

## **Dragon, Karen E. (CDC/NIOSH/EID)**

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**From:** den\_lor2011@yahoo.com  
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**To:** NIOSH Docket Office (CDC)  
**Cc:** Chen, Jihong (Jane) (CDC/NIOSH/EID) (CTR)  
**Subject:** 226 - Implementation of the James Zadroga 9/11 Health and Compensation Act of 2010 (Pub. L 111-347) Comments

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### Comments

My name is Denise Villamia. I was a citizen volunteer responder to the WTC attacks on 9/11/01. I was initially serving with the American Red Cross, at St. John's University, then with the Salvation Army, at the big tent that came to be known as "The Taj". Additionally, I served at other makeshift wooden structured respite sites around the perimeter of the hole, looking down into the pit. At no time while traveling around the site did I wear a protective mask.

I was a healthy, joyful, full of life woman prior to 9/11/01. In the years subsequent to the attack, I have developed, (in order of diagnosis), vitiligo; asthma; depression; GERD; IBS; Obstructive Sleep Apnea; Fibromyalgia; Post Traumatic Stress Disorder; Generalized Anxiety Disorder; Elevated Anti-Phospholipids in the blood; Hoshimoto's Thyroid Disease; Lupus like elevated ANA titers; High Blood Pressure; Reactive Airway Disease; and Chronic Fatigue Immunodeficiency Disorder.

In my own study of my diseases/disorders, I have come to find that Vitiligo, Fibromyalgia, Elevated Anti-Phospholipids in the blood, Hoshimoto's Thyroid Disease, the Lupus like elevated ANA titers, and the Chronic Fatigue Immunodeficiency Disorder all have in common that they are autoimmune disorders, which are conditions in which the immune system mistakenly attacks and destroys healthy body tissue, by antibodies that are supposed to be targeting antigens, rather than healthy body tissue.

In my case, my autoimmune disorders are affecting my blood cells, connective tissues, endocrine glands, muscles, joints and skin. Additionally, as I learned more about my diagnosis, I came to find that the trigger for these autoimmune disorders include exposure to traumatic events as well as exposure to environmental toxins. Ground Zero was both of these.

While I am glad that programs exist to study the declining health of first responders to these horrible attacks, there are only certain things that the programs are focusing on monitoring and treating. In my case, this would include the Asthma, Depression, GERD, Obstructive Sleep Apnea; Post Traumatic Stress Disorder; Generalized Anxiety Disorder and the Reactive Airway Disease. However, this is clearly not capturing the full spectrum of diseases that can emerge from the toxic cocktail we were exposed to.

Disease is a complicated matter, and one could never say with certainty, that problems in one body system or organ will not evolve into problems with other body systems or organs. And so, because of this, the programs must make every effort to carefully record the symptoms we report at our monitoring and treatment appointments. Additionally, because this attack was like nothing else we have ever experienced in this country, with respect to the effects it was to have on people's health, the programs must move towards treatment of the whole person, at that site, for all of their illnesses, and not just what has up to this point been identified as World Trade Center related conditions. Much important information about the impact of our toxic exposure is lost if we are routinely sent out to private physicians, outside the WTC MMTP's, whose training and interest are not necessarily related to those of the effects of toxic exposures.

Additionally, all doctors practicing within the Centers of Excellence should have a general knowledge of all medical areas of practice - such as Endocrinology, Rheumatology, Immunology, Hematology, etc. An example of this in my case, was when I asked my treatment doctor about my elevated ANA titers, and was told that it was not within his area of practice, and that it wasn't necessary that he understand that, because it was not a WTC covered condition. This is unacceptable.

Another area of concern for me personally as a MMTP participant, is that of the quality of the experience a responder has at any of the monitoring and treatment locations. We should not be viewed as "just a patient". We are people who responded to the most horrific event that occurred on American soil, and as such we must be treated with respect, honor and dignity when we go in for our monitoring and treatment appointments. We should not be kept waiting for hours on end, in waiting rooms that seem like emergency rooms rather than programs designed to treat "HERO's". We should be able to get appointments as frequently as we need them, and we should be able to see the specialized doctors we are referred to, without having to first get an approval from our treatment physician, as if this is some type of managed care system requiring our primary care physician to sign off on every decision we need to take over our own care.

Finally, I would like to end with an incident that just happened this past week, at my treatment site, Mt. Sinai Hospital. My regular treatment physician left her position with the program unexpectedly and that required assignment to another physician. I wanted a female physician, and I made an appointment with one of the female physicians that came highly recommended by another participant in the program. The same day of my appointment with my new physician, I was informed that I could not see that physician, and was scheduled with a male physician I did not want to see. My sister as well as my significant other, who both were patients of the physician who left the program, also made appointments to see the same new female physician I requested. They were allowed to keep their appointments with this new physician, while I was not. This is clearly not right. We as participants of a program that is designed to provide care for responders to this terrible, horrible attack that took place, should be treated with respect and dignity. Every possible measure of meeting our needs must be considered in making our experience within the Monitoring and Treatment program a pleasant one, rather than one which contributes to our stress.

The goal of the MMTP's must move from one of providing the physicians a vehicle through which they can use their research to write papers and get published in medical journals, to one that really is driven by what is in the best interest and care of the participant - the individual who responded to the most horrible attack on this country. Respect and Dignity must be the primary concern.

Thank you.