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FACSIMILE TRANSMITTAL SHEET

TO:	FROM:
NIOSH Docket Office	**On behalf of the Sergeants Benevolent Association of New York City**
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RE:	YOUR REFERENCE NUMBER:
Docket # NIOSH – 226	

☐ URGENT ☐ FOR REVIEW ☐ PLEASE COMMENT ☐ PLEASE REPLY ☐ PLEASE RECYCLE

NOTES/COMMENTS:

Attached please find the comments of the Sergeants Benevolent Association of New York City on **Docket # NIOSH – 226**, regarding implementation of the James Zadroga 9/11 Health and Compensation Act (P.L. 111-347), as published in the Federal Register on March 7, 2011. Please contact Chris Granberg at (202) 457 – 7755 or CLG@scllaw.com to confirm receipt or if you do not receive all 11 pages.

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SERGEANTS BENEVOLENT ASSOCIATION

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OFFICE OF THE PRESIDENT
EDWARD D. MULLINS

NIOSH Docket Office
Robert A. Taft Laboratories
MS-C34, 4676
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Cincinnati, Ohio 45226

RE: Docket Number NIOSH-226

On March 7, 2011, the National Institute for Occupational Safety and Health (NIOSH), Centers for Disease Control and Prevention (CDC), Department of Health and Human Services (HHS), published a notice in the *Federal Register* seeking public comments on the implementation of the James Zadroga 9/11 Health and Compensation Act of 2010 (Pub. L. 111 – 347) (the Act), signed into law on January 2, 2011. The Act provides long-term health monitoring and treatment services for those first responders and others who have developed a variety of illnesses as a result of exposure to toxins during the rescue and recovery efforts at Ground Zero following the terrorist attacks of September 11, 2001. Currently, there are more than 70,000 individuals from nearly every State in the Union who are being monitored or treated for a 9/11-related illness according to the World Trade Center Health Registry, including many members of the Sergeants Benevolent Association of New York City (SBA), a labor organization representing more than 11,000 active and retired Sergeants of the New York City Police Department (NYPD). Below are the SBA's comments concerning the implementation of the Act.

* * *

The SBA is an independent union that is not affiliated with any national labor federation. It serves as the collective bargaining representative for Sergeants of the NYPD. Our union also manages a variety of programs that benefit our members and their families, including health and welfare programs. Many of the SBA's members were among those who spent countless hours engaged in both the initial response to the attacks on September 11, 2001, as well as the rescue and recovery efforts which followed. To date, there are more than 30 law enforcement officers of the NYPD who, like Detective James Zadroga in whose honor the Act is named, have died from 9/11-related illnesses. This includes SBA members Sgt. Michael Ryan, who passed away in November 2007, and Sgt. Edward Thompson, who passed away in March 2008. Over the course of the last 5 years, the SBA was at the forefront of the legislative efforts to pass the Zadroga Act. On January 26, 2011 the SBA and eight other organizations representing Federal, State and local law enforcement officers wrote to Secretary Sebelius (attached) to express the

organizations' willingness to work with HHS to ensure that the Act was implemented as intended by Congress, and in the best interests of those who are sick and dying from a 9/11-related illness.

Given the work done by CDC, NIOSH, and HHS over the past ten years through the existing World Trade Center health programs, we hope that these agencies will assist the Program Administrator in implementing the provisions of Title I of the Act by the statutory deadline of July 1, 2011. This is particularly true since the Zadroga Act was designed in many respects to simply provide a formal authorization for the existing monitoring and treatment programs. The SBA is, however, concerned about the manner in which several provisions of the Act may be implemented. In particular, our comments focus on the following provisions of Title I applicable to the first responders who were at the World Trade Center site:

1) The provision at Sections 3304 and 3305 (among others) that ensure the confidentiality of participant medical information, while at the same time allowing for data sharing between and among all parties involved in researching and in providing monitoring and treatment benefits to improve these services;

2) The somewhat ambiguous provisions at Section 3311 concerning the coverage and enrollment in WTC Health Program services for those individuals who are not currently undergoing medical monitoring and treatment but may have need of such services in the future;

3) The provisions at Section 3302 establishing several advisory committees that are supposed to include representatives of WTC Responder organizations; and

4) The provisions at Section 3312 requiring the WTC Health Program Administrator to ensure that it begins as soon as practicable to consider cancers and other conditions for inclusion in the list of covered 9/11-related illnesses.

Protecting the Confidentiality of Participant Medical Information

The current medical monitoring and treatment program for NYPD officers at Mt. Sinai ensures that all health care records of participants are confidential and not subject to disclosure by the program to a patient's employer. For our members the employer is the City of New York and the New York City Police Department. The SBA worked closely with the sponsors of the Zadroga Act to ensure that this same confidentiality was built into the law. This was agreed to after the sponsors of the legislation understood that apprehending suspects, investigating crimes, conducting traffic stops, engaging in patrol and response activities, and responding to emergencies requires intense physical and emotional exertion that causes police departments to carefully monitor the health of police officers. Unfortunately, the SBA has seen that sometimes this concern can result in officers being placed on medical leave or assigned to "light" duties other than what they normally perform simply because they are merely suspected of undergoing monitoring or seeking treatment for 9/11-related conditions. Such adverse actions based on incomplete information are neither necessary for the officer's health nor the protection of the public. They do, however, serve as a deterrent for active duty officers committed to their work to obtain the monitoring and treatment that Congress intends for them to receive under the Act. Given these serious concerns with how employers may use their employees' medical records, it is critical that HHS properly interpret the confidentiality provisions principally at sections 3304

and 3305 to continue the iron-clad confidentiality on which participants in the Mt. Sinai program rely. HHS must ensure that employers are not able to obtain access to participant medical records without the participant's affirmative and informed consent. This is the only way to allow all of the intended beneficiaries to take advantage of program benefits without risking adverse personnel actions that could harm their careers.

This is clearly what the congressional sponsors of the Zadroga Act legislation intended by including language suggested by the SBA that ensured the confidentiality of participants' medical records under the newly authorized WTC Health Program. Section 3305(b)(1)(B)(vi) provides that in order to enter into a contract with a Clinical Center of Excellence, it must be shown that the Center has in place proper safeguards to "ensure the confidentiality of an individual's individually identifiable health information, including requiring that such information not be disclosed to the individual's employer without the authorization of the individual."[1] This confidentiality provision serves to mitigate concerns that may otherwise deter many first responders from seeking treatment for their 9/11-related conditions. It is extremely important that these confidentiality provisions be construed, implemented and vigorously enforced by HHS to address the legitimate concerns that prompted them. Similarly, HHS should ensure that the sharing of health data under sections 3304(d) ("Privacy") and 3305(a)(2)(D) ("Transparency of Data") is conducted in such a way as to protect individually identifiable health information.

Ensuring equitable coverage and enrollment in WTC Health Program Services for those individuals not currently undergoing monitoring and treatment

Under Title I of the Act, the World Trade Center Health Program is required to provide medical monitoring and treatment benefits to eligible responders beginning on July 1, 2011. To meet this deadline, the Administrator of the WTCHP is required to enroll in to the program all those who are currently enrolled in existing monitoring or treatment programs by that date.[2] For all "other responders", the Administrator is to enroll in the program any other individual who is "determined to be a WTC responder" at the time such determination is made.[3] This clause is designed to ensure prompt enrollment of those who are determined to be WTC responders but who are not at present undergoing medical monitoring and treatment and cannot be "grandfathered" in to the WTCHP. Unlike currently identified responders, however, there is no date certain by which the Administrator is to enroll these individuals in the WTCHP. It is therefore unclear if the Administrator has the authority to enroll them into the existing program before the provisions establishing the WTCHP take effect on July 1.

Given this ambiguity, it is important for HHS to clarify the process for enrolling those responders who are not currently receiving benefits. This process must be nationwide in scope,

[1] It is important to note that Section 3305(b)(1)(B)(vi) contains a drafting error. In the context of this Section, the reference contained in clause (vi) to section 3304(c) ("Collaboration with WTC Health Registry") does not make sense. The correct reference should be to section 3304(d) ("Privacy"), which describes the confidentiality of participants' individually identifiable health information consistent with "applicable statutes and regulations, including, as applicable, HIPAA privacy and security law (as defined in section 3009(a)(2)) and section 552a of title 5, United States Code." The SBA urges the Department to so interpret Section 3305(b)(1)(B)(vi).

[2] *See* Section 3311(a)(3)(B)(i).

[3] *See* Section 3311(a)(3)(B)(ii).

and include outreach to those in the public safety community who are potentially affected, for a variety of reasons. First, it is reasonable to presume that in the nearly ten years since the 9/11 attacks, numerous potentially eligible responders may have retired and/or moved away from the area served by the existing Centers of Excellence. Second, the response to the 9/11 attacks was similarly nationwide in scope. Police officers and other first responders from across the country traveled to Ground Zero and were exposed to the toxins during the extended rescue and recovery operations at the site. These are individuals who may be unaware that they are at risk for developing a 9/11-related illness, or unaware that they may be eligible for benefits under the WTCHP. In addition, during the last two months of 2010, the legislative push to enact the James Zadroga 9/11 Health and Compensation Act before the adjournment of the 111th Congress received widespread and nationwide media coverage. It is therefore reasonable to expect that HHS will receive (and may have already received) inquiries from individuals suffering from a 9/11-related illness who were unaware that there was a World Trade Center Health Program. We urge the Program Administrator to, at a minimum, use the authority provided under Section 3303 of the Act to conduct outreach to the public safety community through police departments, law enforcement labor organizations, and police fraternal associations to disseminate information regarding this program.

In addition to ensuring that there is a sufficient enrollment process for those responders who are not currently receiving monitoring and treatment benefits, HHS must also ensure that when an individual receiving care at an existing Center of Excellence retires or relocates that there is a seamless transition to one of the providers in the national network. Any WTC responder who is or will be receiving treatment benefits from the WTCHP has already been diagnosed with a 9/11-related condition. Any disruption in medical services while files and paperwork are being transferred from one location to another could lead to a worsening of the condition. In some instances a resultant break in treatment could be potentially life-threatening. In developing the national network authorized under Section 3313, and in studying whether it is feasible to use Veterans Administration facilities for carrying out the national program component, we encourage HHS to also implement the program in a manner that ensures the flow and transfer of medical data to enable this information to follow WTC responders while maintaining the confidentiality and privacy of participant medical information.

Ensuring the effective functionality of the WTC Advisory and Steering Committees

Section 3302 of the Zadroga Act provides for the establishment of three committees comprised of representatives from, among others, the medical, scientific, and responder communities. These are the WTC Health Program Scientific/Technical Advisory Committee, the WTC Responders Steering Committee, and the WTC Survivors Steering Committee. The role of the three committees varies, but all are equally important. That is why we believe it is critical that the plan for implementation provide that these committees be operational at the earliest possible opportunity. This is particularly important in the formative stages, when they should be required to meet more frequently to address issues about enrollment in the program, coverage of various conditions, and other implementation issues that arise. This is particularly necessary with respect to the study on cancer that the Program Administrator is required to complete by July 2011.[4] One of the two primary responsibilities of the WTC Health Program

[4] *See* Section 3312(a)(5).

Scientific/Technical Advisory Committee is to review the scientific and medical evidence and make recommendations on additional WTC-related health conditions.[5] It is to be comprised of toxicologists, epidemiologists, and environmental health specialists, among others. Their expertise and insights could greatly assist the Administrator in both the initial and subsequent reports on including cancer, or certain types of cancer, as covered conditions. Unfortunately, the legislative text does not define in detail the relationship of that Committee to the Study. Given this ambiguity, the SBA urges HHS to exercise its implementing authority to clarify that role and ensure that the exchange of necessary information, data, and research findings begins as soon as possible.

With respect to the WTC Responders Steering Committee established by the Act, we respectfully suggest that the Administrator not impose arbitrary caps on the number of representatives of responder labor organizations who can serve on the Committee. This is in keeping with the spirit of the law, which does not cap the number of public safety labor representatives allowed to serve.[6] With respect to the NYPD, this is extremely important because there are five labor organizations which each represent a specific segment of the City's police force: patrol officers[7], Detectives[8], Sergeants[9], Lieutenants[10], and Captains and above[11]. The Officers who comprise each of these groups and the labor organizations representing them bring different perspectives to the Committee's deliberations. Not allowing each of these segments of the NYPD to have representation on the WTC Responders Steering Committee would not be fair to entire classes of officers and would ill-serve the work of the Committee.

The inclusion of cancer, or specific types of cancer, and additional conditions as covered 9/11-related illnesses

As noted above, the initial determination which the Administrator must make by July 2011 regarding whether cancer or a specific type of cancer should be included as a covered illness is of the utmost importance to the Sergeants Benevolent Association. On September 11, 2001, the New York City Police Department lost 23 officers in the collapse of the World Trade Center. In the nearly ten years since, more than 30 officers have died of a 9/11-related illness, including the following:

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[5] *See* Section 3302(a)(1).
[6] *See* Section 3302(b)(2)(A)(i)(II).
[7] Patrolmen's Benevolent Association
[8] Detectives Endowment Association
[9] Sergeants Benevolent Association
[10] Lieutenants Benevolent Association
[11] Captains Endowment Association

Officer Thomas G. Brophy
Metastic Colon Cancer
April 21, 2005

Officer Ronald E. Weintraub
Cholangiocarcinoma
November 16, 2005

Detective Sandra Y. Adrian
Cancer
January 11, 2006

Detective John T. Young
Lung Cancer
February 19, 2007

Detective Kevin Hawkins
Kidney Cancer
May 7, 2007

Detective Robert W. Williamson
Pancreatic and Lung Cancer
May 13, 2007

Officer Madeline Carlo
Lung Cancer
July 15, 2007

Officer Robert B. Helmke
Cancer
July 28, 2007

Officer Frank Macri
Lung Cancer
September 3, 2007

Sergeant Michael Ryan
Non-Hodgkin's Lymphoma
November 5, 2007

Detective William Holfster
Non-Hodgkin's Lymphoma
January 22, 2008

Sergeant Edward Thompson
Cancer
March 20, 2008

Source: Officer Down Memorial Page[12]

Two of these individuals were NYPD Sergeants and members of the SBA—Michael Ryan and Edward Thompson. Sergeant Ryan worked 70 to 80 hours a week at Ground Zero for several months. He was diagnosed with three different forms of non-Hodgkin's lymphoma and died on November 5, 2007 from the cancer. He was 41 years old. Sergeant Thompson was a 17-year veteran of the NYPD who contracted lung cancer from exposure to the toxic atmosphere at Ground Zero following the attacks and died on March 20, 2008. He was 39 years old. They are just two of numerous individuals who have died from a 9/11-related cancer, and they will unfortunately not be the last. Indeed published reports have noted that the death toll from 9/11-related illnesses in general is nearly 1,000 individuals. We therefore urge the Administrator to not only review all the current scientific and medical evidence in making the initial determination, but to establish a means for the sharing of medical data, scientific findings, and other information between and among the Advisory Committees, CDC, and NIOSH officials for purposes of the periodic cancer reviews. We further request that the Administrator establish a regular (perhaps annual) cycle for making the periodic review and determination on the issue of cancer in 9/11 responders as required by the Act.

Notwithstanding this review and determination which would be generally applicable to WTC Responders and Survivors, we believe that the Administrator has the authority to cover a

[12] www.odmp.org

form of cancer in specific cases under Section 3312 of the Act, which outlines the treatment of enrolled WTC responders for WTC-related health conditions. This section provides that, in addition to WTC health conditions described in the Act[13], treatment is also available to WTC responders for conditions not on the list but that are determined to be medically associated with a WTC-related condition and provided "certification of coverage".[14] This determination of whether the September 11, 2001 terrorist attacks were substantially likely to be a contributing factor in aggravating, contributing to, or causing an individual's illness is to be made by a treating physician at a Clinical Center of Excellence following an assessment of the individual's exposure to airborne toxins or hazards, and the type of symptoms and temporal sequence of symptoms. The Program Administrator (under rules yet to be promulgated) is then required to provide a timely review of these physician determinations and can certify them for coverage.[15] Therefore, the Administrator has the authority to cover a specific type of cancer in individual cases, notwithstanding the review and determination of when to generally add cancer to the list of covered WTC conditions. Given the prevalence of cancer among police officer WTC responders, the SBA respectfully submits that HHS must recognize and utilize this case-by-case discretion to the greatest practical extent.

Ensuring an effective means of data sharing between and among all parties involved in researching and providing monitoring and treatment benefits

There is little doubt that there is a wide range of 9/11-related illnesses, just as there was a wide range in the exposure levels of WTC Responders to airborne toxins. This includes both identified conditions—such as those on the list provided in the Act—but also others, like Asbestosis, which have not yet presented themselves and may not for several more years. No one can know with any degree of certainty the limits of the effects on WTC Responders from the deadly cocktail of toxins thrown into the air on 9/11 and in the smoke of the fires that burned at Ground Zero for the three months that followed. In addition, it is safe to assume that the farther removed we are from September 11, 2001, the more likely it is that individuals who began treatment at one of the Clinical Centers of Excellence in the New York Metropolitan region will move away and need to continue their treatments at one of the providers in the national network.

These are just two of the reasons why it is critically important to ensure that there is an effective means of sharing medical and treatment data among all parties who will be involved in researching and providing health benefits under the program. To aid in this process, the SBA requests that HHS consider the extent to which the Section 3304 requirements for Uniform Data Collection & Analysis and Section 3305 requirements for Data Centers can be harmonized to encourage information sharing. Through an efficient information sharing network, centers and providers within the WTCHP can keep abreast of new or emerging conditions, share information on new treatment protocols, and track trends in the medical conditions of WTC responders and survivors. This timely and efficient sharing of information will aid in the Administrator's determinations of whether to cover additional health conditions.

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[13] *See* Section 3312(a)(3).
[14] *See* Sections 3312(a)(1)(B)(i) and 3312(b)(2)(A).
[15] *See* Section 3312(b)(2)(B).

Conclusion

Nine years ago the heinous and premeditated terrorist attacks of September 11, 2001 claimed the lives of nearly 3,000 American citizens—including more than 70[16] of our fellow law enforcement officers. Our members and other WTC Responders labored untold hours at Ground Zero searching for friends, colleagues, and fellow citizens who were trapped in the wreckage, working alongside volunteers who traveled to New York City from across the country to assist in the rescue and recovery efforts. We did so willingly in an environment more toxic than any we have seen before or since—and with no concern for ourselves. All too many of us sacrificed our health during those weeks and months that followed the attacks. As WTC responders continue to die as a result of conditions connected to their service, the toll of these terrible attacks continues to rise.

The SBA is committed to helping the survivors of 9/11 whose lives are still being impacted and, in some cases, lost, as a result of that terrible day. This is why the passage of the James Zadroga 9/11 Health and Compensation Act was the SBA's top legislative priority. And it is why we are equally interested in the proper implementation of this important Act. While we are grateful for the efforts of the Department of Health and Human Services and its agencies over the years to provide care under the existing World Trade Center health programs, we are committed to ensuring that the Zadroga Act—which was the product of years of effort and negotiation—is implemented as intended by Congress and in the best interests of those who are its intended beneficiaries. The bill was envisioned as the repayment of a debt owed by a grateful nation to those selfless servants whose lives were forever changed on 9/11. The SBA stands ready to do whatever is necessary to assist HHS in ensuring that the implementation of the Zadroga Act reflects these honorable intentions.

Respectfully Submitted,

Ed Mullins
President,
Sergeants Benevolent Association of New York City

ATTACHMENT

[16] In addition to the 23 officers from the NYPD, this total includes officers from the Port Authority of New York and New Jersey, the Federal Bureau of Investigation, New York State Office of Court Administration, the New York State Department of Taxation and Finance, the U.S. Fish and Wildlife Service, and the U.S. Secret Service.

Federal Law Enforcement Officers Association • National Association of Police Organizations •
National Troopers Coalition • Patrolmen's Benevolent Association (NYPD) •
Detectives Endowment Association (NYPD) • Sergeants Benevolent Association (NYPD) •
Lieutenants Benevolent Association (NYPD) • Captains Endowment Association (NYPD) •
Port Authority Police Benevolent Association, Inc.

January 26, 2011

The Honorable Kathleen Sebelius
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Madam Secretary:

On behalf of the undersigned organizations, representing more than 300,000 Federal, State and local law enforcement officers, we are writing to you regarding the implementation of P.L. 111-347, the "James Zadroga 9/11 Health and Compensation Act," signed into law by President Obama on January 2. We are grateful both for the President's support for the bill and for the efforts of the Department and its agencies over the years to provide care under the existing World Trade Center health programs.

The passage of this legislation was a top legislative priority for our organizations. Nine years ago the heinous and premeditated terrorist attacks of September 11, 2001 claimed the lives of nearly 3,000 American citizens—including more than 70 of our fellow law enforcement officers. We labored untold hours at Ground Zero searching for our friends, colleagues, and fellow citizens who were trapped in the wreckage, and worked alongside thousands of police officers, firefighters, construction workers, and other volunteers who traveled to New York City from across the country to assist in the rescue and recovery efforts. We did so willingly in an environment more toxic than any we have seen before or since—and with no concern for ourselves. All too many of us sacrificed our health during those weeks and months that followed the attacks. And some—like Detective James Zadroga before them—are dying as a result of their service. That is why we are equally interested in the implementation of this important Act.

As we begin the New Year, we know that the Department will work diligently on the implementation of the law. Like you, we are committed to ensuring that the Zadroga Act—which was the product of years of effort and negotiation—is implemented as intended by Congress and in the best interest of those who are sick and dying from 9/11-related illness. We stand ready to work with you to do just that and look forward to an ongoing dialogue with the Department.

Sincerely,

Jon Adler

Jon Adler, President
Federal Law Enforcement
Officers Association

Thomas Nee, President
National Association of Police
Organizations

Dennis Hallion, Executive Director
National Troopers Coalition

Patrick J. Lynch
Patrolmen's Benevolent Association

Michael Palladino, President
Detectives Endowment Association

Ed Mullins, President
Sergeants Benevolent Association

Thomas Sullivan, President
Lieutenants Benevolent Association

Roy Richter, President
Captains Endowment Association

Paul Nunziato, President
Port Authority Police Benevolent Association, Inc.

CC: Hon. Kirsten Gillibrand, United States Senate
Hon. Charles Schumer, United States Senate
Hon. Carolyn Maloney, United States House of Representatives
Hon. Peter King, United States House of Representatives
Hon. Jerrold Nadler, United States House of Representatives