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

From: Bilics, Jessica (CDC/NIOSH/OD)
Sent: Friday, April 08, 2011 9:51 AM
To: Miller, Diane M. (CDC/NIOSH/EID); Dragon, Karen E. (CDC/NIOSH/EID)
Subject: Letter for NIOSH Docket #226

Good morning,

Will you please include the attached letter in NIOSH Docket 226 on the implementation of the James Zadroga 9/11 Health and Compensation Act of 2010? The letter is dated March 25, 2011 and is from NYC Health and Hospitals Corporation's WTC Environmental Health Center.

HHC
NIOSHLTR32511.pdf

Let me know if you need any additional information.

Thanks,
Jessica

Jessica Bilics
Public Health Analyst

Centers for Disease Control and Prevention
National Institute for Occupational Safety and Health
202-245-0671
hvg8@cdc.gov

NEW YORK CITY HEALTH AND HOSPITALS CORPORATION
nyc.gov/hhc

World Trade Center Environmental Health Center
Administrative Offices
125 Worth Street • Room 503 • New York • New York • 10013
212·788.3466• Fax: 212·788.5439

March 25, 2011

John Howard, M.D., M.P.H.
Director
National Institute of Occupational Safety and Health (NIOSH)
Patriots Plaza Building
395 E Street, S.W.
Suite 9200
Washington, DC 20201

Dear Dr. Howard:

RE: Comments on Upcoming NIOSH Proposals and Regulations Related to Zadroga 9/11 Health and Compensation Act of 2010

Thank you for the opportunity for us to provide input regarding the interpretation of this legislation, as well as its proposed implementation. Below we outline four specific areas of concern/question.

Cooperative Agreement Preferable to Contract

The language of the Zadroga Act §3305(a)(4) allows NIOSH to use cooperative agreements rather than contracts to fund Clinical Centers of Excellence. NIOSH currently has cooperative agreements in place with partners working to prevent occupational disease and injury. These agreements combine the expertise of federal and non-federal participants to achieve specific public health goals.

Since the inception of our program, staff from the WTC EHC have worked closely and collaboratively with NIOSH. Our work together began with requests for an understanding of the evaluation (physical, mental) and treatment needs of 9/11 responders and survivors. Medical needs were the driving force and in partnership we have worked hard to respond appropriately to those needs. It is our strong belief that the best way to maintain and strengthen this effective working relationship, which has morphed into a clinical center treating 5,200 patients, is through the use of a collaborative agreement.

Most importantly, a cooperative agreement between WTC EHC and NIOSH will provide the needed flexibility to respond to the ongoing, and evolving, medical needs of the patient population we serve. The evolution of those needs over time makes this program different than

many other healthcare delivery efforts, which may lend themselves more easily to a contract reimbursement model.

Further, there is vast precedent at the federal level for grants and cooperative agreements as opposed to contracts to cover medical care. Specifically, and in our opinion offering a strong parallel, decades of HIV/AIDS work through the Ryan White Act has been administered through grants and cooperative agreements.

For us to successfully treat our 9/11 survivor patients, it is imperative that we have the flexibility to act quickly to respond to their needs. A cooperative agreement includes that flexibility, while a contract likely will not. We feel very strongly that a cooperative agreement mechanism is the most appropriate for the delivery of effective, timely medical care for this vulnerable and specialized population.

Ability to Retain and Analyze Data on our Patients

While we are happy to participate in uniform data collection and agree that centralization of data for research and analysis is important, we would like to ensure that Clinical Centers working hand-in-hand with Data Coordinating Centers retain the integrated ability to store and analyze data. We would like to continue to perform CDC "non-research" using this data from our patients. An associated concern is that we continue to have access to the necessary resources to conduct this important work.

Possible Modification of Proposed Terrorist Watch List Procedure

The WTC EHC must register our strong objections to the proposed procedure for checking patient names against the Terrorist Watch list. As drafted, this involves NIOSH sharing names and other identifying information with the Justice Department before patients will be certified to receive treatment.

Our primary concern is that we believe this will erect a huge barrier for patients and prevent many of them from seeking the healthcare they need. The responder and survivor patient population has an inherent distrust for the federal government, which they perceive abandoned them after 9/11. We fear that once they learn about this requirement they will avoid treatment, seek it if and when they become desperate, and at that point avoid coming to a federal Clinical Center of Excellence.

A related concern is that with this barrier in place, fewer patients will come to us for evaluation and care. Instead, those afraid to seek care at the WTC EHC or through the Responder program would most likely seek care through the public system. They are likely to go to emergency rooms or clinics that will be less than ideal to meet their medical needs. In addition, this will add

an obvious monetary burden on WTC EHC, other Clinical Centers and the City (that is already obligated to pay 10 percent of the overall cost of the bill).

We strongly encourage NIOSH to revisit the proposed procedure/process for verification of names so it reduces what we believe is a potentially large impact on patients seeking the care they need – at our clinic or at others.

Pediatric Program and Current Structure/Reimbursement rates

In our reading, current reimbursement rates do not adequately support a pediatric program to provide the comprehensive services necessary and expected within a Clinical Center/Center of Excellence under the new law.

While the pediatric population remains small, relative to the number of people who were exposed on 9/11 and in the days and weeks afterwards, in order to qualify to treat them, we must have a number of pediatric specialists and sub-specialists on staff to render care (e.g. pediatric psychiatrist, psychologist, developmental specialist, pediatric pulmonologist). As an existing clinic, we are fortunate to have pediatricians in place with World Trade Center specific expertise, which they have gained through treating our patients; however we are concerned about our ability to keep them if we are unable to support their salaries and associated costs under new reimbursement rules.

We request latitude in administering the pediatric portion of the program so that we are able to meet the quality of care and Center of Excellence guidelines of the legislation. Without that latitude, we fear that we risk not meeting the required standards.

Again, thank you for this opportunity to share our comments concerning the implementation of the James Zadroga 9/11 Health and Compensation Act of 2010.

Sincerely,

Terry Miles
Executive Director

Joan Reibman M.D.
Medical Director