#### WORLD TRADE CENTER HEALTH REGISTRY WORLD TRADE CENTER HEALTH REGISTRY

**March 2007** 

New York City Department of Health and Mental Hygiene

Volume 5:1

## Free Medical Treatment

Bellevue Hospital WTC Healthcare Center offers medical evaluations, breathing tests, and mental health screening to people with WTC-related illness. For more information, call (212) 562-1720.

## Workers' Comp Deadline for 9/11 Workers and Volunteers

You <u>must</u> register with the Workers' Compensation Board by August 14, 2007 to preserve your right to <u>ever</u> file a 9/11 related Workers' Compensation claim should you become sick in the future. For a WTC-12 registration form, call (877) 632-4996 or download a form at <u>http://www.wcb.state.ny.us/</u> <u>content/main/forms/</u> <u>WTC-12.pdf</u>.

#### NEW RESOURCES

Our January 2007 Resource Guide provides new and updated information about 9/11- related physical and mental health services and resources - and much more! It's at <u>www.wtcregistry.org</u>. For a paper copy, call us *(See page 4 for contact information)*.

# Why the Follow-up Survey Is So Important

More than 30,000 adults have completed the Registry's first follow-up health survey. The information they've given us is invaluable. From it, we are constructing a more complete picture of the health effects of the 9/11 disaster.

But with almost 69,000 adult enrollees, the Registry is still working to obtain responses from the rest of the adult enrollees. *If you have not yet filled in and returned your survey, please do so now.* It takes only about 15-30 minutes.

There are many reasons people let the survey go unanswered. "I was sick, but I'm better now," they might say. Or: "I have no news to report." Or: "Yes, I was there, but, thankfully, I didn't get ill." Or even: "That was the worst day of my life. Now I want to forget it."

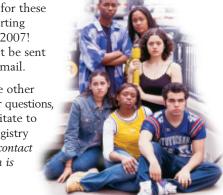
The more people who complete and send back these surveys, the more we all learn about the long-term health effects of 9/11. We will conduct follow-up surveys and special studies every 2 to 3 years to understand and address long-term health implications. If you got well or never got sick in the first place, that's important information, too! These data will help improve the medical care for those still ill and help prevent and treat illnesses in the event of future disasters. If you intend to participate but haven't received your survey, call or e-mail us right away. It is possible that we don't have your latest mailing address or e-mail address. Or your Internet service provider blocked our e-mail as spam. To solve these problems, see Frequently Asked Questions section on page 2.

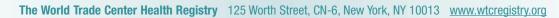
### **Children and teens**

The Registry is almost ready to send out surveys to follow up on the health of the over 2,000 children and teens enrolled in the Registry. <u>Parents and</u>

<u>guardians:</u> Watch your mailboxes for these surveys starting early May 2007! They won't be sent through e-mail.

If you have other concerns or questions, do not hesitate to contact Registry staff. *Our contact information is on page 4*.







nyc.gov/health

THE NEW YORK CITY DEPARTMENT of HEALTH and MENTAL HYGIENE Michael R. Bloomberg, Mayor Thomas R. Frieden, M.D., M.P.H., Commissioner

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## FREQUENTLY ASKED QUESTIONS

If you have other questions, please visit the FAQ page on our website (<u>www.wtcregistry.org</u>) or contact us. *Our contact information is on page 4*.

## I didn't receive a follow-up survey. Am I still enrolled in the Registry?

Yes. Once you enrolled in the Registry you remain enrolled and will be sent information about registry activities (unless you contacted us to tell us that you did not wish to participate in future Registry activities). If you did not receive a follow-up survey, it is possible that we do not have your latest mailing address or e-mail address. Or your Internet service provider may have blocked Registry e-mails as spam.

[To make sure you receive Registry e-mails, add these e-mail addresses to your browser's "safe" list: <u>healthinfo@health.nyc.gov</u>, <u>healthinfo@wtcsurvey.org</u>, and <u>wtchr@health.nyc.gov</u>. If you're not sure how to do this, check with your e-mail Internet service provider (AOL, Hotmail, MSN, Yahoo, etc.]

#### Can my friends and family members still enroll in the Registry?

Enrollment in the Registry ended in 2004. We are, however, keeping a list of interested people in case the Registry is re-opened or a second Registry is created. People who would like

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to be on this list should call or e-mail us and ask to be placed on the *Want to Register List*. They can also visit our website (<u>www.wtcregistry.org</u>) to view updated information, newsletters, resource guides, clinical guidelines, and scientific publications.

#### When will the results of the follow-up survey be available?

It will take several months to begin to analyze the data from the follow-up survey. After that, we'll begin to post our findings on our website (<u>www.wtcregistry.org</u>). In the meantime, new findings from the initial baseline survey in 2003-2004 are posted on our website as soon as reports are finalized.

#### I'm having health problems that I think are a result of my exposure to 9/11. Can I see a doctor through the Registry?

The Registry does not provide medical treatment or screenings. Your own doctor is the best place to start. You may wish to bring a copy of the clinical guidelines with you to your visit (*see box on page 3*). The guidelines provide information to help doctors diagnose and treat 9/11 exposure-related illnesses and provide preventive services and referrals for further care. The Registry's updated Resource Guide provides the most current information on mental and physical health programs and resources for those affected by 9/11. The Resource Guide is available at <u>www.nyc.gov/html/doh/html/wtc/wtc-resource.pdf</u> or contact our office to request a guide by mail.

#### WTC Responders Fatality Investigation Program

The New York State Department of Health, in cooperation with the National Institute for Occupational Safety and Health (NIOSH), is collecting data on all deaths that occur after 9/11 among WTC responders (persons who worked on the WTC site anytime between 9/11/01 and 6/30/02, including barge and morgue workers). Findings will contribute to knowledge about WTC health effects and may be helpful in improving medical treatment for other WTC responders and responders in the event of future disasters. For more information, or to report a death, call (518) 402-7900 or e-mail <u>khg01@health.state.ny.us</u>.

## **Confidentiality Policy**

All Registry information is held in the strictest of confidence. Your answers to surveys and your personal information are legally protected by a Federal Certificate of Confidentiality. The Registry is required by federal law to keep all your personal information confidential.

#### **BACK ISSUES**

All back issues since October 2003 are available at <u>www.wtcregistry.org</u>.

## WTC Health Update: What We Know and What We Don't

Thomas R. Frieden, M.D., M.P.H., Commissioner



Millions of people were affected emotionally, physically, and financially by the 9/11 attacks on the World Trade Center Twin Towers. This large and diverse population had a wide variety of experiences and exposure, and health effects have varied as a result. Thanks to careful research,

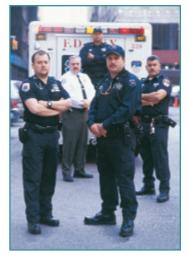
we now know some facts about the short and medium term health impacts on these people. The WTC Health Registry is dedicated to helping answer the unknowns.

#### What we know:

- Most people directly exposed to the intense dust cloud, and many exposed less directly, had acute physical symptoms in the days and months after 9/11. These included sinus problems, cough, and eye irritation.
- Some people developed very severe respiratory illness. At least three such cases are well documented in the medical literature, and clinicians at monitoring programs report other cases.
- In many people, the symptoms of pre-existing illness such as asthma got worse after dust exposure.
- Some people developed new symptoms or illnesses, such as cough or asthma, after exposure to the dust cloud.
- Hundreds of firefighters developed severe respiratory illness and became disabled and could no longer work as firefighters.



- People caught in the dust cloud had the highest risk of respiratory illness; the greater the dust cloud exposure, the higher the likelihood of respiratory symptoms.
- For most people, cough and other respiratory symptoms improved within 1 to 2 years after 9/11. A substantial proportion of people, however, appear to have persistent or worsening respiratory and other symptoms.
- Serious psychological distress occurred. These mental health effects have been documented to persist for at least 2 to 3 years after the event, and probably longer. For some people, these effects may cause lasting disability.



#### What we don't know:

- Exactly how many people developed severe respiratory illness
- How many still have respiratory symptoms today
- What precise types of respiratory or other illnesses are most common
- What risk factors, other than intense dust cloud exposure, contribute to persistent illness
- Whether cancers will develop as a result of dust exposure

Projects like the WTC Health Registry are continuing to study the effects of the WTC disaster to help answer some of these unknowns. By completing your follow-up survey, you help us better understand the long-term health effects of 9/11.

#### New Clinical Guidelines Help Doctors Help You

The New York City Department of Health and Mental Hygiene, together with clinicians at some of the WTC Treatment Centers of Excellence, has published updated clinical guidelines to help doctors treat adults exposed to the World Trade Center disaster. The guidelines provide information to help doctors diagnose and treat exposure-related physical and mental health illnesses and provide preventive services and referrals for further care. The guidelines are available at <u>www.wtcregistry.org</u> or <u>http://www.nyc.gov/html/doh/downloads/pdf/chi/ chi25-7.pdf</u>.

## **OPPORTUNITIES TO TAKE PART IN OTHER WTC-RELATED STUDIES**

We provide this information because many enrollees and others have asked for information about other WTC-related studies. If you want to participate in any of these studies, you may be able to. Call or e-mail the researchers for additional information.

#### Cornell University Study

Doctors at New York-Presbyterian Hospital/Weill Medical College of Cornell University are studying psychological/brain responses to the WTC disaster. Those who escaped from one of the Towers, were in the immediate area, or took part in the initial rescue effort may be eligible to participate. For more information, call (212)746-3782.

#### World Trade Center Evacuation Study (HEED)

British fire safety researchers looking to improve building regulations, designs, and evacuation procedures around the world are seeking face-to-face interviews with people who were evacuated from the Twin Towers on 9/11. The team describes the study as "the largest of its kind ever undertaken." For details, go to <u>www.wtc-evacuation.com</u> or call (212) 484-1329.

#### Exposure to Trauma: Children of First Responders and WTC Evacuees

Columbia University researchers are seeking to identify the mental health needs of children of first responders (police, firefighters, or EMTs) and WTC evacuees. These children may have been indirectly exposed to trauma through their parents' work-related or WTC experiences. First responders and WTC evacuees with a child currently between the ages of 9-15 years may be eligible to participate in a face-to-face interview. For more information, e-mail Dr. Christina Hoven at <u>ch42@columbia.edu</u> or call (212) 543-5688 or (800) 774-8448.

## **Update Your Contact Information**

To get a complete health picture of Registry members, and to stay in touch with you, we need your current contact information. Let us know if your name, mailing addresss, phone number, or e-mail address has changed.

- Visit <u>www.wtcregistry.org</u> and click on the "Update Contact Info" link
- Call or e-mail us with your updated information
- Fill out the form below with your current information and mail or fax it to us

#### HOW TO CONTACT WTC HEALTH REGISTRY STAFF

Questions? Feedback? Need information? Ready to update your contact information?

Here are 4 ways to reach us:

- Call (212) 442-1585 or (866) NYC-WTCR (866-692-9827), Monday – Friday, 9 am – 5 pm EST. After hours, please leave a message. We'll return your call the next business day.
- 2. Fax (212) 788-4127
- 3. E-mail <u>wtchr@health.nyc.gov</u>
- 4. Write The World Trade Center Health Registry New York City Department of Health and Mental Hygiene 125 Worth Street, CN-6, New York, NY 10013

## **WTCHR Enrollee Contact Information Update Form**

First name:	Last name:	Date of	1 1
Street Address:		Apt. #	5555
City:	State Zip:	Country:	
Telephone: Home:	Cell:		
Work:	Ext:		
E-mail address:	Additional E-mail address		
Other changes or corrections: (Please specify)			