Congress of the United States

Washington, DC 20515

April 18, 2007

The Honorable David R. Obey
Chairman
House Committee on Appropriations
2358 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Obey:

As you begin Conference Committee negotiations for the U.S. Troop Readiness, Veterans' Care, Katrina Recovery, and Iraq Accountability Appropriations Act of 2007, we respectfully request that you include $283 million for medical monitoring and treatment for responders who were exposed to the toxins of Ground Zero while participating in the rescue, recovery and clean-up efforts after the terrorist attacks on the World Trade Center. We urge you to include $50 million at a minimum for this effort. As you know Senators Clinton, Schumer and Menendez, among others, have managed to include $3.6 million for these purposes in the Senate-passed bill.

In the aftermath of September 11th, responders and volunteers came from every state in the country to assist in the massive rescue, recovery and clean-up efforts. While they worked in and around Ground Zero, they were exposed to a poisonous cocktail of toxins. It is well documented that thousands have become ill because of these exposures.

On March 16, Reps. Maloney and Nadler wrote to you requesting $283 million in the FY2008 Labor, Health and Human Services and Education Appropriations bill for the World Trade Center Monitoring and Treatment Program administered by the National Institute for Occupational Safety and Health (NIOSH). As you know, $283 million is the level of funding that NIOSH most currently estimated they would need per year to continue the current program of monitoring and treatment for responders. Enclosed please find copies of their letter and the internal NIOSH estimates both from December 2006 and January 2007.

While we look forward to working with you on this issue through the regular appropriations process, we strongly believe that taking care of those who responded to the emergency of 9/11 is a mission that must be fulfilled at least in part by emergency spending. The President says that the wars in Iraq and Afghanistan are in response to the attacks of 9/11, calling his effort the "War on Terror." Those who became sick after responding to 9/11 were among the first victims of the War on Terror, and we must not allow this Administration to forget them. To date, nearly all of the money appropriated for the 9/11 health emergency has come in Emergency Supplemental Appropriations bills.

There are several reasons why this program needs funding in the Emergency Supplemental. First and foremost, it is highly likely that the program as it is currently running will not have enough funds to continue its work through the end of the fiscal year.

In addition, there is simply not enough money this year to analyze and coordinate the monitoring and treatment. For example, the phone bank which determines eligibility for entrance into the monitoring program is woefully inadequate to do its job. In addition, there is crucial need for public health-based disease surveillance staff to analyze data generated by the monitoring and treatment programs to identify possible emerging disease patterns. Similarly, more staff is needed to meet the ongoing data collection and clinical coordination needs created by the growing number of participants. Lastly, emergency funding is needed to provide a centralized, coordinated social work unit. Since current funding is spread so thin, all resources are going to monitoring and treatment services, with no resources available to actually analyze the data that is being collected and coordinate the monitoring and treatment itself.

Some have said that we should not continue to fund monitoring and treatment for 9/11 responders in a piecemeal fashion, but rather work toward a comprehensive plan to address the problem. We wholeheartedly agree that a comprehensive plan is needed: that is precisely what we have been calling on the current Administration to produce for many years now. However, since the Administration has consistently refused to provide a comprehensive plan or deliver to Congress a request for all the resources needed, Congressional efforts to move forward on a comprehensive plan are severely hindered.

Examples abound of how the Administration has neglected, and more often refused, to provide the leadership necessary to address the 9/11 health emergency. Here, we will name just a few of the most recent examples. First, knowing that the current monitoring and treatment programs will likely run out of funding before the end of FY07, the Administration has taken no actions to prevent the impending shortfall. In addition, although they finally acknowledged the need for funds by requesting $25 million as a last-minute "placeholder" in the President's FY08 budget proposal, they have taken no real action to amend or update their request to provide anywhere near the funding needed for next year, let alone to address this year's shortfall. Last, although the treatment program which finally began in November 2006 was intended to serve responders across the country and not just those in the New York Metropolitan area, the Administration has not taken steps to ensure sufficient funding to serve responders where they live. Therefore, those who are sick in Wisconsin, upstate New York, California and across the country cannot access the expert treatment they need without traveling to New York City—an expense that those who are out of work because of their sickness often cannot afford.

Until the Administration provides the leadership needed to address this issue, we have no choice but to fund the piecemeal programs in a piecemeal fashion. The responsibility falls on us to ensure that short-term funding continues for the current programs that are helping people each and every day.

Again, we ask that you include $283 million for medical monitoring and treatment for responders who were exposed to the toxins of Ground Zero while taking part in the rescue, recovery and clean-up efforts after the terrorist attacks on the World Trade Center. At a minimum, we urge you to include $50 million for these purposes. As the new majority, we must provide the leadership that the President has not yet shown to care for the heroes of 9/11. I sincerely thank you for your attention to this matter.

Sincerely,

CAROLYN B. MALONEY
Member of Congress

JERROLD NADLER
Member of Congress

ELIOT L. ENGEL
Member of Congress

EDOLPHUS TOWNS
Member of Congress

ANTHONY D. WEINER
Member of Congress

BILL PASCRELL JR.
Member of Congress

JOSEPH CROWLEY
Member of Congress

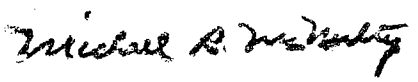
GARY L. ACKERMAN
Member of Congress

GREGORY W. MEEKS
Member of Congress

TIMOTHY BISHOP
Member of Congress

YVETTE D. CLARKE
Member of Congress

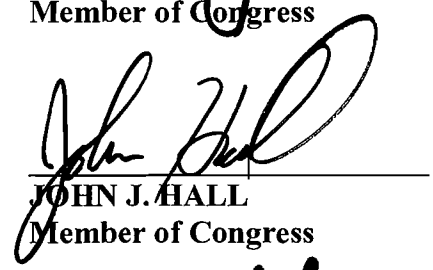
CAROLYN McCARTHY
Member of Congress



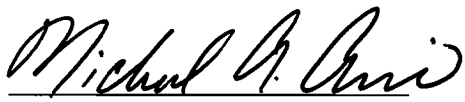
MICHAEL R. McNULTY
Member of Congress

CHARLES RANGEL
Member of Congress

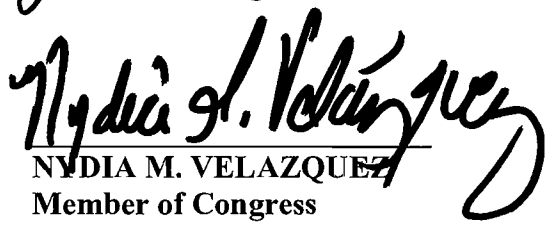
LOUISE McINTOSH SLAUGHTER
Member of Congress



JOHN J. HALL
Member of Congress

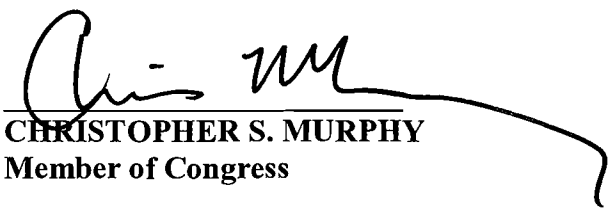


MICHAEL A. ARCURI
Member of Congress

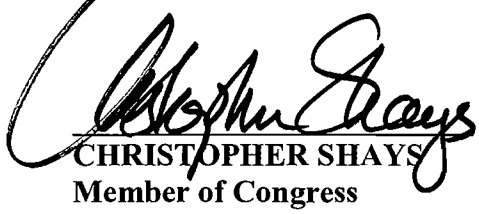


NYDIA M. VELAZQUEZ
Member of Congress

BRIAN HIGGINS
Member of Congress



CHRISTOPHER S. MURPHY
Member of Congress



CHRISTOPHER SHAYS
Member of Congress

JOE COURTNEY
Member of Congress

DONALD M. PAYNE
Member of Congress

KIRSTEN E. GILLIBRAND
Member of Congress

Cc: The Honorable Nita M. Lowey
The Honorable José E. Serrano
The Honorable Maurice D. Hinchey
The Honorable Steve Israel

World Trade Center Monitoring and Treatment Program
Revised Estimate of Annual Costs
January 30, 2007

Background:
In October, 2006 NIOSH committed approximately $58 million for the treatment of World Trade Center (WTC) Responders. These funds are to provide comprehensive medical services for morbidities that are the direct result of WTC exposures that have been identified in the responder population. All medical services and medications needed to treat WTC morbidities are covered by this program. This funding provides continuation and expansion of the medical services provided by philanthropic funding particularly the American Red Cross. In addition, insurance companies excluded WTC responder morbidities as the morbidities are work related.

Population:
As of January 2007, there are approximately 34,000 registered responders (participants) in the WTC treatment and monitoring program. This group is comprised of 14,000 FDNY and 20,000 other responders (includes the National Program). Although this program has been ongoing for approximately four years, the other responder population continues to expand as previously unregistered responders develop WTC morbidities and seek treatment.

Morbidities and Treatment Costs:
To date, the WTC responders have presented with three broad types of morbidities; aerodigestive, musculoskeletal, and mental health. Based on additional analysis of the data from the initial WTC health screening, estimates for the incidence of the morbidities in the participant population have been recalculated. In addition, data from the monitoring exams are strongly suggestive that these morbidities are not resolving and the incidence rates are the same or higher.

Two tables are attached showing the population groups, cohort sizes, morbidities, percentage affected, number of patients, protocol level, protocol costs, and treatment costs. One table shows a cost estimate of $283 million under the assumption that all eligible participants in the cohort will participate. The other table shows a lower cost estimate of $229 million under the assumption that 75% of the cohort will participate. Documentation for data in the table is included in the worksheets contained in the spreadsheet.

This annual cost estimate will increase in future years if more responders are affected, conditions do not resolve with treatment, costs of treatment increase, new conditions are determined to be associated with the WTC exposure from scientific analysis, and new special needs develop such as administrative costs for an expanding National Program as people relocate.

Indirect Costs:
In addition to the direct treatment costs, there are other essential patient management costs associated with treatment. These costs include such items as infrastructure costs (rent, telephones, record security, advisory committees, and financial management), benefit counselors, patient coordinators, data management and analysis, contract management, and general program management. Based on experience these costs are estimated to be 30 percent of the direct cost.

Emerging Issues:
In addition to the WTC morbidities that have been identified to date, there are a number of other morbidities that are likely to emerge over time. These include complicated orthopedic diseases, late emerging diseases such as interstitial pulmonary fibrosis, cancer, and Rheum Autoimmune disease. At present the program has no cost estimates or incidence estimates. It will be necessary to carefully monitor the participant population for these diseases.

Hospitalization:
The program has no experience on the number of hospital procedures that will be required for this group. For this estimate, it is assumed to be 5% to 7% of the annual treatment direct costs which is $7.5 million for the full participation model. These costs will increase significantly over time.

Special Needs:
Many of the non-FDNY responders are non-English speaking, and there are significant additional costs to the treatment program for translators and translation efforts. It is estimated that for each non-English patient the cost will be approximately 35% higher depending on the language. Based on 20 percent of the patient population as non-English speaking, the additional cost for the treatment program will be approximately $5 million.

Monitoring Program:
In order to deliver the treatment program effectively, it is necessary to continue the monitoring program for the participant population. This program consists of a monitoring exam every 12 months and a health contact every 6 months, with different costs for treatment and non-treatment participants.

Summaries of the Annual Cost Estimates for the Treatment and Monitoring Program are given below (see attached tables for details):

Participation	100%	75%
Direct Outpatient Health Care	$150,625,939	$112,969,454
Direct Inpatient Health Care	$7,531,297	$5,648,473
Direct Special Needs	$5,245,316	$3,933,987
Direct Participant Management Services	$15,255,000	$11,441,250
Direct Monitoring of Treatment group	$10,170,000	$7,627,500
Direct Monitoring of Non-Treatment group	$20,490,000	$28,117,500
Total Direct Costs	$209,317,552	$169,738,164
Indirect Costs	$62,795,266	$50,921,449
Federal Administration	$10,884,513	$8,826,385
Total Annual Costs	$282,997,330	$229,485,998

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World Trade Center Monitoring and Treatment Program
Initial Estimate of Annual Costs

Background:
In October, 2006 NIOSH committed approximately $58 million for the treatment of World Trade Center (WTC) Responders. These funds are to provide comprehensive medical services for morbidities that are the direct result of WTC exposures that have been identified in the responder population. All medical services and medications needed to treat WTC morbidities are covered by this program. This funding provides continuation and expansion of the medical services provided by philanthropic funding particularly the American Red Cross. In addition, insurance companies excluded WTC responder morbidities as the morbidities are work related.

Population:
As of September, 2006, there were approximately 32,000 registered responders (participants) in the WTC treatment and monitoring program. This group is comprised of 14,000 FDNY and 18,000 other responders. Although this program has been ongoing for approximately four years, the other responder population continues to expand as previously unregistered responders develop WTC morbidities and seek treatment.

Morbidities and Treatment Costs:
To date, the WTC responders have presented with three broad types of morbidities; aerodigestive, musculoskeletal, and mental health. Based on the analysis of the data from the initial WTC health screening, estimates for the incidence of the morbidities in the participant population have been calculated. In addition, data from the monitoring exams are strongly suggestive that these morbidities are not resolving and the incidence rates are the same or higher.

Morbidity Type	% Affected	Expected Patient Number*	Annual Cost per patient	Annual Cost all patients
Aerodigestive	30	9,600	$9,529	$91,200,000
Mental Health #				
Medicated	10	3,200	$8,811	$28,195,200
Non-Medicated	15	4,800	$6,200	$29,760,000
Musculoskeletal %	5	1,600	$9,000	$14,400,000
			Annual Direct Total	$163,555,000

* Participant population size is 32,000 which is used to calculate patient number
# Mental health patients may or may not require medication.
% Musculoskeletal patient costs are based on very few numbers. In a number of cases surgery is needed to correct the condition which will be more costly.

It should be noted that over 50% of the costs are for pharmaceuticals, and it is anticipated these costs will increase over time.

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In Direct Costs:

In addition to the direct treatment costs, there are other essential patient management costs associated with treatment. These costs include such items as infrastructure costs (rent, telephones, record security, advisory committees, and financial management), benefit counselors, patient coordinators, data management and analysis, contract management, and general program management. Based on experience these costs are estimated to be 30 percent of the direct cost. For the estimate above, this would be $49,066,500.

Emerging Issues:

In addition to the WTC morbidities that have been identified to date, there are a number of other morbidities that are likely to emerge over time. These include complicated orthopedic diseases, late emerging diseases such as interstitial pulmonary fibrosis, cancer, and Rheum Autoimmune disease. At present the program has no cost estimates or incidence estimates. It will be necessary to carefully monitor the participant population for these diseases.

Hospitalization:

The program has no experience on the number of hospital procedures that will be required for this group. For this estimate, it is assumed to be 5% of the annual costs which is $8,000,000. These costs will increase significantly over time.

Special Needs:

Many of the non-FDNY responders are non-English speaking, and there are significant additional costs to the treatment program for translators and translation efforts. It is estimated that for each non-English patient the cost will be 25-50% higher depending on the language. Based on 10 percent of the patient population as non-English speaking, the additional cost (using a 35% average) for the treatment program will be approximately $6,000,000.

Monitoring Program:

In order to deliver the treatment program effectively, it is necessary to continue the monitoring program for the participant population. This program consists of a monitoring exam every 18 months and a health contact every 12 months. This cost is approximately $1,500 per participant per year for a cost of approximately $45,000,000. Because of cost savings when combined with the treatment program, it is estimated the costs would be 2/3 or $30,000,000 per year.

Annual Cost for the Treatment and Monitoring Program

Direct Health Care Delivery	163,555,000
In Direct Costs	49,066,000
Hospitalization	8,000,000
Special Needs	6,000,000
Monitoring Program	30,000,000
Emerging Conditions	?
Total Annual Costs	$256,621,000

Congress of the United States

Washington, DC 20515

March 16, 2007

The Honorable David Obey
Chairman, Subcommittee on Labor,
Health and Human Services, and
Education
House Appropriations Committee
2358 Rayburn House Office Building
Washington, DC 20515

The Honorable James T. Walsh
Ranking Member, Subcommittee on Labor
Health and Human Services, and
Education
House Appropriations Committee
1016 Longworth House Office Building
Washington, DC 20515

Dear Chairman Obey and Ranking Member Walsh:

As your Subcommittee prepares to consider the Fiscal Year 2008 Appropriations Bill for the Department of Health and Human Services, we urge you to recommend at least $282,997,330 for the World Trade Center Monitoring and Treatment Program administered by the National Institute for Occupational Safety and Health (NIOSH), which provides comprehensive medical services for morbidities that are the result of WTC exposures in the responder population.

The attacks of September 11, 2001 were attacks on the United States, not just New York City. In the aftermath, responders and volunteers came from every state in the country to assist in the massive rescue, recovery and clean-up efforts. While they worked in and around Ground Zero they were exposed to a poisonous cocktail of toxins.

As of January 2007, the World Trade Center Monitoring and Treatment Program provides medical monitoring and treatment for 34,000 responders who were exposed to the toxins of Ground Zero. This group is comprised of 14,000 from the New York City Fire Department (FDNY) who are currently enrolled in the FDNY World Trade Center Monitoring and Treatment Program and 20,000 other responders, who are currently enrolled in the WTC Medical Monitoring and Treatment program, a consortium coordinated by Mt. Sinai Hospital in New York, NY.

We are pleased that the President's Fiscal Year 2008 budget proposal included $25 million for "expenses to provide screening and treatment for first response emergency services personnel related to the September 11, 2001, terrorist attacks on the World Trade Center." However, it is clear that $25 million will not come close to meeting the needs to continue the current program. In fact, an internal estimate from NIOSH dated January 30, 2007, shows that the total annual costs for the current program will be $282,997,330. This estimate will certainly increase in future years as more responders experience symptoms or learn about available services, conditions do not resolve with treatment, costs of treatments increase, new conditions are determined to be associated with WTC

exposure, and new special needs develop. In addition, it does not take into account diseases that are likely to emerge over time, including pulmonary fibrosis and cancers. Last, it is important to note that this estimate only covers responders who are in current programs, not area residents, office workers, and students who were also exposed and have become sick as a result of 9/11.

Understanding the limits of this NIOSH estimate and knowing that it is probably a very conservative estimate of what will be needed, we urge you to recommend at least $282,997,330 for the World Trade Center Monitoring and Treatment Program administered by NIOSH.

Sincerely,

CAROLYN B. MALONEY
Member of Congress

JERROLD NADLER
Member of Congress