

Summary of Rights for Parents/Guardians of WTC Health Registry Enrollees New York City Department of Health and Mental Hygiene

The Registry is a research study to learn about the long-term physical and mental health impacts of the 9/11 disaster and health care needs. More than 71,000 people voluntarily enrolled in the Registry in 2003-04 and completed the initial health survey. They were also asked to complete follow-up surveys in 2006-7 and 2011-12.

The Registry is operated by the New York City Health Department with federal funding from the National Institute for Occupational Safety and Health's WTC Health Program. The Health Department plans to maintain the Registry for at least 20 years after the initial surveys in 2003-04.

As the parent or guardian of an enrollee, during this time, you may:

- Be asked to complete surveys about your child's physical and mental health about every 3 years, until your child turns age 18. Your child will be asked to complete the survey once he or she turns age 18. Your answers and those of other enrollees will help us understand the full impact of the 9/11 disaster, plan for future health care needs, and may also help save lives and reduce injuries in future disasters. Completing Registry surveys does not provide you or your child with direct financial benefits.
- Be asked periodically to provide the Registry with your updated contact information so that we can stay in touch with you and send you information about Registry surveys and findings.
- Be contacted by Registry staff with information about 9/11-related no-cost health services based on your or your child's survey answers. The Registry also provides enrollees with assistance in applying for 9/11-related health care services.
- Be contacted by Registry staff occasionally with other health information for your child.
- Receive an invitation from the Registry to join other 9/11-related research studies conducted by the Registry or by researchers outside of the Registry for which your child may be eligible. Some of these outside researchers may ask you to have the Registry share your or your child's survey answers with them. This would only happen with your written permission.
- Be offered a personal visit from a member of the Registry's staff – to help you complete a health survey, get information on health care services, or inform you about a 9/11-related research study. We will always contact you ahead of time, tell you why we'd like to visit, and give you the opportunity to refuse. If you do not want our staff to *ever* visit you at home, please call us at (866) 692-9827.

While, there are no physical risks to taking Registry health surveys, some of the questions may be sensitive or may remind you of the events of 9/11. The Registry will provide you with resources to call if you feel emotional distress while answering survey questions or afterwards. One such resource is LIFENET (1-800-LIFENET), a free and confidential service which provides mental health information and referrals 24 hours a day, seven days a week.

Your and your child's participation in the Registry is voluntary. You have the right to withdraw from the Registry now or at any time in the future without penalty or loss of benefits to which you or your child are otherwise entitled. You and your child also have the right to decline to participate in any of Registry activities at any time. If you fully withdraw your child from the Registry, any information you already provided would remain with the Registry but without a link to your or your child's personal identifying information.

All Registry information is held in strict confidence and protected by a federal certificate of confidentiality. This means that we cannot be forced to reveal identifying information about you or your child, even if a court orders us to do so, unless you say it is okay. But we must report to the proper authorities suspected cases of child abuse or if you tell us you are planning to cause serious harm to yourself or others or if we reasonably believe you are a threat to yourself or others.

As you were told when you first enrolled your child in the Registry, your child's records will be linked periodically to other health data, such as cancer registries, hospital discharge data, and birth and death records to better understand the full impact of the 9/11 disaster.

If you have questions about your rights as a participant in the Registry, contact the chair of the Health Department's Institutional Review Board, at (347) 396-6118 or irbadmin@health.nyc.gov.

For other Registry questions, call (866) 692-9827, email wtchr@health.nyc.gov, or visit nyc.gov/9-11HealthInfo. You can also visit the website anytime to find out about Registry findings.

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