



## **The World Trade Center Registry: *What You Need to Know***

*Many questions and concerns have been raised about the Registry. Here are some issues you might want to consider before deciding whether or not to enroll.*

Among the tragic events of September 11th was the potential exposure of thousands of people to the toxic chemicals released during the explosion and collapse of the World Trade Center towers. Two years after the attacks, the New York City Department of Health and Mental Hygiene, partnering with the United States Agency for Toxic Substances and Disease Registries, has introduced a project to identify and track some of the people who were in Lower Manhattan on 9/11 and after to determine the long-term effects of exposure. This project, the World Trade Center Registry, is an important step. However, a number of concerns raised by scientists, labor unions, and community organizations are not easily dismissed.

### **What is the World Trade Center Registry?**

The World Trade Center Registry is an attempt to study the physical and mental health effects of September 11th. Health registries have several purposes, including:

- ✓ Tracking a disease or condition.
- ✓ Collecting information on exposure.
- ✓ Helping doctors and scientists prepare for disasters.

Health registries are often set up following disasters and have provided useful information. For example, the health registry set up after the Oklahoma City bombing in 1995 found that nearly half of the survivors suffered from a post-disaster psychiatric disorder.

### **What are the criteria for enrollment in the World Trade Center Registry?**

You must have been in at least **ONE** of the following situations:

- ✓ In a **building**, on the **street**, or on the **subway** south of Chambers Street on 9/11/01 in Manhattan.
- ✓ Involved in **rescue**, **recovery**, or **clean-up** effort (including as a day laborer or a janitor) at one or more of the following locations on or after 9/11/01:
  - The **WTC area**, which is bounded by Chambers Street, Broadway, Rector Street and the Hudson river;
  - **WTC Operations on Staten Island**;
  - And/or **the barges** that carried debris between these sites.
- ✓ A **student** or **staff member** at schools (pre K-12) or day care centers south of

- ✓ Canal Street or after on 9/11/01 in Manhattan.
- ✓ **A resident** living south of Canal Street on 9/11/01 in Manhattan.

### **How does the WTC Registry work?**

- ✓ You will be given a 30-minute telephone survey. You will be asked detailed questions about your physical and mental health.
- ✓ Interviews will be conducted in English, Spanish, Cantonese, Mandarin and other languages.
- ✓ The Registry intends to follow subjects' health for the next twenty years.
- ✓ Participation in the Registry will not lead to medical or mental health care, nor will it provide participants with any type of financial compensation.
- ✓ You can drop out of the Registry at any time.
- ✓ Enrollment will not create a record that can be used in litigation.

### **Will the WTC Registry help people who became sick due to exposure on 9/11?**

The World Trade Center Registry will **not** provide medical advice or consultation now or in the future, but it may refer you to health studies that involve treatment.

### **REMINDER!**

You may have access to medical treatment and compensation for 9/11-related injuries regardless of whether you participate in the registry. Please see the **Resources** section of this factsheet for more information.

### **What are some reasons to consider enrolling in a health registry?**

The unprecedented nature of the September 11th made it difficult for medical professionals to predict its impact on public health. It is hoped that by tracking participants for the next twenty years, important information will be learned that will help in dealing with future disasters. Researchers may also learn about WTC-related health problems and their potential treatments. People who enroll can also receive information about health studies and programs related to 9/11.

### **What are some of the concerns being raised about the Registry?**

#### **1. Eligibility**

Some people who may have been exposed to toxic contaminants on or after 9/11 are excluded from participation in the Registry, such as:

- ✗ People working above Chambers Street or living above Canal Street in Manhattan or in other locations, despite evidence that WTC contaminants affected areas beyond Lower Manhattan;
- ✗ Day laborers and janitors who cleaned up toxic dust outside of the WTC site area, which is bordered by Chambers Street, Broadway, Rector Street and the Hudson river;
- ✗ Teachers and students at schools (pre K-12 and college) who were **not** in Lower Manhattan on 9/11/01 but who returned to work or school near the WTC during

the following months and may have been exposed.

- ✘ People who work downtown but were not present on 9/11, even if they returned to work and were exposed to contaminants after 9/11.

## **2. Study Design**

Scientists and medical professionals have concerns about the design of the study, such as:

- ✘ The Registry may not accurately capture the extent of adverse health outcomes. Actual incidents of illness may be overlooked because the registry has no provision for physicians and other health care providers to report on patient exposure and illness.
- ✘ Exposure and symptoms are self-reported by participants and are not verifiable.
- ✘ Exposure is not scientifically defined, and the relationship between exposure and adverse health outcomes is not scientifically defined.
- ✘ The Registry focuses more on mental health issues than on environmental health issues.
- ✘ The population under study is not scientifically determined; rather, it is a population of convenience.
- ✘ The Registry focuses on outdoor exposures at Ground Zero and outdoor exposure to the initial dust cloud. Indoor exposures are not addressed.
- ✘ The Registry has not secured long-term funding, casting doubt on its ability to track health for twenty years.

## **3. Confidentiality**

You are asked to provide your name, address, phone number and birth date. You are also asked for your social security number, but it is not required. You should not be asked about your immigration status. The Department of Health says that it will be empowered to protect this information once it obtains a Certificate of Confidentiality from the National Institutes of Health. It also says it will not share personal information with anyone outside of the Health Registry staff, including federal agencies such as the FBI or Bureau of Citizenship and Immigration Services (formerly the INS). In this time of concern about civil liberties and homeland security, you will have to decide for yourself whether these assurances are sufficient.

- ✘ Data minus identifiers from the Registry will be made available to private and public researchers. What kind of research will be done? Will an oversight committee be established? Will organized labor and community groups be represented?
- ✘ Even though DOHMH says it will not share personal information with other government agencies, concerns about confidentiality under laws such as the Patriot Act persist.
- ✘ The Department of Health is requesting that unions and community groups provide the names and phone numbers of members. This may violate individual confidentiality.

## **4. Labor and Community Not Consulted**

- ✘ Many health researchers, as well as representatives of labor unions and community groups, were not given the opportunity to participate in the design of

the study.

#### 5. **Other Concerns**

- ✘ Why was a non-union research company from North Carolina given millions of dollars to collect and organize information about New Yorkers for the Registry when thousands of people in New York are unemployed?
- ✘ Interviewers have no technical expertise regarding the proper use of respirators or potential sites of exposure other than Ground Zero.

#### **Conclusion**

It is important to have a scientific record of the health effects of September 11th, both to help those affected and to be better prepared for future disasters. However, it is essential that organizations and individuals have all of their questions and concerns satisfactorily addressed before giving out personal information. You should carefully weigh all of these issues as you consider whether or not to enroll in the Registry.

### **RESOURCES**

*The New York Committee for Occupational Safety and Health (NYCOSH)*

**Information** about workers compensation, public health policy, the Registry, or the health consequences of 9/11 at [www.nycosh.org](http://www.nycosh.org)

*World Trade Center Worker and Volunteer Medical Screening Program*

If you worked or volunteered at the WTC site after 9/11, you may be eligible for a free medical screening. **Information** at [www.WTCexams.org](http://www.WTCexams.org) or at **1-888-702-0630**

*Health for Heroes Program*

If you worked or volunteered at the WTC site after 9/11, you may be eligible for free diagnosis and treatment.

**Information** at **212-241-9059**

*New York City Department of Health World Trade Center Registry*

**Pre-register** [www.nyc.gov/html/doh/html/wtc.html](http://www.nyc.gov/html/doh/html/wtc.html)

**General information** within New York City **311**

**1-866-NYC-WTCR**

*New York State Workers' Compensation Board*

If you were made ill or injured while working, you may be eligible for compensation.

**Information** at [www.wcb.state.ny.us](http://www.wcb.state.ny.us)

**1-800-877-1373**

*United Church of Christ*

*National Disaster Ministries*

**Information** at [www.ucc.org/disaster/index.html](http://www.ucc.org/disaster/index.html).

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