About Our Newsletter – A Revised Format

This report is the seventh in a series of quarterly reports providing information and updates about the World Trade Center Health Registry (WTCHR) to both enrollees and the public. The change in format reflects the shift in focus from updates on WTCHR enrollment and preliminary health information to a quarterly newsletter focused on providing information about published articles relating to possible 9/11 health effects (including WTCHR articles as they become available), follow-up studies, announcements, frequently asked questions, and links to resources and other information posted on the Registry website.

How do I update my contact information?

The best way for enrollees to support scientific understanding of the health effects of 9/11 is to remain involved in the WTCHR and to keep Registry staff updated with their most current contact information – i.e. addresses, phone numbers and email addresses. Enrollees may do this by visiting www.wtcregistry.org and clicking on the “Update Contact Info” link at the top of the home page.

If you are updating your information for the first time, click on the “New User Link”. Follow instructions to create a password and update your contact information and then press “submit” to send your updated information.

Enrollees may also submit their updated contact information by mail or by calling the Registry. Please see page 2 for details.

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WTCHR DATA SNAPSHOT

TIMING OF EVACUATION OF BUILDING SURVIVORS ON 9/11/01

Most survivors from the WTC towers reported that they began evacuating between the time when the first plane hit WTC1 (North Tower) on 9/11/01 and the second plane hit WTC 2 (South Tower). However, many survivors from surrounding damaged or destroyed buildings did not start evacuating until after the second plane hit.

http://www.findarticles.com/p/articles/mi_m0984/is_4_125/ai_n6120532#continue


http://gateway.ut.ovid.com/gw1/ovidweb.cgi


---NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE ---

FEATURED ARTICLES & PUBLICATIONS

This section of the newsletter includes citations of published articles and data related to possible 9/11-related health effects. Findings from the WTCHR initial interviews are being analyzed, and reports will be published shortly.

The following articles mark other work by members of our WTCHR Scientific Advisory Committee. Their research examines health issues relating to 9/11/01 and provides health information about a variety of exposure groups. To view the complete article, please click on the web link listed at the end of the article (whenever available). To view the abstract for these articles click here.

PROVIDING FEEDBACK

The World Trade Center Health Registry (WTCHR) is interested in your feedback. If you have suggestions or comments about this newsletter or the work of the WTCHR, or if you wish to submit a question about the Registry to our staff, please contact us via:

Email: wtchr@health.nyc.gov

Mail: The World Trade Center Health Registry
NYC Dept. of Health & Mental Hygiene
125 Worth Street, CN-6
New York, NY 10013

(You may also use the above email and mailing address to send us your updated contact information.)

Telephone: (212) 442-1585 or 311

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ANNOUNCEMENTS

The Registry: A Valuable Public Health Resource

The Registry was established to enable health experts to systematically evaluate the long-term health consequences in those most impacted by the events of September 11, 2001; to inform those at risk; and to help improve preparedness for future emergencies. The Registry, which is the largest effort of its kind in the U.S., will systematically monitor the health of persons exposed to a large-scale disaster.

While analyses of data collected during the initial interviews will provide valuable information on the exposures and health impact of the WTC attacks, the Registry will also facilitate future studies to examine various health impacts of the attacks. Some important health questions may best be answered with additional studies that involve carefully selected populations and, where appropriate, physical exams and laboratory studies. The Registry has a number of features that make it a unique resource for health experts around the country conducting such studies.

WTCHR Follow-Up Surveys

Between September 2003 and November 2004, more than 71,000 people completed an interview providing the WTCHR with comprehensive baseline data, including health and exposure information.

The first follow-up WTCHR survey is being developed and will be distributed to enrollees as early as Fall 2005. While each registrant will be contacted every 2-3 years to complete a follow-up survey, not all registrants necessarily will be contacted for their follow-up survey within the same year. Additional details about the first follow-up survey will be included in the July 2005 WTCHR Quarterly Newsletter.

WTCHR Registrants and External Studies

A majority of the WTCHR registrants (91%) gave consent at the time of their baseline interview to receive information from DOHMH about other health studies.

DOHMH will periodically mail out information materials about other approved health studies to WTCHR registrants who provided consent and who are in the proposed target population for these studies. DOHMH neither encourages nor discourages participation in these other studies, and your decision to participate or not will have no effect on your enrollment in the Registry.

DOHMH will continue to strictly protect the confidentiality of individuals enrolled in the WTCHR and will not release any individual identifying information about any registrant without their written permission.

Guidelines for External Researchers

Guidelines for External Researchers (that include an application) were released in early 2005 and are posted online at www.wtcregistry.org. Researchers may complete and submit an application to request de-identified baseline data or request that DOHMH send information about their study to appropriate WTCHR registrants. Applications are restricted to projects whose purpose is to support medical, public health or emergency preparedness research, or other scientific research.

All applications will be reviewed by the seven-member WTCHR Review Committee, which consists of representatives from the three WTCHR advisory committees (Scientific, Community, and Labor), DOHMH, and the federal Agency for Toxic Substances and Disease Registry (ATSDR). The Review Committee will review applications for scientific value and the expected contribution to study participants and the community.
FREQUENTLY ASKED QUESTIONS

Q: How do I report a change in my health?
A: The best time to report changes in your health is during the follow-up interviews. If you are concerned about a health condition or change in your physical or mental health, please visit your primary care physician.

Q: I’m still experiencing emotional distress since 9/11. Who can help me?
A: Call 1-800-LIFENET, a toll-free hotline operated by the Mental Health Association of New York City. Lifenet is a free, confidential, crisis intervention, referral and information service that provides referrals for free or low-cost mental health services for those directly affected by the 9/11 disaster, as well as other New Yorkers. Lifenet is available 24 hours a day, and is available in English, Spanish, and Asian languages (including Cantonese and Mandarin). You may find information about other available mental and physical health services in the WTCHR Resource Guide on our website at www.wtcregistry.org.

Q: How can I make sure that I receive WTCHR messages, newsletters and/or updates via email?
A: If you provided us with your email address and you have not been receiving our emails, then your ISP (internet service provider) may be blocking WTCHR emails. To counteract “SPAM BLOCKERS” and ensure delivery of WTCHR emails, add the DOHMH address healthinfo@health.nyc.gov to your email browser’s safe list or address book. If you are not sure how to do this, contact your ISP for further instructions.

HIGHLIGHTED RESOURCES

WTCHR Resource Guide
Visit www.nyc.gov/html/doh/html/wtc/wtc-resource.pdf for the latest version of the WTCHR Resource Guide, which is available in English, Spanish and Chinese. The resources inside the guide are available to anyone who believes they have been affected by September 11th, not just to WTCHR registrants.

The American Red Cross September 11th Recovery Program
The American Red Cross Client Assistance Center provides information and referrals about 9/11-related services, including community-based programs funded through Red Cross recovery grants. For information please call (877) 746-4987 or (800) 662-1220 for TTY users, Monday through Friday, 9 a.m. to 6 p.m. or visit www.redcross.org/september11/help.

The WTC Medical Monitoring Program, coordinated by Mt. Sinai, and Mt. Sinai’s WTC Health Effects Treatment Program
The telephone numbers for these programs have changed. To reach Medical Monitoring, please call (212) 241-1554 or (888) 702-0630. To reach Health Effects Treatment, please call (212) 241-9059. For a copy of the WTC Medical Monitoring Program’s newsletter visit http://www.wtcexams.org/newsletters.html.

Scholarships
Many scholarships are available for children who lost a parent on September 11, 2001 or for those who themselves were injured in the attacks on the World Trade Center. For more information call (877) 862-0136 or visit http://www.scholarships911.org/funds.htm.
FEATURED WTCHR STAFF MEMBER

Robert Brackbill PhD, MPH
Principal Investigator

Dr. Brackbill received his Ph.D. from the University of Minnesota in 1977 and his Masters in Public Health from the University of California at Berkeley in 1981. He has worked as a Center for Disease Control/ATSDR assignee in the NYC Department of Health and Mental Hygiene since 1999 and currently resides in Brooklyn.

How did you get involved in the Registry?
I was here on 9/11 and personally experienced the aftermath and how this event touched the lives of the people around me, so I have a personal as well as a scientific interest in contributing to what needs to be done. I had previous experience working on other large survey projects and was working on the Immunization Registry in 2001.

I have been involved with the WTCHR since the first meeting and helped to create the protocol and search for funding to get this project started. In July 2002 the project took off, our staff size increased and we formed a collaborative effort working with ATSDR.

What do you hope the Registry will accomplish?
We hoped to enroll enough people from highly exposed populations to have the scientific basis to draw conclusions about the health outcome of being exposed to the events of 9/11/01. I think we have accomplished that. This project will be a critical public health mechanism to look at the long-term health effects of this unprecedented event. It has been great to see this project evolve and become so successful because so many people have taken the time to complete interviews and become part of the Registry.

What were the biggest obstacles to making this project a success?
There was some skepticism initially about whether the public would enroll. With a lot of outreach work and community support we have created a large, well-represented registry that will provide valuable health information. Our biggest obstacles now are to secure long-term funding for the Registry, publish our results in scientific publications, share our findings, and encourage enrollees to remain active by participating in the Registry’s follow-up studies.

FEATURED WTCHR ADVISORY MEMBER

Peter Yee, M.S.W.
Assistant Executive Director
Hamilton-Madison House;
WTCHR Community Advisory Board (CAB) Member

Mr. Yee received his Masters in Social Work from Columbia University in 1991 and his B.A. in Urban Studies from the University of Pennsylvania in 1979. He has worked at Hamilton-Madison House since 2001, and he currently resides in Manhattan.

Hamilton-Madison House is a voluntary, non-profit settlement house dedicated to improving the quality of life of its community, primarily those in the Two Bridges/Chinatown area of Manhattan. Mr. Yee oversees Behavioral Health Services, including mental health, addiction, and supportive housing services. Since 9/11, Mr. Yee has been instrumental in developing Hamilton-Madison House’s Project Liberty mental health program. He is also the president of the New York Coalition for Asian American Mental Health and serves on several other non-profit boards. (For information on Hamilton-Madison House, visit www.hmh100.com.)

Mr. Yee is a member of the WTCHR’s Community Advisory Board (or CAB), which played a crucial role in getting thousands of constituents to enroll in the Registry. The CAB continues to contribute an essential public service by providing a “voice” for the residents, business and other groups most directly exposed to the environmental effects of 9/11.

Why did you become involved in the Registry?
Along with my agency, I was very much involved in the recovery efforts after 09/11/01, especially efforts that provided assistance to seniors and children in the Chinatown community. So, it was natural for me to be involved in the Registry, which is a very important initiative.

What information are you hoping to gain from the Registry?
We know the residual effects of the tragedy is still affecting the everyday lives of many in our neighborhood, and the Registry will provide important information about the long-term health and mental health of people in our community. I hope that by being a member of the WTCHR Community Advisory Board I can help shape the way outreach and research is conducted.