

Comment read during November 19, 2021 STAC meeting

My name is Anne Marie Principe, I had a small business on Greenwich Street just north of the World Trade Center. I am a 9/11 survivor and advocate. I understand we are speaking today about certifying Ovarian cancer, sadly it is too late for my friend Ari Goodman who died of this disease, one year ago.

I have been part of the WTC Bellevue program since its inception. I have spent the last twenty years battling various 9/11-related medical conditions, including a brain lesion, breast cancer, interstitial lung disease, asthma, rhinitis, sleep apnea, vocal cord paralysis and peripheral neuropathy.

Equally important, I am one of the advocates who fought for our healthcare bills and the VCF. I am so grateful for our program, but I believe we can do so much better.

There have been countless issues with the way the program is administered. Fiscal prudence and financial oversight appear to be non-existent: the pharmacy management company does not bother to negotiate costs.

The onboarding process for participants in the program is extremely detailed and certification can be daunting, yet certification does not guarantee treatment. It takes months to get an appointment, and if we are treated outside of a WTC Center of Excellence, that becomes a logistical nightmare.

In theory, victims can go to outside practitioners for treatment, but physicians are no longer willing to sign up with the program because they literally don't get paid for years. I personally have had bills for approved treatments that took more than two years to be paid. How can we expect anyone to wait two years to be paid? Would any of you?

As a result, the program has left us struggling to find practitioners who will take our federal insurance. Trying to get our medical treatments paid for is a full-time job. I spend hours on the phone every month trying to get my doctors paid, while I should be focusing on my health.

We are still being treated according to the same protocols that were created 20 years ago. I am routinely prescribed addictive narcotic drugs such as Fentanyl, Morphine and Oxycodone -- substances that are as toxic as the dust I inhaled. Yet when I request far less expensive holistic remedies like IV Vitamin drips or acupuncture, my requests are denied.

When I was diagnosed with breast cancer in 2018, Sloan Kettering was insisting on 6 months of chemotherapy and a 6-week course of radiation, which would have cost the WTC program over a half million dollars. It was approved by the program.

I went for a second opinion to Boston's Dana-Farber Cancer Institute(not covered). There, I was given an Oncotype DX test that showed that chemo was not the best course of action for my

cancer. As a result, together with my doctor, I chose natural and alternative treatments. My regimen includes large doses of vitamins and essential minerals, medical marijuana, yoga, meditation, hyperbaric oxygen and cryotherapy. Although the WTC program would have paid \$500,000 for my chemo and radiation, it refused to cover the doctor that saved them that expense, or the holistic treatments that cost less than 5% of what chemo and radiation cost. My functional medicine treatments are doing more than just keeping me alive. No one who sees me today would ever know that I have cancer.

Why doesn't the program cover treatment like acupuncture, hyperbaric oxygen, cryotherapy, infrared sauna, and nutritionists, which will save money in the long run? Common sense dictates that preventative care is far less expensive than waiting to treat a condition that has already become acute or catastrophic. If the program would institute wellness programs and natural therapies, not only would we all be in better health, but it would also lower medical costs.

Are any of you aware that there are numerous social media pages including an LHI complaint page devoted to WTC healthcare issues where hundreds of survivors post about chronic problems with the program? A lack of communication, unpaid bills, uncovered treatments and a failure to certify numerous conditions that many of us share. There are a lot of broken 9/11 survivors out there.

For example, now many survivors are experiencing mental health issues directly related to being denied the very treatment they seek.

My own enrollment in the program was questioned when I tried to get mental health treatment. My daughter was denied mental health care even though she is registered and certified with three conditions. We were told her mental health issues were not really connected to 9/11. My daughter had to watch her single mother fight for her life through three grave illnesses over the last twenty years. She has watched my friends die, one who shared my breast cancer diagnosis. How can anyone say our family's mental health is not impacted by 9/11? And how can PTSD still not be a certified condition?

The disfunction of this program retraumatizes survivors by making them fight for their lives and their healthcare all over again. This must change.

I suggest four action items:

1. Implement wellness and treatment programs that include functional medicine and holistic treatments to reduce program costs and improve the quality of life of 9/11 survivors.
2. Conserve the programs assets by negotiating lower prescription drug costs. There is no reason we should be paying full cost for a program with over one hundred thousand participants, many of whom are experiencing the same medical conditions, like asthma. This will save the program tens of millions of dollars.

3. Overhaul the current payment protocol to guarantee payment to outside providers within 60 days of billing.

4. Create a civilian board comprised of 9/11 survivors with **certified WTC conditions** to identify and respond to on-going issues such as those I have identified today and those being raised on social media. As the program continues to evolve, needs and problems are constantly changing. We need to take advantage of the expertise of the 9/11 survivors who are dealing with the program in real time, so issues can be addressed as they arise and before they fatally impact any more of us.

And as far as redacting my testimony, I will ask you not to do so. Our stories SHOULD be public. Please keep in mind that in order to get our legislation passed, I have had to publicly talk about my medical conditions to inform Congress, the media and additional survivors. Our stories are what made this program possible. Do not silence us using HIPPA as a shield.

Thank you for listening.