

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

The New York City Health Department plans to maintain the WTC Health Registry for at least 20 years after 9/11/2001 to better understand the long-term health effects of the 9/11 disaster.

During this time, you may:

- Be asked to complete surveys about your child's health every 2 to 3 years, until your child turns age 18. Your child will be asked to complete the survey once he or she turns age 18.
- Receive information about 9/11 health services based on your survey answers.
- Receive other health information for your child.
- Receive an invitation to join other Registry studies or other 9/11-related studies for which your child may be eligible. Some of these studies may ask for your written permission to have the Registry share your survey answers with the study. This would only happen after a study had been approved by the Health Department's Institutional Review Board (IRB) and protected by their own federal certificate of confidentiality.
- Be offered a personal visit from a member of the Registry's professional staff – to help you complete a health survey, get information on services, or access to a free medical test. 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. (A description of the Registry's Personal Visit Policy is provided on the next page.)

You have the right to decline to participate in any of these activities at any time. You also have the right to change your mind and give consent to participate in any activity you declined in the past. Your child's information will remain in the Registry whether or not you participate in any of the above activities. 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. But under the law, we must report to the city or state suspected cases of child abuse. We must report to the appropriate authorities if you tell us you are planning to cause serious harm to yourself or others.

As you were told when you first enrolled your child in the Registry, your child's records will be compared periodically to other health data, such as cancer registries, hospital discharge data, 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 Olivette Burton, MSW, MBE, the Health Department's IRB Chair, at (212) 788-4481 or oburton@health.nyc.gov. For other Registry questions, call (866) 692-9827, email wtchr@health.nyc.gov, or visit nyc.gov/9-11HealthInfo.

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The Registry's Personal Visit Policy

Experience has taught the Registry that a personal visit from a member of the Registry's professional staff can sometimes help you complete a health survey or get information on services or access to a free medical test. **Home visits thus will be offered in some WTCHR research studies.** We want to make sure, however, that you're comfortable with our occasional door-to-door outreach. Our policy is that, before making any such visit, we will always contact you ahead of time, tell you why we'd like to visit and give you the opportunity to refuse. Refusing will not affect your status in the Registry or your ability to participate in future surveys. If you do not want our staff to **ever** visit you at home, please call (866) NYC-WTCR (1-866-692-9827), email wchr@health.nyc.gov or write to the Registry at the address below. For more information about the Registry's policy, visit nyc.gov/9-11HealthInfo and click on WTC Health Registry.