

QUESTIONS FOR THE RECORD FOR DR. HOWARD
Senate HELP Committee June 29, 2010 9/11 Health Hearing

From Ranking Member Enzi

1) In your verbal testimony, you indicated that, beginning in 2004, NIOSH installed procedures to account for how 9/11 health funds were spent.

a) Please provide a copy of each version of those procedures, and identify their respective effective dates.

Beginning in 2004, NIOSH implemented the World Trade Center (WTC) Responder Health Consortium program by announcing a Request for Applications (see Attachment 1) and awarding eight cooperative agreements to support six Clinical Centers and two Data Centers. Appropriate procedures to account for expenditure of funds were put in place for these awards by placing requirements in the award documents (see Attachment 2), which included standard procedures for submitting annual progress reports, plans for the next year with a budget request, Financial Status Reports that are due 90 days after the end of the budget year, and Cash Transaction Reports that are due 45 days after the end of each Federal fiscal year. There are also references in item 8 of Attachment 2 to OMB administrative guidelines, HHS Grant Administration Regulations at 45 CFR part 74 and 92, and other HHS, PHS, CDC and NIOSH grant administration policy statements, which the grantees agreed to comply with as a condition of their awards.

Beginning in 2007, the program was authorized to provide funding for the treatment of WTC-related health conditions detected through the screening and monitoring exams, and NIOSH added requirements to the Notices of Award to implement quarterly reporting of information on responders participating in the program (see Attachment 3). After discussions between NIOSH and the Consortium members, quarterly reports were adopted to provide more information to NIOSH on the number of participants and the overall costs of the monitoring and treatment components (see Attachments 4 and 5, respectively), which were used to evaluate the status of the program.

b) Please provide a copy of each cooperative agreement, grant, contract or other like instrument between NIOSH and any grantee, vendor or other counterparty regarding 9/11 health matters.

The latest award documents establish the current relationships between NIOSH and all of the components of the WTC Program (see Attachment 6).

- c) Please indicate when Mt. Sinai or another party acted as a subgrantor, provide copies of subgrant procedures and agreements, and identify their respective effective dates.

The Mount Sinai School of Medicine funded the National Responder Monitoring Program through a subcontract, within their grant budget, from 2005 to 2008. Mount Sinai was responsible for providing monitoring services for responders outside of the NY-NJ metropolitan area and issued contracts to several clinics and to QTC, Inc. to conduct the monitoring exams. Mount Sinai used their institutional procedures to establish those contracts, which were required to be in compliance with the standard award provisions mentioned in the answer to question 1) a).

- d) Please identify and provide contact information for the NIOSH employees responsible for administering the procedures and agreements.

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- e) Please identify and provide contact information for all grantee, vendor or other counterparty employees responsible for administering the procedures and agreements.

Contact information for Principal Investigators of the grants and the Project Manager of the contract is provided in Attachment 7.

- f) Please provide a detailed breakdown of how the \$475 million appropriated to NIOSH for 9/11 health purposes was spent. If you cannot provide a complete answer, please explain each information gap, and furnish as complete an answer as you can.

Awards for 9/11 health purposes, plus Federal operating costs, account for \$461 million of the \$476 million appropriated, as shown in the attached table (see Attachment 8). The remaining \$15 million is unobligated and is available to provide supplemental funds to the awards if needed to ensure that the planned objectives are met and to cover potential cost increases of patient care. Unobligated funds that remain at the end of FY 2010 will be carried over to FY 2011.

- 2) Please provide a detailed breakdown by grantee or vendor of sums that the NIOSH program has recouped from workers compensation, disability, private health insurance, public entitlement programs and other benefit delivery systems.

To date, three of the Clinical Centers have recouped a total of \$136,220 funds from workers compensation as shown in the table below. The Community Program has filed claims for recouping funds from private health insurance companies, but no funds have yet been reported to NIOSH.

Institution	Recouped Amount
Mount Sinai School of Medicine	\$127,386
City University of New York (Queens)	\$5,812
State University of New York (Stony Brook)	\$3,022
Total	\$136,220

- 3) Please list all lung transplants and other high cost inpatient procedures performed within the NIOSH program since 2002.

Two FDNY responders have received lung transplants. No other procedures of that high cost have been performed in the program, but there have been numerous lower cost inpatient procedures for both physical and mental health conditions.

- 4) Please list how many patients are being treated for what type of 9/11 related conditions within the NIOSH program now. For each common condition, please identify the usual treatment regimen and itemize the regimen's costs. Please explain whether there are any specialized treatments that only the Centers for Excellence can provide.

The number of responders who were treated for 9/11 related conditions within the past year are displayed in the table below. The number of total patients is greater than the sum of the patients in the health condition categories because many responders have more than one type of health condition. Similar types of health conditions have been observed among the 2,629 patients who were treated in the Community Program within the past year. No data are currently available on the costs associated with these categories because that level of detail on cost information was not required as part of the quarterly reports. However, starting this year, the grantees have agreed to begin developing systems to provide that type of information by next year.

Number of Responders in Treatment from April 1, 2009 to March 31, 2010

Total Patients	13,260
Health Condition Category	
Upper Airway	7,201
Lower Airway	6,592
Gastrointestinal	6,258
Musculoskeletal	1,009
Mental Health	4,601

The special aspect of the Centers of Excellence is that they have a unique group of doctors who have gained a tremendous amount of experience by serving a group of patients who had an unprecedented exposure. The doctors understand the needs and concerns of this group and are able to work collaboratively in teams to provide more comprehensive services, which increases the likelihood of improving the health of responders because they know what to do and what not to do. Below is a list of the main features of Centers of Excellence.

- Utilize an integrated, centralized-provider approach instead of a multiple, separate-provider approach to create a comprehensive suite of health services to an assembled cohort of responders
- Conduct specialized physical and mental health assessments designed to identify acute and emergent morbidities associated with the unprecedented exposure from the WTC 9/11 attack
- Use scientifically-guided treatment approaches to address the complex synergy between physical and mental health diseases that are exhibited by WTC responders and others affected by the 9/11 attacks.
- Maintain electronic linkage with a Data Center to enable a systematic collection of high-quality data for disease tracking and surveillance system, analyzing and interpreting the findings, and integrating the information into the monitoring and treatment program activities
- Communicate with patients in numerous languages
- Assist with workers' compensation, insurance, pension and disability claims

From Senator Dodd

1. How many residents of CT are participating in the WTC National Responder Health Program to monitor and treat responders outside of the NYC metropolitan area? Can you provide the committee with state-by-state data of participants?

As of June 2010, out of over 4,000 responders who are enrolled in the National Program, 3,279 are currently participating and the distribution of these responders by state is given in Attachment 9. There are 40 responders from Connecticut who are participating.

2. How many participants in the WTC Response Program are children?

No children are enrolled in the WTC Responder Program, 53 are enrolled in the WTC Community Program, and nearly 3,000 children and adolescents participated in the baseline survey of the WTC Health Registry.

3. It is my understanding that there are very small numbers of children receiving treatment or monitoring the national program or at the Centers of Excellence in New York. Why is that? What is being done to track longitudinally the physical, and in particular the mental health of children who were at Ground Zero or affected by the loss of a loved one because of 9/11? Why has so little research been done on children?

In an effort to promote the pediatric services offered at the WTC Environmental Health Center (EHC) in New York City (the lead Center in the Community Program), the WTC Health Registry has sent information about these services to all of its enrollees. In addition, the WTC EHC and the NYC Department of Health and Mental Hygiene recently sent information about how to get care for 9/11-related pediatric care to more than 15,000 downtown parents. The WTC EHC provides possible reasons (see below) to explain why so few parents of WTC-exposed children have enrolled them in 9/11-specific health care program of the WTC EHC, despite extensive outreach efforts.

- The WTC EHC is the only program that is able to treat children affected by the collapse of the World Trade Center towers. The six Centers of Excellence in New York (Fire Department of New York, Mount Sinai School of Medicine, State University of New York at Stony Brook, City University of New York at Queens, New York University at Bellevue, and University of Medicine and Dentistry of New Jersey) and the National Program focus on adult rescue workers and responders and were developed from occupational clinics for adults.
- Parents with private health insurance may prefer to initiate or continue their children's care with a community pediatrician. It may be that children eligible and in need of WTC EHC services are far more likely to be insured than adults would be. Having insurance means that the child is likely to be under the continuing care of a local pediatric provider – be that a pediatrician, child health clinic, school health clinic, or a community health center. Many of these pediatric providers may not recognize the presence of a WTC-related illness in their patients. As such, the provider does not see the benefit of referring the child to the WTC EHC.
- In the months and years following 9/11, many families moved out of Lower Manhattan. Children in schools may have transferred or graduated. Identifying and locating these children is challenging.

The World Trade Center Health Registry enrolled nearly 3,000 children and adolescents under the age 18 in its 2003-2004 baseline survey. Findings from the survey were reported in the following publication: *Thomas PA, Brackbill R, Thalji L, DiGrande L, Campolucci S, et al., Respiratory and Other Health Effects Reported in Children Exposed to the World Trade Center*

Disaster of 11 September 2001. Environ Health Perspectives 2008; 116:10. The investigators reported that half (53%) of the children had at least one new or worsened respiratory symptom at some time after 9/11, including shortness of breath, cough, sinus problems, throat irritation, or wheezing (5.7% has new asthma diagnoses). Additionally, eye irritation or eye injury on 9/11 was reported in 22% of children, and injuries (sprains, lacerations, burns, broken bones, or concussions) were reported for 3%. In 2008 the Registry completed its second survey of the physical and mental health conditions among 2,000 children and adolescents who remained under age 18; analysis is currently underway. The Registry plans a third survey of children and adolescents in 2011.

There are several barriers to conducting research among children, including:

- In order to do research on children, parental consent would have to be granted. Parents want to protect their children from further harm by excluding them from research studies. Parents want their children to move past 9/11.
- Parents believe their children are healthy and therefore there is no reason for them to participate in studies.
- Several schools refused to participate in the study, not wanting to perpetuate the focus of 9/11.

From Senator Casey

1. How have the 9/11 World Trade Center programs in existence helped to track, and provide care for, children and youth who were affected that day? What sort of long-term commitment needs to be made to understand how children and youth have been impacted; how do the 9/11 programs discussed today help to do that?

The WTC Environmental Health Center (EHC) in the Community Program has a pediatric component dedicated to the assessment and treatment of WTC-related conditions in children and adolescents. Children who enroll in the EHC program enter it as a *treatment* patient. That is, the child has a WTC-related medical, developmental, and/or mental health problem requiring treatment. All new pediatric patients undergo an initial medical and mental health screening, which is different from the adult program because it is enhanced to include pediatric needs. The EHC offers a wide range of pediatric services including assessment and care by a pediatrician with WTC expertise, a pediatric pulmonologist, or a developmental pediatrician. In addition, children can undergo psychotherapy or psychopharmacologic evaluation and treatment, as needed, with pediatric psychologists or psychiatrists. The recruitment of specialists with these skills who are able to work together in a coordinated manner is a major advantage to treatment. The EHC also offers art therapy and child life services to pediatric patients.

Because there were so many unknowns in the pediatric population, the EHC expanded their inclusion criteria to include children whose mothers were pregnant during the above-referenced time period. Also included are children of sickened responders/rescue workers

and/or children who lost a parent, both parents, or other custodial care taker on 9/11. Although the WTC EHC offers a comprehensive program that includes medical treatment, mental health and developmental treatment programs, there has been a low response to date. However, as news of the program spreads and local pediatricians gain trust in the program, it is anticipated that the program will continue to grow.

The WTC Health Registry does not provide direct healthcare services, but the Registry does the following activities related to children: (1) routinely surveys the health of children and adolescents enrolled in the Registry to determine if changes in their health that may be attributable to 9/11; (2) disseminates its health findings and recommendations to enrollees, and to the public and policy makers; (3) informs enrollees of 9/11-related services, resources and health promotion programs; (4) develops and provides data resources for, and responds to inquiries from, enrollees and the public; and (5) developed and disseminated *Clinical Guidelines for Children and Adolescents Exposed to the World Trade Center Disaster* to physicians and parents in New York City and to college health centers throughout the Northeast.

From Senator Franken

1. Dr. Howard, in your testimony, you discuss the mental health needs of survivors of the 9/11 tragedy, noting that the effects can linger for years. What type of mental health infrastructure do we need to have in place to respond appropriately to the acute and long-term effects of such events?

CDC/NIOSH is committed to providing programs and services to help meet the on-going and long-term health needs of those directly exposed to smoke, dust, debris and psychological trauma in the September 11, 2001 WTC attacks. NIOSH currently addresses the psychological trauma and mental health needs of program participants via the WTC Health Program, NYC Police Foundation's Project COPE and the Police Organization Provided Peer Assistance (POPPA).

- The WTC Program provides monitoring and treatment for both physical and mental health conditions attributed to WTC exposures and embraces a comprehensive model to address the issues that influence long-term recovery of those affected by this disaster. The WTC Clinical Centers work to identify program participants who are suspected of having mental health conditions related to WTC exposures and intervene as early as possible to minimize adverse health impacts over time. Program participants complete standardized mental health symptom surveys as part of their (annual) medical monitoring exam process. The surveys are scored and reviewed by health care staff and used to guide decisions about further mental health evaluation or referral for mental health treatment services. A program participant may also be referred for mental health treatment services as part of the treatment program, should such health complaints or requests be presented to the program provider (physician, nurse or social worker). The WTC Program gathers information to describe the rates and trends of conditions experienced by program participants. Analysis of individual case reports, data from monitoring programs and the WTC Health Registry report that

certain mental health conditions are cited consistently: anxiety, depression or post-traumatic stress disorder (PTSD).

- The NYC Police Foundation's Project COPE and the Police Organization Provided Peer Assistance (POPPA) also provide mental health services, such as counseling and support groups, to the police responder population.

NIOSH and CDC recognize that mental health conditions can be persistent in a small percentage of the WTC Health Program cohort, and may require long-term monitoring and treatment.

List of Attachments:

- 1 [Request for Applications for the World Trade Center Responder Health Consortium in FY 2004](#)
- 2 [Terms and Conditions for procedures in the first-year awards for six Clinical Centers and two Data Centers](#)
- 3 [Additional Terms and Conditions that established Quarterly Reporting](#)
- 4 [Quarterly Monitoring Report](#)
- 5 [Quarterly Treatment Report](#)
- 6 [Award documents for all current components of the WTC Program: NYC Responders, National Responders, NYC Community members, and WTC Health Registry](#)
- 7 [Contacts for each cooperative agreement, grant, and contract that make up the WTC Program](#)
- 8 [Table of funds spent by fiscal year for each cooperative agreement, grant, and contract that make up the WTC Program](#)
- 9 [Table of participants by state in the National Responder Health Program](#)