

You're Invited! The Registry's Public Meeting and Resource Fair on May 31st

Please join us on Wednesday, May 31st, from 5:30-8:30 p.m. at the Schimmel Center for the Arts at Pace University. We will be sharing our most recent health findings related to September 11th. Representatives from more than a dozen organizations that provide 9/11-related services and resources will also be present. As we begin a new phase, moving from enrollment to follow-up, we would like your feedback and advice.

Space is limited. RSVP via email to wchrmeet-ing@health.nyc.gov (include your name, telephone and email) or call 212-442-1585.

Visit our website www.wtcregistry.org in May for more information and directions.

BACK ISSUES

Interested in looking at previous editions to see what you've missed? Visit the WTC Health Registry's website – www.wtcregistry.org – where you can read newsletters published between October 2003 and July 2005.

Follow-up Survey Set for May 2006

If you're among the 71,437 World Trade Center Health Registry (WTCHR) members, then you're about to receive our first follow-up survey. Developed with input from the registry's community, labor and science advisors, and tested with a group of adult enrollees, the survey will be sent to adult registry members in May 2006. The survey takes about 15 to 30 minutes to complete.

The survey being sent to you this month is the first of several follow-up surveys the World Trade Center Health Registry will conduct over the next four or five years. "This follow-up survey is absolutely crucial to our work because it will allow us to find out if trends that we discovered in our first survey continue, and to see whether there are new trends as well," said Dr. Mark Farfel, the Registry's Director.

"Ultimately, this will help us to identify the health effects of 9/11 and to determine how to help the members of the Registry and others who were directly affected by 9/11," Dr. Farfel said. A separate follow-up survey will be sent out this spring to the parents and guardians of the approximately 2,000 enrollees who are under 18 years of age.

Be sure to tell us if your contact information has changed so we can send you the survey. See page 3 for ways to update your contact information.

If you received this newsletter by e-mail, you will receive another e-mail with a link to the on-line version of the survey.

If you received this newsletter by regular mail, we'll send you the survey by mail, too, along with a postage-paid return envelope for your convenience. You can choose to complete the on-line survey instead of the paper survey. The survey you receive in the mail will provide the Web site address for the on-line survey.

Your participation is voluntary. The information you provide will be completely confidential,

like all Registry information. You will remain in the Registry even if you choose not to take part in this particular follow-up survey. This survey includes:

- An update on your health – both physical and mental – in the past two years.
- Follow-up questions to clarify information we collected in the first survey.
- Questions intended for specific groups in the Registry – such as residents and rescue, recovery, or clean-up workers – will also be included.

In the initial baseline survey, completed in fall 2004, we found that:

- Many enrollees in the Registry reported having respiratory problems that either began or got worse after the September 11, 2001 attacks;
- In the 30 days prior to their initial Registry interview (two to three years after 9/11), a higher percentage of adults reported having symptoms of psychological distress, compared to the New York Citywide average;
- 48 percent of enrollees who were below Chambers Street on 9/11 reported some kind of injury, with eye injury or irritation the most common.

"The Registry is the largest of its kind, and it depends completely on its members taking a few minutes of their time every so often to complete a survey," said Dr. Farfel. "I'm confident that our registrants will come through again this time."



Registry Members Help in Study of Evacuation Procedures

We recently spoke with Dr. Robyn Gershon, principal investigator of a Columbia University study on evacuation procedures from the World Trade Center on 9/11.

The \$1.5 million, three-year study, funded by the federal government's Centers for Disease Control and Prevention, is intended to understand what worked and what did not in evacuating the two World Trade Center towers on September 11th.

The study included a written survey of 1,767 people who escaped from the World Trade Center on 9/11, including nearly 1,050 people who volunteered to participate from the Registry ranks.

Dr. Gershon and her team hope to suggest changes in high-rise evacuations that can be used in other buildings. They also offer ideas on changing building design and codes that will make it easier and more efficient to get out of buildings in emergencies.

You recruited a number of people from the Registry. What were you trying to find out from them?

Dr. Gershon: The study is looking at the factors related to the individual, organizational and structural aspects of getting out of the building, so things that helped or hindered them in actually evacuating the World Trade Center One or Two.

How has the registry helped?

Dr. Gershon: Most importantly, it has put us in touch with people who wanted to tell us their story. It's linking together researchers with interested registrants.

What did you ask?

Dr. Gershon: We asked them everything imaginable about what happened that day: where they were, how they knew something had gone wrong. We were especially interested in learning how long it took from the time they realized something was wrong until they actually began evacuating. And once they started evacuating how long it took them to get to the ground floor and then out to the street and so forth. We're looking here for lessons, of course, that we can apply to other high-rises.

We also asked open-ended questions that deal with things like what really helped that day, or what the registrant would recommend other high-rise management do for their occupants, and that sort of thing. It's quite detailed.

What have you learned so far?

Dr. Gershon: The most striking thing we've found is that it's probably not feasible to totally prepare all tenants for these high-rise occupancy evacuations. The best response is to prepare a cadre of people that can serve as the guides and leaders on the way out.

How will you release your findings?

Dr. Gershon: We're due to complete this study by September 1, 2006...but we're going to hold a series of meetings – for both the general public and of course the people who were in the towers and all the families of victims and other survivors.

We want to reach back out to the community and share our findings. When World Trade Center Health Registry members see how important their participation was to our study they'll realize sticking with the Registry makes sense. It's not just the right thing to do; it really can help them and other people like them and it's just a good public service thing to do.

Information about Dr. Gershon's public meetings will be placed on the Registry's website as soon as this information is available.

A NEW EVACUATION STUDY

British fire safety researchers looking to improve building regulations, designs and evacuation procedures around the world are seeking help from Registry enrollees who evacuated from the World Trade Center Twin Towers on 9/11. Funded by the British government and three British universities, the study's experts plan to conduct face-to-face interviews with participants to learn more about the evacuations. The British team describes the study as the "largest of its kind ever undertaken." For details, please contact the study team directly at www.wtc-evacuation.com or call 212-484-1329.



FREQUENTLY ASKED QUESTIONS

Please visit the FAQ page on our website (www.wtcregistry.org) and the FAQ page in previous editions of our newsletter to read additional questions and responses. If you have other questions, please do not hesitate to contact the Registry.

I provided the Registry with my e-mail address. How can I make sure to receive messages, newsletters and/or updates through e-mail?

To ensure delivery of Registry e-mails, you should add the following e-mail addresses to your e-mail browser's address book or "safe" list: healthinfo@health.nyc.gov, healthinfo@wtcsurvey.org, and wtchr@health.nyc.gov. If you're not sure how, check with your e-mail service provider (e.g. Hotmail, Yahoo Mail, AOL, or MS Outlook) or visit www.wtcregistry.org (Instructions are listed under FAQs).

How can I contact the Registry with a change of address or to tell you about a change in my health?

For address, telephone, and e-mail address changes, see below for four ways you can contact us. If your health has changed, make sure to fill out our first follow-up survey in April 2006. That will be your best way of keeping us up to date and will help us understand the health consequences of September 11th.

I have other questions about the Registry. Where can I get answers?

The World Trade Center Health Registry website – www.wtcregistry.org – is the best place to start to receive the most updated information about our work and findings. More questions? Please contact us via e-mail at wtchr@health.nyc.gov or by phone at 212-442-1585 or toll-free at 866-692-9827.



Update Your Contact Information

To get a complete health picture of Registry members, and to stay in touch, we need accurate contact information for you. Please contact us if your mailing address, telephone number, or e-mail address has changed.

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

HOW TO CONTACT WORLD TRADE CENTER HEALTH REGISTRY STAFF

Here are four ways to reach us if you have any questions, need information, would like to provide feedback, or would like to update your contact information:

1. Call us at 212-442-1585 or toll free at 866-NYC-WTCR (866-692-9827). (Monday – Friday, 9 am – 5 pm EST)(If after hours, please leave a message and we'll return your call the next business day.)
2. Fax us at 212-788-4127
3. E-mail us at wtchr@health.nyc.gov
4. Send mail to us at The World Trade Center Health Registry
NYC Dept. of Health & Mental Hygiene,
125 Worth Street, CN-6, New York, NY 10013

WTCHR Enrollee Contact Information Update Form

a) First name: _____ Last name: _____ b) Date of birth: ____/____/____
mm dd yyyy

c) Current address: Address: _____ Apt. # _____
City: _____ State _____ Zip: _____ - _____ Country: _____

d) Current home phone #: _____ Current cell phone #: _____
Current work phone #: _____

e) Current e-mail address: _____ Additional e-mail address: _____

f) Report another change or correction: (Please specify) _____

CONNECTING YOU TO RESOURCES: UPDATED RESOURCE GUIDE

The Registry's newly updated Resource Guide: – March 2006 – may be found on-line on the Registry homepage at www.wtcregistry.org. The Resource Guide provides information about new resources, and updated descriptions and contact information for organizations that provide physical health and mental health services and other 9/11-related assistance.

Highlights from the Registry's March 2006 Resource Guide

Free Medical Treatment Available at Bellevue for People Exposed to WTC Dust and Ash

Residents, first responders and workers who were exposed to the dust and ash that resulted from the collapse of the World Trade Center can get free medical treatment at Bellevue Hospital/New York University. To find out more, please contact Beyond Ground Zero Network at 212-358-0295.

StoryCorps WTC Recording Booth

Would you like to record memories of your 9/11 experience? For more information please call 646-723-7025 or 800-850-4404 or visit www.storycorps.net/wtc (the password is "remember").

World Trade Center Disability Law

A New York State law signed June 14, 2005 by Governor Pataki offers a 75 percent pension to certain NYC government workers and retirees who developed debilitating physical ailments after working at the World Trade Center site on or after September 11th. Contact your current pension system or visit www.nycers.org to view the WTC Disability Law Fact Sheet. Deadline for filing is June 13, 2007.

Scholarships

Many scholarships are available for children who lost a parent on September 11th, 2001 or for those who were injured in the WTC attacks. Call 877-862-0136, visit www.scholarships911.org or email scholarships911@scholarshipamerica.org. Information about additional scholarships can be found at www.voiceofsept11.org.

WTCHR's FIRST SCIENTIFIC PUBLICATION

The Registry's first scientific article, "Surveillance for World Trade Center Disaster Health Effects among Survivors of Collapsed and Damaged Buildings," appeared April 7, 2006 as a "Surveillance Summary" in *Morbidity and Mortality Weekly Reports*, a U.S. Centers for Disease Control and Prevention publication.

The article discusses our findings on reported injuries on 9/11, new respiratory and non-respiratory health problems after 9/11, and serious psychological distress among 8,418 of the Registry's adult enrollees who escaped collapsed and damaged buildings. Visit <http://www.cdc.gov/mmwr/PDF/ss/ss5502.pdf> to check on this publication.

Registry staff are preparing reports on key health findings among other Registry groups, including residents, children, and rescue and recovery workers and volunteers. Information about these other Registry reports and findings will be included in future newsletters.

FEATURED 9/11-RELATED PUBLICATIONS AND REPORTS

Members of the Registry's Scientific Advisory Committee and the Registry's approved external researchers have produced articles related to possible 9/11 health effects. We've listed several of them here, and hope you find them informative about health issues that may affect you or a loved one.

Asbestos Exposures to Truck Drivers During World Trade Center Cleanup Operations. By Patrick Breyse and others. *Journal of Occupational and Environmental Hygiene*. 2:400-405 (2005)

Invited Commentary: Considering Bias in the Assessment of Respiratory Symptoms among Residents of Lower Manhattan following the Events of September 11, 2001. By David Vlahov and Sandro Galea. *American Journal of Epidemiology*. 162(6): 508-510 (2005). <http://aje.oxfordjournals.org/cgi/reprint/162/6/508>

Participant Reactions to Survey Research in the General Population after Terrorist Attacks. By Sandro Galea and others. *J Trauma Stress*. 18(5): 461-465 (2005). <http://dx.doi.org/10.1002/jts.20053>

Response to Assessment of Respiratory Symptoms after September 11. By Shao Lin and others. *American Journal of Epidemiology*. 162(6): 511-512 (2005). <http://aje.oxfordjournals.org/content/vol162/issue6/index.dtl>

Upper Respiratory Symptoms and Other Health Effects among Residents Living Near the World Trade Center Site after September 11, 2001. By Shao Lin and others. *American Journal of Epidemiology*. 162: 1-8 (2005). <http://aje.oxfordjournals.org/cgi/reprint/kwi233v1>

Interested in looking at other 9/11-related scientific articles? Please visit the Registry's website (www.wtcregistry.org) to view other articles listed in the May 2005 and July 2005 newsletters.