



January 30, 2024

Dr. John Howard,
Director, World Trade Center Health Program
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, Georgia 30329

Dear Dr. Howard:

I write to you not only as an attorney and retired firefighter of the New York City Fire Department (FDNY) but also as someone who deeply appreciates the decades of dedication you have shown towards the World Trade Center (WTC) community. Your leadership in the WTC Health Program has been instrumental in addressing the health concerns of thousands who were affected by the tragic events of September 11, 2001.

My experience, which includes over 200 hours of work at Ground Zero, has given me a first-hand perspective on the long-term health impacts faced by first responders. In particular, I am writing to address the urgent need to consider including Amyotrophic Lateral Sclerosis (ALS) as a covered condition under the WTC Medical Monitoring and Treatment Program.

The inclusion of ALS is a matter of pressing concern, underscored by several pending petitions, including one from [REDACTED] now battling this devastating disease. These petitions highlight the growing evidence of ALS cases among first responders. In the FDNY alone, there is a potential occurrence of 18 ALS cases within a workforce of about 11,000 affected members, a rate that is alarmingly disproportionate to the general public.

Given your authority under the program's regulations to add new conditions, I urge a thorough review of this situation. The Scientific/Technical Advisory Committee (STAC), under your guidance, is well-equipped to undertake this review. I believe that the recent research and data regarding ALS among first responders warrant serious consideration.

In this effort, the Uniformed Firefighters Association and I am collaborating on the state level with Stacey Amato-Pfeffer from the New York State Assembly, Chair of the Committee on Governmental Employees, and Committee Member Michael Reilly. We are working to add ALS to the presumptions for first responders to apply for disability benefits with New York State. We stand ready to assist and provide any support needed in your endeavor.

Your long-standing commitment to the health and wellbeing of the 9/11 heroes is both recognized and deeply appreciated. Including ALS as a covered condition would be a significant step in continuing to honor and support those who have given so much to our nation.

NAPOLILAW.COM

400 BROADHOLLOW ROAD, SUITE 305 MELVILLE, NEW YORK 11747 | (631) 224-1133



Thank you for your continued service and for considering this important matter. I look forward to the opportunity to contribute to this cause and am hopeful for a positive response.

Yours truly,

[Redacted signature]

ALS through Exposure Risk

Connection through Mechanistic Approach:

ALS AND HEAVY METALS:

2020 study: Blood Metal Levels and Amyotrophic Lateral Sclerosis Risk: A Prospective Cohort

Results found an increase in lead and cadmium poisoning in living ALS patients suggested associations with increased ALS risk.

2019 Study: Heavy Metal Neurotoxins Induce ALS-Linked TDP-43 Pathology

Results: Evidence of a direct mechanistic link between heavy metals, which are a commonly cited environmental risk of ALS, and molecular changes in TDP-43, the primary pathological protein accumulating in ALS.

2019 Study: Occupational Exposures and Neurodegenerative Diseases—A Systematic Literature Review and Meta-Analyses

Results: Weighted relative risk for ALS after exposure to metals and lead led to increased risk of ALS 1.57 to 1 for non-exposure.

FIREFIGHTING AND HEAVY METAL EXPOSURE:

2016 Study: Polycyclic aromatic hydrocarbon (PAH) and metal contamination of air and surfaces exposed to combustion emissions during emergency fire suppression: Implications for firefighters' exposures

Results: These results indicate that firefighters are significantly exposed, via multiple routes, to combustion by-products during on-shift fire suppression. These INCLUDE: Antimony; Cadmium; Lead; Polycyclic aromatic hydrocarbons (PAHs)

WORLD TRADE CENTER EXPOSURE AND ALS

More than 91,000 rescue, recovery and clean-up workers, and volunteers—including virtually all of the Fire Department of New York (FDNY)—were exposed to the environmental hazards at Ground Zero during their work on “the pile” and at other WTC-related locations in the days and months that followed.

The dust from the WTC contains numerous potential neurotoxins, including heavy metals and complex hydrocarbons.

Confirmed cases of ALS with the FDNY: ■ (■■■■■■■■■■) /20 year study post 9/11)

Other FDNY 9/11 cases discovered post-2020: 13

THE NUMBERS

- .. The annual incidence is about 2 per 100,000 people
- .. The annual prevalence is about 4 to 6 per 100,000 people
- .. The mean duration of the disease is approximately 3 years

Firefighters in New York City:

11,000 (approximate)

Expectations for 11,000 members:

Annual incidence (based on confirmed cases): .22 members (should be one every five years)

Annual prevalence: .55 (should be one every two years)

Issues:

- Reporting: No incentive to self-report-not covered condition. Not line of duty.
- Burn Pits: Multiple studies indicate that United States veterans have an increased risk of developing amyotrophic lateral sclerosis (ALS) compared to civilians. However, the responsible etiological factors are unknown. In the general population, specific

occupational (e.g. truck drivers, airline pilots) and environmental exposures (e.g. metals, pesticides) are associated with an increased ALS risk. As such, the increased prevalence of ALS in veterans strongly suggests that there are exposures experienced by military personnel that are disproportionate to civilians. During service, veterans may encounter numerous neurotoxic exposures (e.g. burn pits, engine exhaust, firing ranges). So far, however, there is a paucity of studies investigating environmental factors contributing to ALS in veterans and even fewer assessing their exposure using biomarkers. Studies conducted by epidemiologists at Harvard's School of Public Health published in 2009²¹ and 2015²² further reported evidence for a nearly 60% greater risk of ALS in men with a history of military service in the last century.

Federal government did not know why but they are not waiting for the science to catch up-