

To: Dr. John Howard / NIOSH / Docket #226 Zadroga Act
From: Rhonda Villamia

4/25/11
Re: Statement

Dear Dr. Howard,

After 9 months volunteering at the World Trade Center site with the Red Cross, Salvation Army, and St. Paul's Chapel, like most in our community of 9/11 responders and survivors, I've developed a number of medical conditions.

The toxic cocktail to which our community was exposed is without precedent. The combination of pulverized matter: construction and airplane materials, building contents, human remains, and the chemical effects produced by the sudden collapse and subsequent combustion of all these over a 4-month period...has never occurred in history. There have been other tragic events such as Hiroshima, Chernobyl, Bhopal...and the exposures of Vietnam's Agent Orange...but none of these was composed of the unique mixture present at the WTC.

According to a 2008 report titled "An Overview of 9/11 Experiences and Respiratory and Mental Health Conditions Among WTC Health Registry Enrollees" published in the *Journal of Urban Health: Bulletin of the NY Academy of Medicine, Volume 85, No. 6*, the number of persons believed to have been affected by toxic exposure has been estimated at nearly 410,000. This figure includes responders; volunteers; area residents; employers/employees; students; and those who just happened to be in the vicinity when the Towers fell. Of this number, only 71,437 are enrolled in the WTC Health Registry, reflecting a mere 17.4% of the estimated exposed population. And this figure includes an overlap of those who may also be enrolled in the WTC Medical Monitoring and Treatment Centers of Excellence, FDNY, NYPD, and WTC National Responder Programs. The WTC Health Registry provides monitoring only by way of periodic questionnaires, and the figure is capped...so there can be no new enrollees participating.

Even with the additional number of people not currently enrolled in any monitoring or treatment program who will be permitted to enroll and be covered under the Zadroga Act/WTC Health Program, the total number of persons being monitored and treated for their WTC illnesses will still be a fraction of the affected population. As such, the monitoring of this group must be of the highest caliber since the research data obtained would be indicative of what is likely occurring in the balance of the population that is not being tracked.

Unfortunately, the current monitoring and treatment programs are not adequately tracking ALL the conditions manifesting in our 9/11 community. More often than not, if we come to the doctors with symptoms of conditions other than those 26 on the NIOSH list, we are consistently reminded that the program cannot treat us for these "non-WTC-related" illnesses. We are then instructed to see our private physicians for these matters. The problem is two-fold. First, doctors outside the WTC programs are not experts in the field of toxic exposure trained to evaluate and treat environmental/occupational illnesses.

Secondly, much valuable data has been lost because it has been excluded by the WTC doctors monitoring us. The 26 conditions initially determined to be WTC-related must have been established when an inordinate number of people within our 9/11 community were presenting with the same symptoms & doctors began to make note of them. But if data other than the 26 conditions is not being recorded by the WTC doctors, then there is no tracking mechanism in place to determine new conditions to add to the list.

We are a large population that has been exposed to a rare combination of contaminants...not just radiation, not just chemicals, not just biological...not just whatever may have been the basis for other devastating exposures prior to 9/11. To the degree that our exposure is unique and multi-pronged...is the degree to which we should be receiving treatment for these resultant conditions. And the monitoring component should have been tracking emerging patterns of conditions all these years, regularly informing our community of spikes in the radar.

The new WTC Health Program under the Zadroga Act must not dissect our care. Program participants should be treated for ALL our conditions - whether they are one of the 26 already established as WTC-related, or any of the numerous other conditions with which most in our 9/11 community struggle.

These conditions include cancer, disorders of the thyroid, autoimmune system, blood, connective tissue, neurological system, reproductive system, and skin to name a few.

Since we are a population unlike any other, the WTC Health Program covering us should be unlike any other. It should be the best of the best. We should be treated as a "whole" person...not just the "parts" of us deemed to be linked to our exposure at the WTC site. As the years have passed, more conditions have manifested. Our government should not draw a line and say they'll cover some conditions but not others. I reiterate that the complexity of the contaminants warrants monitoring and treatment of ALL conditions, and I therefore implore NIOSH to effect the WTC Health Program to include comprehensive coverage for our incrementally deteriorating community.

The reality is that many of us are not going to be around too long. Many of us have lost our health insurance because we are no longer able to work. I would ask our government to do the right thing and give us some dignity and respect as we live out whatever years we may have left. Those of us who volunteered made a choice to respond and help out in our nation's worst disaster. The first responders carried out what their chosen vocations called for...they went into the towering inferno when folks were running out...and toiled hour after hour excavating the tangled mess to bring closure to those who lost a loved one. The survivors who happened to be in the vicinity that day, lived, worked or went to school in the neighborhood had no choice in the matter. Fate happened. These various components of the affected population need care now and we are asking our government to provide us the level of care appropriate for an unprecedented exposure.

Part of this care should include Integrative/Alternative Medicine. WTC Health Program

participants should be given an option of seeking this type of "holistic" treatment. If medical providers could treat the root of the condition and bring the body to proper balance so it will function optimally...rather than prescribing medications to temporarily relieve the symptoms...causing additional conditions to manifest from the side effects...makes no health sense, nor does it put to best use the funds of the program. An acupuncture needle costs a few cents compared to prescribed medications which can be hundreds of dollars. Nutritional supplements/herbs used therapeutically are significantly less expensive than pharmaceuticals. Incorporating more "Complimentary Medicine" approaches will net better health...and save money. There should also be stress reduction and musculoskeletal wellness modalities such as therapeutic massage available.

I recognize that not everyone is of the mind-set to seek alternative health measures, but there is a large number who prefer this...so all I'm suggesting is that the WTC Health Program provide the option.

Lastly, I would ask that coverage under the WTC Health Program be implemented in such a manner that participants who may live in 2 states...ie: "snowbirding" northerners who spend winters in the south...are able to be treated in both states. The participant should not have to relinquish coverage in one state to be able to be treated in the other. The current coverage is divided into 2 entities: the WTC Medical Monitoring/Treatment Program in the New York City metropolitan area and the National Responder Program for everywhere else outside New York...and participants can only be enrolled in one or the other. If a participant lives in NY part of the year and in a warmer state the balance of that year, the WTC Health Program should provide seamless coverage at both. Actually, similar to Medicare, the coverage should be available anywhere in the US the enrollee may be at any given moment. A program photo ID card should be issued to enable this.

Dr. Howard, I can only imagine how burdened you must feel in your responsibility of putting this new health program into place. I ask that you please put yourself in our shoes and take into consideration how this horrific event has prematurely shortened our life span. Please implement a program that is of the highest quality, the most extensive coverage, and administered by staff that is sensitive to our particular population which struggles with extraordinary physical, emotional, and psychological illnesses. It is difficult enough to battle any of these individually, but when our bodies are being bombarded with all 3, it is more than most can bear. Our lives are not what they were before 9/11/01. The constant focus on our medical issues has forced us into this "new normal" which is far from the natural course our lives would have taken had there been no 9/11. Having our health care needs met should not be an additional source of stress on an already very compromised community.

We were there when our nation needed us. Please let our country now be there for us.
Gratefully,

Rhonda Villamia
Rhonda Villamia, ZAT member