Diana, Sherri A. (CDC/NIOSH/EID) (CTR)

From: Pearl Duncan <pearlduncan@att.net>
Sent: Wednesday, January 18, 2012 5:54 AM
To: NIOSH Docket Office (CDC)
Subject: Regarding the Parients with 9/11-Related Cancers

Of course cancer caused by 9/11 toxins should have been included on the list of medical ailments covered. Last summer I sent the following statement to Dr. Howard, and I include that statement here. I do not like to think about 9/11 issues, so I submitted to the recent 9/11 Health Compensation Program all my documentation very early and I feel for the people who have to wait to see if their symptoms are covered. I have multiple pulmonary symptoms and a well-documented toxin-triggered neurological disease I submitted as a injury, because these were on the list of illnesses covered, so I make the following statement on behalf of patients who have 9/11-related cancer.

Comments from the doctors in Bellevue's 9/11 Health Program resonate in my ear. When I had debilitating symptoms my doctor could not identify, she said, 'But Pearl, I am only a pulmonologist." That was when I realized that in a country with our medical knowledge, the whole country had truly failed victims of 9/11 illnesses. I was lucky when the pulmonologist referred me to Bellevue Clinic's neurologist, Dr. Katherine Henry, who said she had several patients from the 9/11 clinic with similar symptoms. She said, toxins that entered our bodies and were trapped in our lungs did not remain in our lungs. They could cause damage in any other tissue, especially the nerves and circulatory system. The toxins were transported to other tissue where they lodged and also caused damage. It was her statement that saved my life, because having had two neighbors who died of cancer, at that point, I used all my finds to hire doctors and researchers here and abroad to help diagnose and monitor my health.

That is the statement below I sent to Dr. Howard last summer. Since the onset of my 9/11 symptoms I saw dozens of doctors who are pulmonologists, neurologists, vascular specialists, toxin specialists, acupressurists, dermatologists. In the medical documents I submitted to the 9/11 Health Compensation Program, my main doctor wrote that given the history of my 9/11 ailments, going forward, I am at risk for more serious complications from symptoms he currently monitors, dysesthesias, paresthesias, erythromelalgia.

I paid to have my symptoms monitored.

The fact that the country did not assign specialists and researchers, not only pulmonologists, to test, monitor and treat patients is a shame, and reflects very poorly on America's claim to being a leading reservoir of medical knowledge. I spent a fortune to get diagnosed and treated by a handful of specialists nationally and worldwide who a trained to detect toxin-triggered diseases. By now, the country

should have identified specialists and researchers who can detect 9/11 toxin-triggered cancers. Acknowledgement of 9/11-related cancers is long overdue. It is ignorant to say we don't know because researchers and medical specialists were not assigned.

Shame.

I include my letter to Dr. Howard below.

Pearl Duncan

June 30, 2011

Dr. John Howard
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Dear Dr. Howard,

I am writing to you as someone who lives and works in the 9/11 World Trade Center neighborhood. I am taking the time to write to you, because there is discussion of 9/11-related medical problems in the news, which do not include some of the medical problems we faced and still face.

This is a note from someone who had to do her own research to find out what my symptoms were. I am enrolled in Bellevue's 9/11 Program, where I was diagnosed with reduced lung function, and the assistance I received as tests and diagnosis of my pulmonary symptoms was excellent, but there was not much assistance with my other symptoms. The Program did an excellent job of documenting neurological symptoms, but there was not much research available about neurological symptoms, triggered by metals or toxins.

I am asking your team to review the medical neurological diseases caused by 9/11 metals and toxins.

First, I read that the scientists who designated the neighborhood that will be covered by the medical fund reviewed photos of the dispersion of dust only on 9/11. As a resident who lives and works in the area, I am asking that the scientists also review the dispersion and impact of the dust and toxins, not only on 9/11, but in the following months that the debris burned and singed. As each level of debris burned in ensuing

months, dangerous toxins were re-released into the air, and depending on the wind direction, we were assaulted again by deadly toxins for weeks and months after 9/11.

On 9/11, my apartment was overwhelmed by dust and smoke, but there was also much smoke in the following months, especially on windy days and as workers penetrated the layers of debris.

Second, your scientists reviewed the reports, issued by the centers that have been diagnosing and treating the first responders and residents, so I ask that they pay attention to all the symptoms noted in these reports. The 9/11 Bellevue Program, where I have been evaluated and tested has issued reports. The 2008 report, for example, noted among the various respiratory and other illnesses, the symptoms the doctors called, "tingling hands and feet."

I was tested and diagnosed with reduced lung function by the pulmonary specialists. Since the doctors could identify the medical causes of my "tingling hands and feet," and the Bellevue neurologist to whom my respiratory doctor referred me, for my severe burning in my hands and feet, noted pain sometimes so debilitating, I could not touch anything with my red burning hands, or put my feet on the floor, because any movement and most foods and any change in the temperature triggered the symptoms, I became alarmed when no doctors, not even the doctors in the 9/11 program knew the medical name for these symptoms. I became even more alarmed when my neurologist in the program noted that she had several patients with similar symptoms.

Symptoms the doctors called, "tingling hands and feet," have been noted in the 9/11 reports for many years.

After consulting dozens of doctors who did not know these symptoms, and then finding a dermatologist who said the symptoms were caused by nerves that triggered the peripheral blood vessels to open and not close, and that was what caused the redness and burning, I consulted a vascular specialist and a rheumatologist who referred me to a neurologist. After consulting with a neurologist at Weill Cornell Medical Center, and also with peripheral neuropathy specialists and researchers at Harvard Medical School and Yale Medical School, the doctors and researchers were able to identify the name of the symptoms of tingling hands and feet.

My symptoms were diagnosed as sporadic adult-onset erythromelalgia. Erythromelalgia is a form of peripheral neuropathy.

When I checked with the Mayo Clinic, the specialists there said the ailment was very rare, so I told my 9/11 doctors that they have a cluster. I did genetic screening and other tests to trace the causes. Specialists and medical researchers here and in the Netherlands (where my blood was sent by specialists at Mount Sinai Hospital)

determined that my symptoms were sporadic adult-onset erythromelalgia, triggered by toxins. The lab screened for the SCN9A mutations and genetic damage, related to erythromelalgia. My symptoms are not genetic; they began after exposure to 9/11 dust, debris and toxins. I was especially susceptible, because I live and work here; on 9/11 and after I spent 24 hours being exposed, because I both live and work in the area.

Once my symptoms were identified medically, I was able to work with the neurologists at Weill Cornell to ease them, and although there is no treatment, understanding what the 9/11 doctors called, "tingling hands and feet" in their reports was very beneficial.

Of course I depleted my savings and retirement accounts to determine what these symptoms were. As a resident who had allergic reactions to 9/11 toxins (I was treated at St. Vincent's Hospital's Emergency Room as late as December 2001 when air from the sweltering pit still reached my windows.)

I am writing to you to ask that the scientists who are reviewing the reports and the test results from various patients do a thorough review of the medical symptoms that were noted in the reports, but have not been identified medically as diseases by specialists. It took me years and a small fortune to find specialists at research centers here and around the world to identify the medical condition that our own physicians were unable to identify. Still, I am grateful to the doctors, the practitioners in the 9/11 program who noted the tingling hands and feet symptoms. There were no researchers assigned to determine the underlying medical conditions and the causes. As a patient, I refused to die, because my neighbor across the hall and another neighbor two doors down the hall died from complications in the years after 9/11. The barge that held the debris was under their windows.

A program that investigates medical causes and conditions 10 years after an event of course will miss some things, so I had to write to inform you that some patients like me have done the work that the government specialists should have done years ago. Unfortunately, because of the psychological shock of 9/11, there was delayed attention paid to the medical conditions the toxins caused, especially in 24-hour residents.

I am very proud to be a survivor, for when no one had the answer, I had to check with dozens of doctors and researchers to find out about my tingling hands and feet that more accurately feels like I walked through a field of poison ivy, then someone lit hot iron needles and had inserted them in my hands and feet, sometimes all the way up to my legs and thighs.

Few doctors knew that toxins can trigger the nerves to trigger the blood vessels to cause such pain.

For several years, and currently, I have been a patient of the neurologists, Dr. Norman Latov and Dr. Russell Chin at Weill Cornell Hospital's Peripheral Neuropathy Center.

Neurologists like Dr. Latov should be included in the team of specialists you consult, because they have treated 9/11 patients. Dr. Latov, in his book, *Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop* has a section called, "Neuropathies Caused by Toxins." He says, "Neuropathies can be caused by exposure to certain toxins, including heavy metals and various chemicals. . . . Exposure usually occurs in industrial and environmental settings where multiple people are affected, providing a clue to the cause."

I found Dr. Latov when he was recommended by Dr. Anne Oaklander, a neurologist at Harvard Medical School who is researching primary erythromelalgia. She helped my doctors distinguish between the inherited genetic neuropathies and those triggered by toxins, and she was the one who pinpointed my erythromelalgia, as distinguished from the other neuropathies. The symptoms are bilateral, occurring in both hands and feet.

I also consulted with Dr. Stephen Waxman at Yale Medical School, whose research distinguishes between genetic-based adult-onset erythromelalgia, and new cases of sporadic adult-onset erythromelalgia in patients who have no underlying genetic mutations. He has done extensive genetic research. In his research, he distinguished between primary erythromelalgia, a form of inherited neuropathy and secondary erythromelalgia, "which is triggered by hematologic/circulatory or neurological toxins or metabolic problems." I then consulted Dr. Joost Drenth in the Netherlands, whose research identified what the researchers are now calling tertiary erythromelalgia, triggered by toxins.

As a 9/11 resident and worker (I live and work in the neighborhood), I have experienced all the symptoms of sporadic adult-onset erythromelalgia, from months of exposure. Unfortunately, it took years to identify the name of the disease the 9/11 reports called "tingling hands and feet." I have erythromelalgia, caused by exposure to 9/11 toxins, made worse by metabolic problems caused by ongoing swallowed 9/11 smoke, which caused major nutrient absorption problems in my digestive system, and toxin-impaired nerves that caused rare symptoms in my circulatory system. The disease manifests itself as bright red, burning hands and feet, what the 9/11 reports call, "tingling hands and feet." There is a medical name for these symptoms, it is erythromelalgia.

As you can see, I did extensive research on my own, into what Bellevue's 9/11 medical report noted as "tingling hands and feet."

Thank you.

Sincerely,

Pearl Duncan

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