

# Congress of the United States

Washington, DC 20515

July 11, 2006

Dr. John Howard, MD  
Director  
National Institute for Occupational Safety and Health  
Hubert H. Humphrey Bldg.  
200 Independence Avenue, SW  
Room 715H  
Washington, D.C. 20201

Dear Dr. Howard:

Since your appointment as the first federal coordinator of 9/11 health issues in February, we have been impressed with your commitment to this new assignment. We have heard from many groups and individuals working on 9/11 health issues regarding their meetings with you, and all have reported positive encounters. As we know from our meeting with you in New York on April 28<sup>th</sup>, much work remains to be done before our goal of medically monitoring everyone who was exposed to the toxins of Ground Zero and treating everyone who is sick is achieved. However, the goals that you have laid out are certainly a step in the right direction.

At the April 28<sup>th</sup> meeting you indicated that you see your charge as the federal coordinator of 9/11 health issues as threefold – coordinating existing federal programs, ensuring scientific reporting and identifying unmet needs. We would like to know the status of your review in the areas you laid out.

## **I. Coordinating Existing Programs**

In the first area that you identified, coordinating existing programs, we want to make sure that proper consideration is given to how the newly funded treatment programs will be operated and the involvement of federal employees in the monitoring programs.

With regards to the treatment program, you have informed us that you are involved in developing a protocol for treatment. It is our understanding that funding is scheduled to be released early this fall. As you consider this protocol and the outlay for the funding, we want to ensure that the spend rate and treatment options for this funding is based on the needs of eligible patients, rather than a set rate over a specified date range or specific prohibition on certain treatments. Spending this funding based on need rather than a set rate would be consistent with commitments you have made while testifying before the House Government Subcommittee on National Security, Emerging Treats and International Relations back in February. Additionally, we want to ensure that this treatment program will be available nationwide and not just in the New York metropolitan area.

Another topic heavily discussed at this hearing was the status of medical monitoring of federal employees. We would be interested in the progress that has been made to reconstitute the medical screening program for current federal employees and what has been done to allow former federal employees to participate in medical screening and/or monitoring.

To better understand the status of your work to coordinate existing federal programs, we ask a response to the following questions:

1. What is the projected date for the availability of treatment funding?
2. What is the decision-making process for determining what medical conditions and services will be covered by the treatment program?
3. Will treatment funding cover inpatient care?
4. What will be the governance of the treatment program and how will you ensure that the designated labor representatives of the current monitoring program continue to have a say in the development and implementation of the treatment program?
5. What plans are being developed to care for patients outside of the New York metropolitan area and when will they be up and running?
6. What progress has been made with the medical screening program for federal employees?
7. What has been done to incorporate federal employees who have left federal service into existing medical monitoring programs?
8. How will all of these programs coordinate with each other so that we have a uniform standard for monitoring and treatment?
9. Are there operational or medical justifications for having separate programs or should they be merged?

## **II. Ensuring Scientific Reporting**

The second area that you have identified is ensuring scientific reporting. One of the first projects you have planned for this is to work with the New York City Department of Health and Mental Hygiene to update guidelines for clinicians on 9/11 health effects that can be shared with doctors around the country. The purpose of the clinical guidelines would be to inform doctors about what to look for and how to treat patients who were exposed to the toxins of Ground Zero. It is our understanding that the clinical guidelines should be complete and ready for dissemination early this summer. Please keep us informed on the status of this project.

One issue related to the release of the guidelines is the potential involvement of the City of New York's law department. It has come to our attention that the city's law department may be involved in reviewing the document before it can be released. We would be interested to learn if this is consistent with previous health protocols released by local health departments. It is important that good science is used to determine both the protocols and any causality conclusions.

The potential involvement of the city's law department in the release of a medical protocol or any other 9/11-related research or advisory could potentially raise a conflict of interest between providing the best medical advice for the citizens of New York City, while at the same time protecting the city from potential liability for officially identifying medical concerns directly related to 9/11. One area in which this could be an issue is conclusively linking recent deaths of 9/11 responders with their work at Ground Zero.

In April, when a New Jersey coroner released the autopsy of retired New York City Police Detective James Zadroga, he found scientific evidence that linked his death to exposure to the toxins of Ground Zero. Following the release of the autopsy, the New York City Department of Health and Mental Hygiene challenged the findings and has refused to link the death of James Zadroga or the death of any other 9/11 responder with his or her work at Ground Zero. Similar concerns have been raised with the release of data from the World Trade Center Health Registry. We want to ensure that information gathered by the registry is compiled and released in a timely manner, is scientifically valid, and that measures are in place to ensure reporting is not influenced or prevented by liability concerns.

To better understand the status of your work to ensure scientific reporting, we ask a response to the following questions:

1. What is the status of the release of the clinical guidelines for 9/11 related illnesses by the New York City Department of Health and Mental Hygiene?
2. What is the review process for the clinical guidelines?
3. What is the review process for 9/11-related research and/or presentations produced by the NYC DOHMH?
4. Is it unusual to have a legal review of a medical protocol before it is released?
5. Is there careful monitoring to ensure there are no potential conflicts of interest between the requirement to provide the best health advice and the City's desire to protect itself from liability?
6. Once the clinical guidelines are disseminated, what plans are being developed, if any, to collect information from physicians on the incidence of potential 9/11-related illnesses?
7. How will the federal government collect information about potential 9/11-related deaths?
8. What will be the role of the federal government in making determinations regarding causality for deaths potentially related to work at Ground Zero?
9. What will be done to aggregate data recording recent deaths and future deaths that may have been caused by 9/11 related exposures when multiple jurisdictions and/or states are involved?
10. Are there any reports that link cancers to exposure from 9/11 toxins? If any reports exist, is HHS investigating them and does HHS have an opinion regarding their findings?

11. Are you comparing the rate of new cancers among 9/11 responders and lower Manhattan residents to the expected rate of cancer development in the general population?

### **III. Identifying Unmet Needs**

With regards to the third area which you designated as identifying unmet needs, we are interested in knowing when you anticipate having information available to us. As discussed in our meeting in April, the largest unmet needs you have identified are the lack of treatment for people who are sick as a direct result of 9/11 and the exclusion from any federally funded program of thousands of people who were also exposed to the toxins at Ground Zero, but who are not rescue workers or volunteers. In any report that you prepare, we are interested in specific recommendations about how existing medical monitoring and treatment programs should be expanded and for how long they should operate to fully care for the needs of everyone exposed and who are sick. Specific budget projections would be helpful as we make our case for additional funding for these programs. Moreover, we are interested to learn what budget recommendations you or others at the Department of Health and Human Services plan to make to continue to fund existing programs and to care for the unmet needs.

To better understand the status of your work to identify unmet needs, we ask a response to the following questions:

1. When do you anticipate releasing a report that identifies the unmet health needs related to 9/11?
2. Will these findings take into account the needs of residents, area workers and schoolchildren who were also exposed to the toxins of Ground Zero, but are not currently eligible for any federal program for monitoring or treatment?
3. What is HHS's estimate of the total amount of funding needed over the next two years for medical monitoring and treatment for everyone currently enrolled in a federally-funded monitoring program?
4. What is HHS's estimate over the next twenty years?
5. What is HHS's estimate of individuals who should be a part of a medical monitoring program, but are not eligible since no program exists for them (i.e. residents, are workers, area schoolchildren)?
6. What is the estimated two-year cost for medical monitoring and treatment for individuals who are not eligible, but should be monitored based upon exposure?
7. What is the estimated cost over twenty years?
8. Does HHS have an estimate for the total number of individuals who were exposed to the toxins of 9/11?
9. Will you or the Department of Health and Human Services make any budget recommendations to fulfill these unmet needs?

Again, thank you for the time and commitment you have made to this important problem. We have a tremendous amount of work ahead of us as we ensure that everyone who was exposed is medically monitored and everyone who is sick has access to treatment. As you complete your work, please do not hesitate to contact our offices.

Sincerely,

  
CAROLYN B. MALONEY  
Member of Congress

  
VITO FOSSELLA  
Member of Congress