

What is the purpose of the RAPIDD Study?

The purpose of the RAPIDD Study (Rapid Acquisition of Pre- and Post-Incident Disaster Data) is to answer questions about the health effects of disaster exposures. The goal of the study is to create a registry of participants, collect biological samples and gather health data that will be made available in the future to researchers who will use the information to research potential short and long-term health effects related to exposures to natural or man-made disasters.

Who is conducting the study?

The National Institute of Environmental Health Sciences (NIEHS) and Social & Scientific Systems, Inc. (SSS), a professional research firm, design and carry out all of the activities of the RAPIDD Study. SSS and their partners are helping the NIEHS conduct the initial enrollment to collect information as close to the time of the disaster as possible. You may be contacted in the future by other researchers who want to build on the information you provide to answer their research questions in the area of disaster research. SSS and NIEHS provide trained and equipped research staff to conduct study related activities. All research staff follow guidelines and procedures approved by the NIH Office of Human Subjects Research. This office exists to protect people in research studies.

Who is eligible for the study?

You are eligible if you are at least 21 years of age and are deployed to a disaster area to conduct emergency response activities.

What will I be asked to do?

- Provide research staff with your contact information for yourself and someone else you know who can be reached if we are having trouble getting in touch with you.
- Provide blood, urine, saliva, cheek cells, nail, and hair samples.
- Have your vital signs and body measurements taken.
- Complete a lung function test.
- Complete a questionnaire about your health, habits, and lifestyle.

Will I receive compensation for participating in the study?

You will be reimbursed for your time and effort depending on the number and type of samples collected. Compensation will be \$35 for the blood draw, \$15 for urine, \$10 each for saliva, cheek cells, or hair, \$20 for nail clippings, and \$20 for spirometry. The maximum amount you may receive is \$120. You will be compensated in accordance with NIH guidelines.

Will results be shared with my employer to evaluate my fitness for deployment?

No, the study will not ask for your employer, and the information collected will not be shared with your employer for any purpose. However, you are allowed to share information with your employers and insurance provider if you wish. Participating in this study will not have any bearing on your fitness for deployment.

What tests will be done with my specimens?

All of your specimens will be frozen and stored in a secure laboratory. At a later date, we may use your samples for research. We will look for signs of various exposures and health effects related to disasters. We may test samples for a variety of chemicals, hormones, or other biological changes. The exact number and specific types of tests that will be done on your samples is not yet known. Not all research tests will be done on all participants. We will not test for illegal drugs.

Will I be given my study results?

The information we collect from this study and the registry examination is not a substitute for an exam conducted by a doctor. You may receive individual test results for blood pressure, heart rate, blood oxygen level, and lung function test measurements (if collected). You can share your results with a doctor or other healthcare provider. We will let you know if we think you should share your results with a doctor or clinic. If you do not have a primary care provider or cannot afford to pay for care, you will be given a list of local clinics that provide care for services based on a sliding scale.

It may be many years before your samples are tested. You will not receive any results from the future analysis of your samples unless we discover an abnormal finding.

How will you protect my privacy?

We will make every effort to protect your privacy and keep your data confidential. We will not use your name or information in any reports or presentations. Furthermore, a law called **The Federal Privacy Act** protects your information. We will label the information from your visit with a special number instead of your name, so you will not be identified. Only authorized staff will see your private information.

In order to help protect your privacy, the study has a Certificate of Confidentiality. The Certificate of Confidentiality helps to prevent the study team from being forced to give out information that could identify you, even by a court subpoena. However, the Certificate cannot be used to resist a demand for information by personnel from the United States Government, or other authorized people. Even in those cases, we will try to protect your identity.

The Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in the study. With your written permission, information can be provided to an insurer, employer, legal aide, or other person who you wish to release your information.

What should I do if...

- **I want to find out if the study is legitimate?** You may contact the Public Affairs/Communications Office at the NIEHS at 1-919-541-0073. You may also call the NIEHS Office of Human Research Compliance, at 1-919-541-3852.
- **I have questions about the study?** If you have questions about the study, you may call [INSERT CONTACT INFORMATION].
- **I have a problem, complaint or injury related to the study?** Please call RAPIDD research study staff at [INSERT CONTACT INFORMATION/#] as soon as possible. We will relay your concerns to the investigators and take any action that is necessary to remedy the issue. You may also contact the Principal Investigator, Dr. Stavros Garantziotis, at (919) 541-9859.