clinic's social worker about the issue throughout that period of time. Unfortunately, even with the meeting, little changed.

Shortly after the Zadroga Act was made law on 1/2/11, NIOSH scheduled a public meeting on 3/3/11 to discuss "Implementation of the James Zadroga 9/11 Health & Compensation Act of 2010" CDC Docket #226. A group calling ourselves the Zadroga Action Team (ZAT) met regularly those weeks prior to the public meeting & drew up a 17-page document elaborating protocols we wanted to see implemented in the nascent WTC Health Program, that we personally handed to Dr. John Howard. Most of these were drawn from our collective experiences & a consensus of all sectors from whom we'd received input. The ZAT was formed as an initiative of our disaster volunteer community & included responders & survivors.

Pages 8 through 12 of our ZAT document...which is publicly available as part of the transcript for the 3/3/11 meeting...specifically address the matter of data gathering, research gaps, & tracking, though some of this also appears in other sections. Aside from this document, I also made an oral public comment, which focused almost exclusively on data collection during both treatment & monitoring visits.

In my 4/25/11 public comment for Docket #226, I further elaborated on the need for tracking...suggesting that per a 2008 report published in the *Journal of Urban Health: Bulletin of NY Academy of Medicine, Volume 85,*

No. 6, the estimated # of 9/11 community members believed to have been affected by toxic exposure was 410,000. Of this figure, only 71,437 were enrolled in the NYC Department of Health & Mental Hygiene's WTC Health Registry, reflecting a mere 17.4% of the exposed population...at that time. The WTCHR enrollment was capped at that figure, & was closed to any additional enrollees. And, over the years, attrition had reduced the # of enrollees who completed the WTCHR surveys, which was the primary method used in tracking enrollees' health status. This made data gathering by the WTC Health Program even more crucial. Please feel free to read my 3-page public comment as it offers numerous arguments for the importance of data collection & research. At the time of that letter, there were 26 conditions on the NIOSH list that were deemed WTC-related.

In my 7/13/12 public comment # CDC-2012-0007-0028, & comment #CDC-2012-007; NIOSH-257 from myself & 2 other board members of the Ground Zero Fellowship, a group founded by Franciscan Friar Brian Jordan who officiated the Sunday Mass at the Ground Zero Cross (crucifix-shaped WTC steel beams found in the debris which became the spiritual center of the WTC site), we raised again that emerging conditions were not being tracked. This was when the WTCHP was considering adding cancers as certifiable conditions. Aside from cancers affecting both genders, we voiced concerns about there not being sufficient tracking of women's health issues.

In my comment, I stated "If the data collection has been flawed, then the results are flawed. Aside from women's issues of early menopause, fibroids, miscarriages, breast/uterine/ovarian cancer, many in our community have thyroid abnormalities/cancer, fibromyalgia, IBS, skin & blood disorders". In our GZ Fellowship group comment, we stated "We support ongoing monitoring for patterns of emerging cancers among all affected populations. We encourage NIOSH to provide adequate resources for proper data analysis of monitoring data, especially with respect to cancers & autoimmune diseases". WTC annual monitoring questionnaires were not asking questions about women's health.

Fast-forward to now. My concern is that during the research process in determining whether a non-cancer condition is WTC related, there is insufficient data to work with...if any scientific review only considers the research studies on our 9/11 community. It will be essential for scientists to look beyond WTCHP studies to research on non-9/11 exposed populations, basic studies, etc..

I myself have twice requested to have my Urticaria (hives) certified as related to PTSD...in 2016 & 2021...yet in both cases, it was not approved. My condition likely started prior to having it documented in my PCP's OV notes in 2009 because I recall previously having had a rash on my arms that I initially thought was from insect bites...but I never went to a doctor about it. From 2009 to 2016...I had 8 eruptions. From September 2019 to March 2022, I had 45 eruptions. The eruptions happen when I'm under extreme stress. I have photos of every eruption. I lost my father the end of 2020, whose caregiver I was the final 6 years of his life, which resulted in exponential anxiety during the weeks of declining health leading up to his death...& the depression afterwards. And in 2020-2021, I had ongoing unresolved issues with LHI regarding unpaid claims for 5 of my providers & a sudden termination of my acupuncture coverage. Yet despite documentation from dermatologists, NIOSH determined my Urticaria unrelated to my certified mental health conditions. Nevertheless...in doing a simple internet search, I have found a number of studies linking Urticaria to stress.

There is also the matter of other autoimmune disorders. Besides Chronic Urticaria, I have been diagnosed with Fibromyalgia, CFIDS, Ankylosing Spondylitis, Erythema Nodosum, Hashimoto's Thyroiditis, & Periodic Limb Movement Disorder. These conditions, along with others such as Rheumatoid Arthritis, have been prevalent in our 9/11 community.

Thankfully, with the exception of my thyroid for which I take a hormone, my bent towards holistic protocols has enabled me to manage my symptoms...so at this point, I'd like to request that the WTCHP expand their coverage of complementary protocols to at least be in parity with the VA's "Whole Health" program. I'm grateful that the WTCHP on 1/4/23 approved long-term acupuncture coverage for chronic musculoskeletal pain...for which I'd been advocating since March 2021. Thank you. I hope this is the initial step in adopting holistic protocols for our community...which was requested in pages 11-12 of our ZAT booklet that we presented at the 3/3/11 public meeting.

I understand that the WTCHP as a federal program cannot be a pioneer in launching a full-scope of complementary medicine that other federal programs do not offer. But I would graciously ask that going forward, additional modalities besides acupuncture be incorporated at minimum to the degree they're covered by other federal programs. These protocols would greatly benefit our members' wellbeing, while preserving program funds by not creating secondary conditions...resulting from pharmaceuticals being used to treat their certified conditions...that would ultimately have to be covered by the WTCHP.

I'd like to end my comment by addressing the matter of the NPN's current 3rd-party administrator Sedgwick, which took over from our previous coverage under LHI. Per stats on the WTCHP website, as of 12/31/22, there are a total of 116,730 enrolled in the WTCHP, of which 28,525 are served via the NPN throughout the US...& covered by Sedgwick.

Granted, I understand nothing is "perfect" on this side of Heaven...however, we seem to have gone from the "frying pan" of LHI into the "fire" of Sedgwick. While I know there were a myriad of complaints about LHI & I myself experienced some of what many were voicing, I felt that they were making efforts to rectify issues, though perhaps more slowly than most wished. While we were in that frying pan, at least there was some cooking going on which was hopefully leading to a somewhat palatable meal. But now in the fire of Sedgwick, the meal has been burned possibly to a crisp.

Since Sedgwick taking over on 8/1/22, I personally have experienced: interruption of treatment due to previous LHI/UMR/UHC providers not being credentialed with Sedgwick/Prime Health Services; providers appearing on our patient's portal as being "in-network" with Prime when they aren't; & delays in providers being credentialed even after months of their having submitted their contracts. I could continue, but these are a few of the many issues encountered by our 9/11 community outside of NY & NJ.

I started a FB page in September 2021 called "9/11 Community WTC Health Program Member Concerns" to create a venue where our community could post situations they were experiencing with their coverage, & offer suggestions for improvements, so that our community's needs are best met, while optimally utilizing the limited program funding.

I assume that Sedgwick was contracted because they were the lowest bid, & while I can understand that the WTCHP is looking to properly steward their funds, the amount of staff hours being spent to rectify the various issues with Sedgwick 6 months into their coverage I believe is already outweighing the cost savings of the lower bid...while greatly disrupting the coverage of many...which in some cases is literally life-threatening.

I kindly request consideration of all I've shared in my comment. Thank you.