

QUARTERLY NEWSLETTER

Understanding the Health Impact of 9/11

NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE

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INTRODUCTION

Our Quarterly Newsletter provides Registry enrollees and the public with information and updates on the World Trade Center Health Registry (WTCHR), including information on follow-up studies, published articles relating to possible 9/11 health effects, announcements, frequently asked questions, and links to resources and other information posted on the Registry website.

Bellevue Hospital Announces its World Trade Center Health Impacts Program

Bellevue Hospital/New York University, working in collaboration with the Beyond Ground Zero Network and other community organizations such as 9/11 Environmental Action, have received a two-year \$2.4 million grant from the American Red Cross to offer medical treatment services for residents, first responders and workers who were exposed to the dust and ash that resulted from the collapse of the World Trade Center. For more information about this program contact Dr. Joan Reibman at (212) 263-6479.

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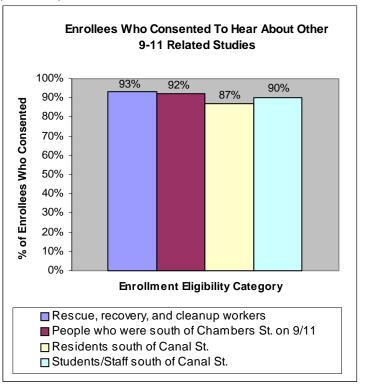
Featured WTCHR advisory member

Updated WTCHR Resource Guide Now Available

The newly updated June 2005 Resource Guide may be found on the Registry homepage at http://www.nyc.gov/html/doh/html/wtc/wtc-resource.pdf. The Resource Guide provides updated information about new resources, descriptions and contact information for organizations that provide a range of physical health and mental health services and other 9/11-related assistance. Please see pages 5-6 for more information and a list of highlighted resources.

WTCHR DATA SNAPSHOT

Overall, 91% of registrants gave consent at the time of their baseline interview to receive information from the NYC Department of Health And Mental Hygiene (DOHMH) about other 9/11 – related health studies.









FEATURED ARTICLES & PUBLICATIONS

This section of the newsletter features published articles related to possible 9/11-related health effects. The following articles mark new work by members of our WTCHR Scientific Advisory Committee and approved external researchers. Findings from the WTCHR initial interviews are being analyzed, and future newsletters will include published articles based on findings from the WTCHR initial interviews.

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.

Alcohol Use In New York After The Terrorist Attacks: A Study Of The Effects Of Psychological Trauma On Drinking Behavior. Boscarino JA, Adams RE, Galea S, et al. Addict Behav. (Epub ahead of print, 2005)

An Analysis Of Human Behavior During The WTC Disaster Of 11 September 2001 Based On Published Survivor Accounts. Blake SJ, Galea ER, Westeng H, et al. <u>Human Behavior in Fire Symposium 2004</u>, Belfast, Northern Ireland, UK. 181-192. (2004)

Cardiac Events In New Jersey After The September 11, 2001, Terrorist Attack. Allegra JR, Mostashari F, Rothman J, et al. J. Urban Health. (Epub ahead of print, 2005)

http://jurban.oxfordjournals.org/cgi/reprint/jti087v1

Collection And Analysis Of Human Behaviour Data Appearing In the Mass Media Relating To the Evacuation of The World Trade Center Towers Of 11 September 2001. Galea ER, Blake S. Office of the Deputy Prime Minister (London) (2004)

http://www.odpm.gov.uk/stellent/groups/odpm_fire/documents/downloadable/odpm_fire_033348.pdf

Biomonitoring Of Chemical Exposure Among New York City Firefighters Responding To The World Trade Center Fire And Collapse.

Edelman P, Osterloh J, Pirkle J, et al. <u>Environ</u> <u>Health Perspect.</u> 111(16): 1906-1911. (2003)

http://ehp.niehs.nih.gov/docs/2003/6315/abstracts.html

Induced Sputum Assessment In New York City Firefighters Exposed To World Trade Center Dust. Fireman EM, Lerman Y, Ganor E, et al. Environ. Health Perspect. 112(15):1564-1569 (2004)

http://ehp.niehs.nih.gov/members/2004/7233/7233 .html

Injuries And Illnesses Treated At The World Trade Center, 14 September – 20 November 2001. Perritt KR, Boal WL, The Helix Group, Inc. Prehospital Disaster Med. 20(3): 177-183 (2005)

http://pdm.medicine.wisc.edu/current/20-3%20PDFs/Perritt.pdf [the username is "test" and the password is "test"]

BACK ISSUES

May 2005 Quarterly Newsletter – Summaries of published articles relating to possible 9/11 health effects

January 2005 Quarterly Report – WTCHR Enrollment Summary

November 2004 Quarterly Report – Preliminary report on health conditions reported by enrollees







ANNOUNCEMENTS

WTCHR Follow-Up Surveys

The first follow-up WTCHR survey is being developed and will be distributed to all registrants in early 2006. Registrants will be contacted every 2-3 years to complete subsequent follow-up surveys.

Registrants who provided an email address during their initial interview will be sent an email with a link to a website and instructions on how to fill out the survey online. All other registrants will receive the survey by mail with a postage paid return envelope.

If your mailing address or email address has changed, please let us know so we can make sure you receive your survey. This can be done through our website at www.wtcregistry.org (click on the link "Update Contact Info"); through email at wtchr@health.nyc.gov; or call our office at (212) 442-1585.

World Trade Center Disability Law

On June 14, 2005, the World Trade Center ("WTC") Disability Law was signed into law. The bill establishes a presumption that certain New York City employees who worked at one of four specified WTC sites for at least 40 hours during the period beginning on September 11, 2001 and ending on September 12, 2002 (or were unable to work 40 hours due to an injury incurred during WTC related work on September 11 or 12, 2001) and have developed, or develop in the future, certain enumerated physical conditions, will be deemed to have a work-related condition that can form the basis of an accidental disability retirement application. The enumerated conditions include, but are not limited to, certain pulmonary diseases, cancer, asbestos-related disease, certain skin diseases, and various psychological disorders. The presumption is available to Fire, Police, and Sanitation Department WTC workers and other City WTC workers who had a pre-employment physical exam that did not reveal the condition upon which the application for disability retirement is based.

The bill contains a mechanism by which retired workers can seek to have their retirement reclassified as an accident disability retirement.

To be eligible, both active and retired employees must file a statement indicating the dates and locations of employment with the retirement system. The deadline for filing statements is June 13, 2007. For a fuller description of the bill and what it provides, please visit the NYC retirement system websites listed below. Individuals may contact their retirement systems for further information on this bill starting in mid – August 2005.

Retirement Systems and Centers

NYC Employees' Retirement System: (347) 643-3000 (NYC residents) (877) 669-2377 (toll free outside NYC) (347) 643-3501 (TTY) 335 Adams St., Brooklyn, NY 11201 www.nycers.org

Fire Department Pension Fund: (718) 999-7041 or (718) 999-0148; 9 Metrotech Center Brooklyn, NY 11201

Police Pension Fund: (212) 963-5100 233 Broadway, 18th FI., NY, NY 10007 www.nyc.gov/nycppf

Board of Education Retirement Systems: (718) 935-5400 65 Court St.18th Fl., Brooklyn, NY 11201 www.nycbers.org

Teachers' Retirement Systems: (888) 8-NYC-TRS 55 Water St., NY, NY 10041 www.trs.nyc.ny.us

Update on Total Enrollment

Our January 2005 Quarterly Report stated a total of 71,773 enrollees in the World Trade Center Health Registry.

The enrollment number has been revised to 71,437 following internal data verification.







ANNOUNCEMENTS (continued from page 3)

Update on External Research Studies

The <u>Guidelines for External Researchers</u> were released in early 2005 and are posted online at http://www.wtcregistry.org. Researchers may complete and submit an application to request deidentified 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, emergency preparedness research, or other scientific research.

All applications will be reviewed by the sevenmember WTCHR Review Committee comprised 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 WTCHR Review committee has recently approved three of these external research studies.

Materials will be sent to those enrollees who gave consent at the time of their baseline interview to receive information from DOHMH about other 9/11– related health studies.

The NYC Department of Health and Mental Hygiene neither encourages nor discourages participation in these other studies, and an enrollee's decision to participate or not will have an effect on their enrollment in the Registry.

WTCHR External Research Requests Approved Between February-July 2005

Functional Neuroimaging of Post-Traumatic Stress Reponses to Terrorism

External Researcher: David Silbersweig, MD, Weill Medical College of Cornell University, NYC Type of Request: Information sent to via email and mail to adult registrants who were in damaged or destroyed buildings (including the WTC towers) on 9/11 and people who were below Chambers St. on 9/11.

Status: Mailing date to be determined

The World Trade Center Evacuation Study

External Researcher: Robyn R. M. Gershon, DrPH, Columbia University, Mailman School of Public Health, NYC

Type of Request: Information (recruitment letter, consent form, study questionnaire, pre-addressed, pre-stamped returned envelope) sent by mail to all adult registrants who worked in and/or evacuated from WTC Towers 1 and 2.

Status: Materials mailed May 2005

HEED: Development of the High-Rise Evacuation Evaluation Database Based on Data Arising from the WTC Disaster

External Researcher: Edwin Galea, PhD, Fire Safety Engineering Group, University of Greenwich, UK

Type of Request: Information (one page introductory letter and a two page study information sheet) sent to all adult registrants who evacuated from WTC Towers 1 and 2. Information sent through email if registrant supplied an email address and through mail for those who did not. Status: Materials will be sent September 2005 as requested

Reminder: Update Your Contact Information

To help us understand the possible health effects of 9/11, it is vital that we have the most current contact information for all people enrolled in the Registry. Enrollees may update their contact information by clicking on the "Update Contact Info" link at the top of the home page at www.wtcregistry.org.

To update information for the first time, click on the "New User Link". Follow instructions to create a password, update your contact information, and then press "submit" to send your updated information. Enrollees may also update their contact information by mail or telephone. Please see the "providing feedback" box on page 5 for contact information.







FREQUENTLY ASKED QUESTIONS

Please visit the FAQ page on our website and the FAQ page on our May newsletter for other questions and responses. If you have additional questions, please contact the Registry using the information in the "providing feedback" on this page.

Q: How I can change my consent to receive information about external research studies?

A: To remove your name from our list of WTCHR registrants who agreed to receive information about external studies, contact the WTCHR office. (See the feedback box on this page.) You can also contact our office to have your name added to this list

Q: What kinds of questions are going to be asked in the WTCHR follow-up survey?

A: The WTCHR follow-up survey will ask you about your current physical and mental health symptoms and conditions. The survey includes questions on breathing problems, coughing, heart disease, smoking habits, depression, and anxiety as well as other symptoms and conditions. Questions will also be asked about health care utilization, union membership, and post-9/11 symptoms. There will be space for you to write additional comments and concerns that have not been addressed by the survey questions. Additional cleaning questions will be asked of residents south of Canal Street.

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

HIGHLIGHTED RESOURCES

WTCHR Resource Guide

Visit our website at www.wtcregistry.org to view the newly updated June 2005 resource guide which lists 59 resources, including seven new resources. Chinese and Spanish versions will be available soon. The Resource Guide is for anyone who has been affected by 9/11, not just WTCHR enrollees. Below are some new or highlighted resources that will be added to the December 2005 Resource Guide.

September Space - World Cares Center, Inc.

Responds to the support needs of the 9/11 community by providing a variety of services including support groups, resilience training, communication workshops, wellness programs, career workshops, and family fun activities. September Space Midtown is located at 520 8th Avenue, 11th Floor, NY, NY 10018 and will be opening a Lower Manhattan Community Center on September 6, 2005 to focus on the local population who lived through the 9/11 attacks and are now witnessing the rebuilding and relocation efforts. Please call (212) 563-7570 or visit www.worldcarescenterinc.org for more information.

Disaster Preparation and Trauma Mitigation

Also run by The World Cares Center, Inc., this program offers nationwide training in self-care and personal resilience for anyone, including volunteer responders, chaplains, mental health professionals, firefighters, law enforcement personnel, emergency medical personnel, and emergency management professionals. World Cares Center Inc. is located at 520 8th Ave., 11th Floor, NY, NY 10018. For more information contact Chris Paquet at (212) 563-7570 x203 or visit www.percs.org.







HIGHLIGHTED RESOURCES (continued from page 5)

StoryCorps WTC Recording Booth

Story Corps, the nationally acclaimed oral history project, opened a second booth on the concourse level of the Path Station at the World Trade Center site. Another booth is located in Grand Central Terminal. The World Trade Center StoryBooth is a recording studio where people can go to share their 9/11 stories. People are encouraged to come with a partner. The interview partner may be a friend or family member. If you would prefer to come alone, a facilitator will be available to interview you. The booth is open to the general public with special access given to families to remember those they lost on September 11th and to rescue workers and survivors.

Upon arrival at the StoryBooth for an interview, a trained facilitator will explain the process. The recording booth has been designed as a peaceful, safe space in which to record your 9/11 story. The recording will take 40 minutes. The booth also has listening stations where you can hear clips of recorded stories.

At the end of the session, you will receive a broadcast quality CD of your interview to take home. With your permission, a second CD becomes part of the StoryCorps Archive, an oral history of America, at the Library of Congress. A third copy of your interview will be given to the World Trade Center Memorial Museum, which is scheduled to open in 2009.

For more information or to make a reservation, please call (646) 723-7027 or visit www.storycorps.net/wtc (the password is "remember").

Association of Occupational and Environmental Clinics

The AOEC is a non-profit organization that provides occupational health referrals in your area: 1010 Vermont Ave., NW #513, Washington, D.C. 20005, (888) 347-2632 or (202) 347-4976, www.aoec.org

New York State WTC Volunteer Fund

This nationwide program settles claims filed for benefits due to work related injuries, illness or death. To be eligible, you must have worked in the immediate vicinity of the World Trade Center or Staten Island Landfill between 9/11/01 and 10/6/01. Volunteer workers and undocumented immigrants are also eligible. Please note that claims must be filed within two years after the date of injury, accident, or knowledge that the disease/death was caused by employment. (800) 877-1373; www.wcb.state.ny.us

9/11 Mental Health and Substance Abuse Program

The contact information for this program has been changed to: (800) 543-3638 or visit www.9-11mentalhealth.org

Safe Horizon 9/11 Mental Health Programs

Safe Horizon offers individual, couples, and family counseling and support groups to family members, those who were injured, evacuated, or witnessed the events, individuals displaced from their homes, or those who were financially impacted or lost their jobs. Services are also available for disaster responders and the families of responders, including public safety workers, firefighters, police, medical personnel, mental health professionals, food and clothing distributors, journalists, any staff or volunteer, and others affected by 9/11. Anyone affected by the media coverage of 9/11, or with 9/11-related health concerns are also eligible. Masters level clinicians provide free, confidential services open to all regardless of immigration status. Appointments are at the Family Assistance Center, 575 Lexington Ave, Manhattan, or in downtown Brooklyn. Contact Ellen Strahs Fader at (212) 729-5516.

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Visit http://nyc.gov/health and select "WTC Health Registry" (under Health Topics A-Z)



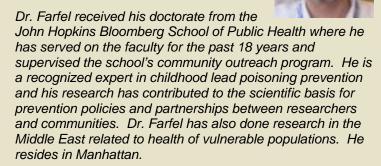




FEATURED WTCHR STAFF MEMBER

Dr. Mark Farfel, ScD

Dr. Farfel joined DOHMH as the new Director of the WTCHR in July 2005



What made you decide to shift your career from academia to local government?

I recognized the important role of local agencies in promoting public health. I have a history of policy-relevant, community-based research that has documented and addressed public health problems. This new position is an opportunity for me to contribute to the next phase of WTCHR activities. My motivation is based on wanting to make a difference because I care deeply about the issues being addressed by the WTCHR.

What are your goals for the Registry?

At this point in time, long-term funding for the Registry has not been secured, and that's going to be a major goal of ours in the next couple of years. A solid financial footing will enable the WTCHR to reach its full potential as a resource for public health

Another goal is to continue the good work that's already been started; there's a strong foundation of communication with the registrants, the public and the three advisory boards. We need to continue to meet Registry objectives, including documenting the long-term health effects, promoting follow-up studies and identifying public health needs.

How do you think your past experiences in community outreach will help you with your new position at the Registry?

Over the years, I have done collaborative research with community organizations, neighborhood associations, city agencies and private sector entities. What made our research successful was seeking input from stakeholders and involving them as partners from the outset.

It is very important that the Registry be able to communicate and reach out to the diverse communities of New York and to build good working relationships with various stakeholders, including our advisory board members. We need to build and sustain trust and collaboration to move the science forward.

FEATURED WTCHR ADVISORY MEMBER

Captain Peter Gorman

President, Uniformed Fire Officers Association Local 854; member of the WTCHR Labor Advisory Committee



Mr. Gorman has been the president of Local 854 for six years and has been a firefighter in the FDNY for over 30 years. His work as a member of the LAC has helped relations between the Registry and labor representatives. He currently resides in Yonkers, NY. (For more information on UFOA Local 854, please visit http://www.ufoa.org)

How did you get involved with the Registry?

There was confusion on the part of labor because there was already a World Trade Center Medical Monitoring program by Mt. Sinai in effect. So the first part of the process was having to inform our members that the WTCHR was quite different than Mt. Sinai's program.

I then invited Registry staff to our general union membership meeting, where they explained what the WTCHR was all about. This was a great breakthrough for us because people were a lot more receptive to the idea of registering once it had the endorsement of the UFOA.

What is the Labor Advisory Committee's role in the Registry?

It was really important to make sure the men and women of labor were included in the Registry. It is very possible that some of the diseases or symptoms that might be discovered later on could be more severe amongst the workers because of their unique exposure to Ground Zero.

What are the primary health concerns of your members?

Their concerns are long-term health effects – things that may not show up for 15 years. There has not been a tracking system in effect for past fires and disasters, and some firefighters who were exposed to hazardous chemicals long ago, later developed cancers and blood disorders.

With the WTCHR we have a mechanism to track the health of a large group of people and can look at the different exposures for specific workers. Having firefighters from surrounding communities, like New Jersey and Westchester also registered in the WTCHR, will provide data on their health effects and a tracking tool to stay in touch with them, which is an added benefit for labor.





