

Dear 9/11 Responders:

This issue of the *WTC Responder Health Watch* is dedicated to answering questions many of you have raised as participants in the World Trade Center Medical Monitoring and Treatment Program (WTCMMTP). We reviewed the questions you sent us by e-mail, and talked to the Phone Bank workers who pick up your calls to find out what questions you are asking them. We asked doctors, nurses, therapists, social workers, and your labor union representatives: What do 9/11 responders want to know about our program? What are their concerns? What answers do they need from us?

We learned that there are a few pressing questions that many 9/11 responders have asked time and time again over the lifetime of our program. These questions are:

1. Is my health information kept safe and confidential? How? (Pg. 2)
2. How are decisions made about what illnesses are covered by the program? (Pg. 2)
3. Why are the medical monitoring exams so long? Why do I have to answer so many questions over and over again? (Pg. 3)
4. Is this program a research project and what does that mean for me? (Pg. 4)
5. How is my health information being used by the program? (Pg. 5)

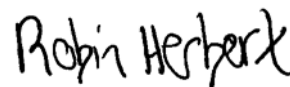
You will find answers to your questions in this newsletter, and we hope that the information will be helpful to you and your loved ones in better understanding the care you are receiving from our program.

We are aware that these may not be the only questions you have. But, hopefully, this is a helpful and informative place to start. Your concerns matter to us, and I encourage you to contact us at any time to ask a question or give us feedback. You can reach us by telephone at 888-702-0630 and by e-mail at wtcexams@mssm.edu.

We want to know your questions and concerns as they help us to better understand and meet your health-care needs.

Have a happy and healthy summer. I look forward to hearing from you.

Sincerely,




Robin Herbert, MD
 Director, The World Trade Center Medical Monitoring and Treatment Program Data and Coordination Center, Associate Professor of Community and Preventive Medicine, Mount Sinai School of Medicine, NY, NY

Clarification on Benefits Assistance

We want to clear up some confusion that may have been caused by an article about benefits assistance in the previous issue of the *WTC Responder Health Watch*.

At all Clinical Center locations in the New York/New Jersey metropolitan area (locations listed on mailer page), there are social workers and other staff available who can answer questions about Workers' Compensation, assist 9/11 responders in finding healthcare resources, and provide help with other disability-related resources and the Crime Victims' Board. The same social workers and other staff can also make referrals to agencies that may give you assistance with housing issues, legal aid, financial assistance, other basic needs such as food and utilities, and vocational training. However, the Clinical Centers' staff do not provide direct assistance with those needs.

Responders who are enrolled in the National Program (outside of the New York City area) may contact Logistics Health Incorporated (LHI) at 1-877-498-2911. The National Program is not currently designed to provide direct social service counseling; however, LHI can provide social service points of contact upon request.

Letter from a 9/11 Responder

1.) Is my health information kept safe and confidential?

DEAR WTCMMTP: I've been to the WTCMMTP and your doctors are taking care of my asthma and Post Traumatic Stress Disorder. I'm a police officer, and, in my line of work, you can run into a lot of problems if your employer finds out you are seeing a counselor for emotional issues. I'm happy with my treatment, but I'm nervous about this. I certainly can't afford to lose my job right now. Would your program ever give any of my health information to my employer?

— CONCERNED COP

DEAR CONCERNED COP: NY State law and the federal Health Insurance Portability and Accountability Act (HIPAA) protects the confidentiality and safety of your protected health information (PHI)*. Under the law, we are required to keep all your personal and medical information confidential and secure. We may not give any part of your PHI to your employer without your written permission. Even the fact that you have had a mental health encounter is protected and may not be released.

YOURS TRULY,
THE WTCMMTP DATA AND COORDINATION CENTER

*PHI includes demographic, psychosocial, clinical, and financial information.

How do we keep your information safe?

All your data is stored electronically in servers (computers) in a secure location according to industry standards and best practices. We restrict access to program data to authorized workers (such as doctors, nurses, schedulers, etc.). Each of them has an individual user account and password that can be audited, if needed. Authorized workers are not allowed access until after they have completed a series of training sessions that deal with privacy of information and data security.

— Jon Mercado, Director of Data Management, WTCMMTP,
Data and Coordination Center



2.) Q: How are decisions made about what illnesses are covered by the program?

A: First, exposure and health information was collected from 9/11 responders participating in the World Trade Center (WTC) Screening and, later, Medical Monitoring programs. Then, doctors and public health professionals reviewed the findings and counted the number of participating 9/11 responders with the same health conditions.

The conditions covered by this program fall into three categories:

1) Conditions found in a large number of 9/11 responders;

2) Conditions that occur less often but have enough of a scientific basis to link them with WTC-related work exposures;

3) Unusual conditions that may occur, and often take years to develop, as a result of WTC-work exposures.

The health of 9/11 workers continues to be monitored. New conditions are added to the list of covered conditions as indicated. For a complete list, see <http://www.cdc.gov/niosh/topics/wtc/FAQ.html>

3.) Why are monitoring exams so long?

Responders often ask us why medical monitoring exams take so long. In fact, some of you have told us that they are too long, making it difficult for you to take the time to come in for follow-up monitoring visits.

This concerns us. Your time is very valuable. We recognize that the exams are lengthy.

In order to best answer this question, we asked the directors of all the Clinical Centers of our program to explain why the exam is designed the way it is, why it is so long, and why it is also well worth your time to undergo monitoring exams.

A proactive approach

Most of the time, people go to the doctor when they are feeling sick. They tell the doctor about a specific problem or symptom, the doctor makes a diagnosis and prescribes treatment. That can take as little as a few minutes.

Here, we take a proactive approach to your medical care by making it our responsibility to identify every symptom you feel or have felt since September 11, 2001 so that we don't miss anything. That means our exams take more time than a typical doctor's visit, but **we get a more complete picture of your health.**

We based the exam's questionnaires on the exposures we knew were present at the WTC site as a result of the 9/11/01 terrorist attacks. Some of those exposures—both physical and

psychological—are known to cause specific health conditions. The medical monitoring exam is designed to screen for every health **condition that could be caused** by any of the exposures that we know were present at the WTC site. So, we ask systematically about every possible symptom for every known condition that could be caused by those exposures. For example, when we ask about a cough, we also ask how long you've had it, whether it's dry or wet, and even the color of your phlegm. This way, we are sure we have covered all the bases. We also give you an opportunity to tell us about any unusual symptoms you may be experiencing that are not asked about in the questionnaires.

We take a proactive approach to your medical care by making it our responsibility to identify every symptom you feel or have felt since September 11, 2001.

Not just talk

In addition to the questionnaires, we evaluate your health with blood and urine tests, a chest x-ray every other year, and a pulmonary function test (PFT).

PFTs give us information about your lung function. And if you get one regularly, we can see changes over time. It can tell us whether your lung function has been reduced by more than what would be expected as part of the normal aging process. And, sometimes this can happen even if you don't feel any symptoms. As a result, we feel it is very important that responders have a PFT at each and every monitoring visit even if feeling well.

Standard blood and urine tests are another tool to evaluate your health. They might identify problems that are WTC-related. Or, they might identify problems that are not WTC-related, such as diabetes and hypertension. We believe it's important for a monitoring exam to be as comprehensive as possible—to screen not only for health conditions known to be caused by WTC exposures, but for other general medical conditions as well. It is part of your health, and even if it is not WTC-related, we can make a referral for your treatment. And this can be especially helpful for responders who don't go to see doctors on a regular basis.

Early detection

There are certain conditions that can appear years after exposure to a toxin. The monitoring exam is designed to help us catch developing health problems early so that you can get the **treatment needed in a timely manner.**

(continued)



Finding patterns

Every monitoring exam helps us learn more about 9/11 responder health. By looking at how all the responders in our program are doing, we can find trends in

health status, and see any spikes in diseases. It is through looking at trends that additional medical conditions could become covered by the program.

Thorough, personal care

At the WTCMMTP, you can have a nurse or doctor spend an hour or more with you, asking you about your health. If you feel okay—that's great—a full health evaluation will confirm that you are healthy. But sometimes people forget or ignore symptoms, especially if they not very severe. But when a doctor asks them some of these questions, it reminds them of the problem. This is important because **catching problems when they are minor helps prevent bigger problems later.**

4.) Is the WTCMMTP just a research project?

We hear this question a lot, and it makes perfect sense! After all, during your monitoring exam, we ask you so many questions. At times, it must **feel like you're being "studied."**

The primary purpose of this program is to provide 9/11 responders with comprehensive medical monitoring exams, expert medical and mental health treatment, and social services assistance. The answers you give us help us better understand your healthcare needs, so that we can provide you with the best care possible.

In addition to providing medical monitoring exams and treatment, the WTCMMTP performs two functions that you may think of as "research."

1. **Public health reporting.**

The information is reported to government agencies and legislators to show that 9/11 responders have ongoing healthcare needs. In order to do this, the program reviews and analyzes

the health information reported by 9/11 responders who participate in the program in order to identify patterns of symptoms and illnesses common amongst large numbers of responders. (Before this happens, we "**de-identify**" **the information**, meaning we take out information such as your name, contact information, social security number, and other things that can be traced back to you specifically. For more on de-identification, please read "What does it mean that my information is de-identified?" on page 5.)

We ask so many questions during your medical exams so that information can be collected in a thorough and standardized way. This information helps us improve medical and mental health treatment for 9/11 responders who participate in the program. In other words, the health information you give us not only helps you-- it helps all 9/11 responders being

seen in the program.

2. **Actual research.**

Researchers use the information you give us to try and answer questions they pose. Papers are published based on the findings, and these publications both increase the understanding of the health effects of 9/11 on responders and the health effects of disaster recovery in general.

It is important for you to know, however, that you do not need to participate in the research part of the program in order to receive services. During your medical monitoring exam, a nurse or other staff member will explain this to you. You will have the opportunity to choose whether you want your information to be used. That information will be recorded on a consent form that you sign during your visit. If you choose to opt out there is absolutely no penalty to you at any time.

5.) How is my health information being used by the program?

We're glad you asked! The health information you give to the WTC MMTP is helpful in many ways and to many people. Below, we list some of the ways in which your information is useful and helpful:

1 Your health information directly **HELPS YOU**. Program doctors use what you tell us about your medical symptoms to:

- Help them detect any health issues you might have at the time of the exam so that you can get treated as soon as possible for any and all conditions, whether 9/11-related or not;
- Write you a detailed letter about the findings of your monitoring exam so that you have a written summary of your health status at the time of visit;
- Keep track of your health and any changes that occur over time.

2 Your health information directly **HELPS OTHER 9/11 RESPONDERS**. Your health information is de-identified (for more about de-identification, see box at right) and grouped with other participating responders' health information so that we can:

- Identify patterns of illnesses among responders in our program to better understand the health effects of 9/11 on WTC responders and how to treat them;
- Identify new diseases emerging in the responder population over time so that we can modify our program-covered conditions to ensure you get the treatment needed;
- Track whether certain conditions worsen or get better over time to evaluate whether treatment has been effective;
- Provide responder health data to program allies to help them advocate for legislation that pays for your medical care in this program;
- Provide responder health data to worker allies to help them advocate for legislation important to responders and workers in general (such as Workers' Compensation law).

3 Your health information **HELPS FUTURE DISASTER RESPONDERS**. Health information gathered from 9/11 responders:

- Illustrates how an environmental disaster changed the health of responders;
- Influences policies and procedures to better protect responders in the future.



What does it mean that my information is "de-identified?"

Before we analyze the health information of 9/11 responders in our program for trends and patterns in symptoms and illnesses, we take out all information that can be traced to you, your family, or your employer. Federal law mandates that we remove 19 data elements including your name, address, telephone number, other contact information, birth date, social security number, medical record number, the dates of your medical visits, Health plan beneficiary number, Account Numbers and any other identifier. (45 CFR 164.514(e)(3)(ii)).

For more information regarding how your information must be de-identified go to:www.lawyersandhipaa.com/514.htm#514a



WTC MEDICAL MONITORING & TREATMENT PROGRAM PARTICIPATING CLINICAL CENTERS

■ Mount Sinai - Irving J. Selikoff Center for Occupational & Environmental Medicine

■ Bellevue Hospital Center/NYU Occupational & Environmental Medicine Clinic

■ Long Island WTC Medical Monitoring and Treatment Program, SUNY Stony Brook

■ The World Trade Center Medical Monitoring and Treatment Program, Queens Clinical Center

■ UMDNJ Environmental & Occupational Health Sciences Institute

These Clinical Centers offer medical monitoring exams, medical and mental health treatment, and social services assistance at locations in Manhattan, Queens, Staten Island, the Hudson Valley, Long Island (Suffolk and Nassau counties), and Piscataway, New Jersey.

For more information, to make an appointment, or to register, call 888-702-0630



WTC Medical Monitoring and Treatment Program

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Address Service Requested

The World Trade Center Medical Monitoring and Treatment Program Data and Coordination Center

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We welcome feedback.

To update contact information or clinical center preference, call us or visit www.wtexams.org and click on "Forms."

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