

Appendix L

Web Site Contents & Frequently Asked Questions (FAQs) Hurricanes Katrina and Rita Exposures (KARE) Registry

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Public Web Site Contents

Hurricanes Katrina and Rita Exposures (KARE) Registry

Hurricanes Katrina and Rita Exposures (KARE) Registry Highlights

People who lived in trailers furnished by the Federal Emergency Management Agency (FEMA) after Hurricanes Katrina and Rita are concerned about whether living or staying in the trailers has harmed their health. To begin to look for answers, ATSDR is testing the idea of creating the Katrina and Rita Exposures (KARE) Registry. A registry is a list of people with something in common. Registries can help us understand changes over time in people who may have something in common. Common living conditions of interest to those who have lived in FEMA trailers might include exposures to moisture and mold, exposure to chemicals used in building materials, or stresses associated with upheaval experienced by many Gulf Coast residents who were impacted by the storms. Key highlights of the Registry include the following:

- The KARE Registry will help us see if enough eligible people can be found, and if they are willing to be a part of the Registry.
- ATSDR will enroll up to 3,000 people from Louisiana, Mississippi, Texas, and Alabama who lived or stayed in FEMA trailers after the hurricanes. RTI International will help ATSDR contact people who could be enrolled in the Registry.
- Enrolling in the Registry will take about 20 minutes. You will be asked questions about the type of trailer you stayed in, how much time you spent there, and where the trailer was located.
- We will respect your privacy and keep all information about you safe and secure. We will never link your name with your information.

Homepage

Welcome to the **Hurricanes Katrina and Rita Exposures (KARE) Registry** Web site!

The Agency for Toxic Substances and Disease Registry (ATSDR), a federal health agency of the U.S. Department of Health and Human Services, is asking you to help us create the KARE Registry. A registry is a list of people with something in common, or who may have been exposed to substances that might be harmful.

The KARE Registry is a survey of people who lived or stayed in trailers furnished by the Federal Emergency Management Agency (FEMA) after Hurricanes Katrina and Rita. The KARE Registry is ATSDR's first step in creating a registry of people who lived or stayed in FEMA trailers after Hurricanes Katrina and Rita.

Registries can help us understand changes over time in people who may have something in common. Common experiences of interest to those who have lived in FEMA trailers might include exposures to moisture and mold, exposure to chemicals used in building materials, or stresses associated with upheaval experienced by many Gulf Coast residents who were impacted by the storms.

The questions that we are asking on the current survey will help us determine if enough eligible former trailer residents can be found, and if they are willing to be a part of the Registry. If we are able to successfully compile the KARE Registry, we can use it to help us learn more about trailer resident's possible exposures.

About the KARE Registry

- The experiences reported by the FEMA trailer residents will be recorded in the Registry.
- ATSDR is contacting some of the trailer residents and asking them to take part in the KARE Registry. ATSDR has asked RTI International to help contact people about the Registry.
- We will enroll in the Registry trailer residents who may have come in contact with air pollutants while they were in the trailers.
- The KARE Registry is the first step in creating a complete Registry of all people who lived or stayed in a FEMA trailer. Because many people left the area after the hurricanes, this first step will help us see if enough eligible people can be found, and if they are willing to be a part of the Registry. If this first step is successful, ATSDR may be able to begin a full registry that could include many more people.

Importance of the KARE Registry?

Hurricanes Katrina and Rita damaged the U.S. Gulf Coast more than 7 years ago but the region is still feeling many of their effects. After the hurricanes, many homes were destroyed and families were moved into FEMA trailers.

In the years since the hurricanes, ATSDR and other Health and Human Services departments began working with FEMA to look into the health concerns of the trailer residents. The current survey will help us learn more about whether developing a registry is possible. The full Registry will be large and designing and planning it is not a simple task. The Registry will help us see if enough eligible people can be found, and if they are willing to be a part of the Registry. The work done during this first step, the first 2 years of the Registry, will actually be a test to see if creating a full Registry, which will involve many more people, is possible.

Who Can Take Part in the KARE Registry?

During this first step, up to 3,000 people from Louisiana, Mississippi, Texas, and Alabama who stayed in FEMA trailers after the hurricanes will be enrolled in the Registry.

RTI International will call people to ask if they will take part in the Registry. If you are eligible and agree to enroll, a Registry staff member will ask you some questions over the phone. The interview will take about 20 minutes. Some of the questions will be about:

- the type of FEMA trailer you stayed in
- family members or friends who shared the trailer with you
- dates when you moved into and out of the trailer
- number of hours per day or week you spent in the trailer
- the location of the FEMA trailer you stayed in

Because this is the first step in creating the Registry, not every trailer resident affected by Hurricanes Katrina and Rita can be included. If this first step is successful, ATSDR may be able to begin a full registry that could include many more people.

Who Is Working With the KARE Registry?

The Agency for Toxic Substances and Disease Registry (ATSDR), a federal health agency of the U.S. Department of Health and Human Services has asked RTI International to test whether it is possible to develop a registry. ATSDR serves the public by using the best science, acting on public health needs, and providing trusted health information about harmful exposures and diseases related to toxic substances. We do this by learning how hazardous substances in the environment may affect public health. For more information about ATSDR, visit <http://www.atsdr.cdc.gov>.

RTI International is one of the world's leading research institutes. Their goal is to improve the condition of the people of the world by turning knowledge into action. RTI International's staff of more than 2,800 experts provides research and technical experience to governments and businesses in more than 40 countries. RTI International works in many areas including health and medicine, education and training, survey research, and energy and the environment. For more information about RTI International, visit www.rti.org.

The Louisiana Public Health Institute (LPHI) is a nonprofit organization that helps improve health outcomes. Their mission is to promote and improve health and quality of life by working with many partners including foundations, schools, community groups, community businesses, and parish and state governments. LPHI manages public health programs and helps develop health systems that promote health and prevent disease. LPHI also provides many services to meet the needs of local and national partner organizations. For more information about LPHI, visit www.LPHI.org.

Privacy

We respect your privacy and we will keep all information about you and your family safe and secure. We will never link your name with your information, and nobody will be given your name or any other information that could identify you. All information published about the Registry will be written so that you and your family will not be identified.

Frequently Asked Questions (FAQs)

Q: What is the Katrina and Rita Exposures (KARE) Registry?

A: The KARE Registry is a survey of people who lived or stayed in trailers furnished by the Federal Emergency Management Agency (FEMA) after Hurricanes Katrina and Rita. The goal of the survey is to determine if enough eligible former trailer residents can be found, and if they are willing to be a part of the full Registry. A registry is a list of people with something in common. Registries can help us understand changes over time in people who may have something in common. Common experiences of interest to those who have lived in FEMA trailers might include exposures to moisture and mold, exposure to chemicals used in building materials, or stresses associated with upheaval experienced by many Gulf Coast residents who were impacted by the storms.

The current survey is the first step in creating a complete Registry of all people who lived or stayed in a FEMA trailer. Because many people left the area after the hurricanes, this first step will help us see if enough eligible people can be found, and if they are willing to be a part of the Registry. If this first step is successful, ATSDR may be able to begin a full registry that could include many more people.

We will enroll in the KARE Registry up to 3,000 people from Louisiana, Mississippi, Texas, and Alabama who lived or stayed in the FEMA trailers after Hurricanes Katrina and Rita. People who enroll will take part in a 20-minute phone survey and will be asked questions about the time they stayed in the FEMA trailer.

Q: What is the purpose of the KARE Registry?

A: We want to know if enough eligible people can be found, and if they are willing to be a part of the Registry. If this first step is successful, ATSDR may be able to begin a full registry that could include many more people

Q: Hurricanes Katrina and Rita occurred in 2005, more than 7 years ago. Why is the Registry Important?

A: While it has been more than 7 years since Hurricanes Katrina and Rita damaged the U.S. Gulf Coast, the region continues to experience many of their effects. After the hurricanes, many homes were destroyed and families were moved into FEMA trailers.

In the years since the hurricanes, ATSDR and other Health and Human Services departments have been working with FEMA to look into the concerns of the trailer residents. If a Registry proves feasible, we believe that it will help us learn more about these concerns and how to help affected gulf coast residents. The Registry would be large and designing and planning it is not a simple task. The current survey will help us see if enough eligible people can be found, and if they are willing to be a part of the Registry. The work done during this first step, the first 2 years of the Registry, will actually be a test to see if creating a full Registry, which will involve many more people, is possible.

Q: Who can participate in the KARE Registry?

A: For now, up to 3,000 people from Louisiana, Mississippi, Texas, and Alabama who stayed in FEMA trailers after Hurricanes Katrina and Rita will be enrolled in the Registry.

Because this is the first step in creating a full Registry, not every trailer resident affected by Hurricanes Katrina and Rita can be included. The Registry will help us see if enough eligible people can be found, and if they are willing to be a part of the Registry. If this first step is successful, ATSDR may be able to begin a full registry that could include many more people.

Q: What will I be asked to do if I agree to take part in the KARE Registry?

A: RTI International will call people to ask if they will take part in the Registry. If you are eligible and agree to enroll, a Registry staff member will ask you some questions over the phone. The interview will take about 20 minutes. Some of the questions will be about:

- the type of FEMA trailer you stayed in
- family members or friends who shared the trailer with you
- dates when you moved into and out of the trailer
- number of hours per day or week you spent in the trailer
- the location of the FEMA trailer you stayed in

If we call at a time that isn't good for you, please tell us. We will be happy to set up a better time to talk with you. If you prefer, you can call us back on our toll-free phone number, 1-xxx-xxx-xxxx, to enroll. All information will be kept private and secure.

Q: How long will it take to enroll in the KARE Registry?

A: We expect the telephone interview will take about 20 minutes. Remember, if we call at a time that isn't good for you, please tell us. We will be happy to set up a better time to talk to you. If you prefer, you can call us back on our toll-free phone number, 1-xxx-xxx-xxxx, to enroll. All information will be kept private and secure.

Q: Do I have to answer all the questions you ask to enroll in the KARE Registry?

A: No. You can refuse to answer any question that makes you uncomfortable and still be a part of the Registry.

Q: Why should I take part in the KARE Registry?

A: People who stayed in trailers and take part in the Registry can help us begin to understand possible effects associated with staying in FEMA-supplied trailers. By taking part in the Registry, you also help us see if enough eligible people can be found, and if they are willing to be a part of the Registry. If this first step is successful, ATSDR may be able to begin a full registry that could include many more people.

Q: Will I be paid for taking part in the KARE Registry?

A: No. We cannot pay anyone for taking part in the Registry.

Q: Will I risk losing my government benefits or social services if I take part in the KARE Registry?

A: No. There is no risk of losing any government benefits or social services you receive. Taking part in the Registry cannot affect any benefits or services you receive.

We do not share any information about you or your family with any other organization or any government agency.

We respect your privacy and we will keep all information about you and your family safe and secure.

Q: Do I have to take part in the KARE Registry?

A: No. We hope to find and enroll enough people to demonstrate that a full Registry of all people who lived or stayed in a FEMA trailer would be possible. Because many people left the area after the hurricanes, this first step will help us see if enough eligible people can be found, and if they are willing to be a part of the Registry. If this first step is successful, ATSDR may be able to begin a full registry that could include many more people. By joining the Registry, you can play an important part in helping us understand the effects of staying in the FEMA trailers.

Q: How do I know if I can take part in the KARE Registry?

A: RTI International will call people to ask if they will take part in the Registry. Also, these people will receive a letter and brochure in the mail asking them to enroll in the Registry. If you know anyone who might be eligible for the Registry, please give them our toll-free phone number (1-xxx-xxx-xxxx) and our Web site (www.KARE.org) so they can get more information.

Q: Who are the sponsors of the KARE Registry?

A: The Agency for Toxic Substances and Disease Registry (ATSDR), a federal health agency of the U.S. Department of Health and Human Services has asked RTI International to test whether it is possible to develop a registry. ATSDR serves the public by using the best science, acting on public health needs, and providing trusted health information about harmful exposures and diseases related to toxic substances. We do this by learning about the effects that hazardous substances in the environment may have on public health.

Q: Will my personal information be kept private if I enroll in the KARE Registry?

A: We will respect your privacy and we will keep all information about you and your family safe and secure. We will never link your name with your information, and nobody will receive your name or any other information that could identify you. All information published about the Registry will be written so that you and your family will not be identified.

Q: How do I know my privacy will be protected if I enroll in the KARE Registry?

A: Your privacy is the most important thing to the KARE Registry staff. All Registry staff signed a privacy pledge and we take that pledge very seriously. Here are some examples of how we will protect your information:

- **We do not link your information with your name.** We look at all of the information by *groups* of people, not specific individuals. You will never be identified in any report that uses information from the Registry. All information published about the Registry will be written so that you and your family will not be identified.
- **Only authorized staff and researchers will see your information.** We will *respect* and *protect* your privacy and only let KARHE Registry staff and researchers see your information when it is necessary.
- **We will not share your name or any information you give us with any government agency.** All information you give us will be kept private and will not be shared with any government agencies.

Q: Will you sell the information you collect for the KARE Registry?

A: No. We will not sell anything that is part of the Registry, including information or results. This Registry is for research purposes only, to help us see if enough eligible people can be found, and if they are willing to be a part of the Registry.

Q: Who can I contact if I have questions about the KARE Registry?

A: To speak with a Registry staff member, please call our toll-free phone number, 1-xxx-xxx-xxxx, or e-mail us at: info@[KARE.org](mailto:info@KARE.org). If you call our toll-free phone number, a Registry staff member will call you back within 24 hours.