



December 2005

Dear Registrant:

I would like to thank you for participating in the World Trade Center Health Registry. Over 71,000 people have joined the Registry, and the data collected through the Registry will provide us with a better understanding of the long-term health effects of exposure to the environmental effects of 9/11.

I am contacting you today because you had expressed an interest in receiving information about other 9/11-related research studies at the time you completed the WTC Health Registry interview. One such study is now available to you, and information about this study is attached to this letter.

The New York City Department of Health and Mental Hygiene (NYC DOHMH) and the World Trade Center Health Registry project neither encourage nor discourage you to participate in this other research study. The decision whether or not to participate is entirely up to you. Your decision to participate in other WTC-related studies conducted by other organizations will have no effect on your enrollment in the WTC Health Registry. We are contacting you only to provide you with information on additional research studies that may be of interest to you.

If you decide that you wish to participate in this other research study, please contact that study directly. (See the attached letter or brochure for information on how to do so.)

At the time of enrollment, NYC DOHMH made assurances to you to protect your confidentiality by not releasing your personally identifiable information to outside researchers. This has not changed. The New York City Department of Health and Mental Hygiene continues to take great measures to protect your confidentiality. The institution conducting this new research study has not received and will not receive any information about you or the answers you provided during the WTC Health Registry interview.

If you have any questions about this letter and wish to contact us, you can write to the address listed below or send an email via the NYC DOHMH's website at <http://nyc.gov/html/doh>. At the top left of the home page select "Contact Us" to send an email.

Data and results from the WTC Health Registry are available at www.wtcregistry.org. Click on the "Contact Update" page on this website to send us any address, email or telephone changes.

Thank you again for your participation in the WTC Health Registry.

Sincerely,

A handwritten signature in blue ink that reads "Robert M. Brackbill". The signature is written in a cursive style.

Robert Brackbill, Ph.D., M.P.H.
Principal Investigator
World Trade Center Health Registry
New York City Department of Health and Mental Hygiene



Invitation to Participate

We invite you to participate in the world's largest study of the evacuation experiences of the occupants in the World Trade Center (WTC) on 9/11. Our study commenced in January 2005, and since then we have attracted the interest and support of local and national survivor groups, WTC tenant companies and individual evacuees. To complete this important research in 2006/7, we need you to participate in our study.

Why have I been asked to participate?

You have been invited to participate in this study because you were in the WTC towers 1 or 2 on 9/11. Your evacuation experience is unique and crucial to this study. By telling us your story, you will be contributing to the development of safer high-rise buildings world-wide.

What is the aim of the study?

The aim of the study is to collect and collate the evacuation experiences of occupants who were inside the WTC towers on 9/11. This will provide a more comprehensive understanding of evacuation and procedures relating to high-rise buildings. The information we collect will be stored in a database and used as a resource to make high-rise buildings safer places to live and work.

Who is organising the study?

The WTC-Evacuation Study is a collaborative project involving the people of New York and New Jersey, and three leading Universities in the United Kingdom, the Universities of Greenwich, Ulster and Liverpool. These universities specialize in the area of fire safety engineering and human behavior in fire and evacuation. The study is endorsed by the New York City Department of Buildings and the Fire Department of New York and is supported by the John Jay College of Criminal Justice (New York City); Pace University and Poly University. However, the study is independent from any US Government department.

What will I be asked to do?

We invite you take part in a single interview. The interview will take place at a time, date and location convenient to you. Your experiences will be listened to and documented by our team of professional researchers. The information we collect from you will be treated as confidential. Please see "Your Questions Answered", enclosed with this invitation, for more detailed information.

What if I want to know more before I decide to participate?

Detailed information about our study is given in the enclosed document, "Your Questions Answered". You can learn more about the project from our web site www.wtc-evacuation.com, by emailing our research team wtc@gre.ac.uk or by phoning 212 484 1329 (voicemail). You can also contact the project director Professor Ed Galea personally by email at E.R.Galea@gre.ac.uk or by phone +44 208 331 8730.

How do I take part in the study?

To take part in our study please register on our website www.wtc-evacuation.com and click on the link '**I'd like to take part - register now to help make high rise buildings safer>>**'.

Thank you for your time. We look forward to your participation.



Your Questions Answered

How can I take part in your study?

To take part in our study please register on our website www.wtc-evacuation.com and click on the link 'I'd like to take part- register now to make high rise buildings safer »' or 'participant registration'. You will be asked to enter your contact details and choose an interview date, time and location to meet. After you have done this we will email you or call you to confirm arrangements. You will also be asked to complete an online pre-interview questionnaire at your convenience. The information we collect from you is confidential. We will not pass on your details to anyone outside the research team.

Why do I need to complete a pre-interview questionnaire?

So that we make best use of your time we ask that you complete a simple 5 minute pre-interview questionnaire before we meet. The questionnaire asks details about your gender, education, health status, location in the WTC and brief details about your managerial and fire safety roles etc. You can also access the pre-interview questionnaire by selecting the following link 'I am a registered participant and would like to complete the online questionnaire »'

What will the Interview be like?

You will meet with one of our researchers for your face-to-face interview. You can find out more information about our interviewers on our website www.wtc-evacuation.com. The interview will last up to 1.5 hours and will be divided into two parts.

In the first part we will ask you to recall your evacuation experience in your own words. In the second part of the interview we will ask you a series of specific questions about your experience, present images of crowd densities and ask you to complete brief questionnaires about risk. Because what you say is important, the interview will be audio-recorded.

What type of questions will I be asked?

Sample Interview questions

- What was the first indication you had that something unusual was happening?
- Did you try to gain more information about what was going on?
- What route did you decide to take to leave the building?
- Did you leave with a group of people?
- Did you need to make use of signs identifying exits to help you make your way out?
- Did your planned evacuation route change at any time?
- How fast did you progress down the stairs?

When and where will the interview take place?

Dates:

- January 30th 2006 - March 31st 2006
- April 24th – June 16th 2006

Days and Times:

- Mondays, Wednesdays and Fridays
- Between 9am and 6pm
- Evening and weekend interviews can be arranged if necessary.

Locations:

- John Jay College of Criminal Justice, 445 West 59th Street (between 9th and 10th Avenue), NY 10019
- September Space, locations at both 520 8th Avenue, 11th floor (between 36th and 37th Street), NY10018 and 11 Broadway, 11th floor, NY10004
- Pace University, 163 William St (cross street Ann Street), 3rd Floor, NY 10038.
- Poly University, Room 201B, Rogers Hall, 6 Metrotech Center, Brooklyn, NY 11201.
- Alternatively you can nominate your home or place of work/study as your preferred interview location

What will happen to the information collected?

The information that we collect from you is confidential. That is, your name will not appear on any of the information you give. Instead, you will be allocated a research number. No one outside the research team will be able to identify the information you give. All identifiable information, such as names of people, will be replaced with allocated research numbers. The interview recording will be erased once typed copies of the interview have been checked. You are free to request a copy of your own interview transcript. However, please note this may take some time. The data collected from the interview will be stored in a database. Upon completion of the project the database will be made available to all genuine researchers working in fire safety and building design.

What are the possible benefits of taking part?

Participation in this study is beneficial to both those taking part and to the future of safe building design and evacuation. If you participate in this study your voice will be heard. Some people who we interviewed in 2005 found that talking to us about their evacuation experience was beneficial to them:

"As a survivor, some of us believe that the openly way to deal with the aftermath of the event is to talk about it and that ANY lessons learned from the events of the WTC evacuation on 9/11/01 should be shared, so that we can be better prepared for not just the "before", but for dealing with the "after" as well when the next event of similar proportions occurs. The reality is that an event like this will occur again. This type of study lets us use our negative experience in a positive fashion and the ability to do so is enriching and fulfilling for those of us who have done so. I appreciate your study and your efforts."

J.D, 2005 study participant

Everyone who takes part will also have access to our participant online forum where you will be able to share your experiences with other survivors participating in this study. Also regular progress updates will be posted on our website www.wtc-evacuation.com

What other aspects should I consider?

The interview is a joint process between you and the interviewer. In this study you are the expert. However, some people may find recalling their experience upsetting. Please bear this in mind when you are considering whether to take part. You do not have to answer any question you feel uncomfortable with. If you decide at any point that you no longer wish to take part, please tell the researcher. You do not have to give a reason. Any information you have given will then be destroyed.

For some people the interview may occasionally raise issues that they would like to discuss further. For these reasons, all participants will receive a list of useful resources and in some specific circumstances will be advised to contact their Physician or Therapist.

What if I want to know more before I decide to take part?

You can learn more about the project and the research team by visiting our website

www.wtc-evacuation.com You can also email us with any questions or comments regarding the study wtc@gre.ac.uk.

Thank you for your time.
