

WORLD  
TRADE  
CENTER  
HEALTH REGISTRY

ADOLESCENT  
FOLLOW-UP  
SURVEY 2007



If your adolescent's personalized ID number does not appear directly below, please contact us at 866-NYC-WTCR (866-692-9827)

## READ THIS FIRST

Dear Parent or Guardian:

The World Trade Center Health Registry is contacting you about this research because your adolescent was one of 71,000 persons enrolled in the Registry. It is important that we regularly contact you for an update on your adolescent's physical and mental health. This survey is for adolescents aged 11 to 17 years old as of April 1, 2007. A separate survey is being sent to the parents or guardians of enrollees 5 to 10 years old.

This first follow-up survey is your opportunity to update us about the health of your adolescent. Your answers are very important. They may help us understand the potential long-term health effects of the 9/11 disaster.

**About the Survey.** This survey contains TWO booklets: A parent/guardian booklet and an adolescent booklet. In order to maintain privacy, you and your adolescent should each fill out your booklets by yourselves. However, if your adolescent has difficulty understanding the questions and needs your help, or if your adolescent simply prefers to complete his/her booklet in your company, you may answer the questions in the adolescent booklet together. In any case, please let us know how the adolescent booklet was completed by checking one of the boxes on the last page of this parent/guardian booklet.

The survey will take 15 to 30 minutes to complete. Participation by you and your adolescent is voluntary. We will link answers in this follow-up survey to the survey completed for your adolescent in 2003 or 2004. All information provided will be kept strictly confidential. Answers provided by yourself and your adolescent are legally protected by a Federal Certificate of Confidentiality. Your adolescent will remain in the Registry even if you choose not take part in this survey. The New York City Department of Health and Mental Hygiene (NYC DOHMH) may contact you to provide information about health care services for your adolescent based on the responses to this survey.

Once you and your adolescent complete the surveys, each of you should place your survey booklet in one of the smaller envelopes included in this packet. Both envelopes should then be placed in the larger, pre-addressed, postage-paid envelope and mailed back to the Registry. If possible, please return both survey booklets together **within 10 days**.

The Registry is a long term effort; the information you provide us over time will be used to inform future public health policy. We understand, however, that many people have concerns related to September 11 that need immediate attention. We refer you to the enclosed updated January 2007 Resource Guide which provides information about physical and mental health services and resources, as well as other 9/11-related services and resources provided by over 70 organizations. We hope this resource guide will assist you in linking with health facilities, services, and other resources as needed. You may also call LifeNet (1-800-LIFENET), a free and confidential mental health service which provides information and referrals 24 hours a day, 7 days a week.

We thank you and your adolescent for being a part of the World Trade Center Health Registry.

Sincerely,

Thomas Frieden, M.D., M.P.H.  
Commissioner, NYC DOHMH

Mark Farfel, Sc.D.  
Director, WTCHR  
Principal Investigator, WTCHR

Robert Brackbill, Ph.D., M.P.H.  
Founding Principal Investigator, WTCHR

The Registry is an important effort of the NYC DOHMH in partnership with the federal Agency for Toxic Substances and Disease Registry (ATSDR). Macro International Inc., a research company, is working for the NYC DOHMH to conduct this survey and is required to keep the information strictly confidential.

**SURVEY INSTRUCTIONS****Who should complete this survey?**

This survey was sent to households with an adolescent enrolled in the WTC Health Registry who was between the ages of 11 to 17 years old as of April 1, 2007. There are two booklets. This is the **PARENT or GUARDIAN BOOKLET**. It should be completed by a parent or legal guardian of the adolescent enrolled in the Registry. If you are not the parent or legal guardian for the adolescent, please give this survey to the appropriate person.

If the adolescent does not live at your address, but you are the parent or guardian, it is okay for you to complete this survey. Please make sure your adolescent completes the adolescent booklet of the survey. If the adolescent lives at another address and you are not the parent or guardian, please forward it to their current address or call us at 212-442-1585 or 866-NYC-WTCR so we may send another survey to the appropriate address.

If this survey has been sent to a household where the adolescent enrolled in the Registry has passed away, please accept our sincere condolences. We are very sorry for your loss. Please do not complete the survey. Instead, contact the Registry at 212-442-1585 to notify us.

**How should this survey be completed?**

Mark answers with an X or enter a number where appropriate. Answer questions based on your adolescent's experiences. Report all health issues, not just those that may be related to 9/11. Please pay careful attention to the wording of questions. For example, some questions ask about your adolescent's health in the "last 30 days" or "last 12 months" or "last 4 weeks". For most of the questions in this survey, we are interested in ALL of your adolescent's symptoms and experiences in the time frame specified, not just those that seem unusual or those that might be related to the events of September 11, 2001. For those questions where we do want to know specifically about symptoms that may be related to September 11, this has been noted in the instructions for those questions.

**What do I do if more than one adolescent or child in my household is enrolled in the WTC Health Registry?**

A separate survey will be sent for each adolescent or child enrolled in the Registry. The surveys are being sent in batches, so they may not arrive at your home at the same time. Please be sure to use the correct survey for each adolescent. You will have the opportunity to write the name of the adolescent or child for whom you are completing the survey.

**What if I get upset while answering questions?**

Many people still get upset when thinking about 9/11. If you want to talk about these feelings, you can call LifeNet (800-LIFENET) which is a confidential and free mental health referral and crisis hotline. It is available 24 hours a day, 7 days a week.

**What do I do when I am done with my booklet?**

You should place your completed booklet in one of the small envelopes that came in your packet. To maintain privacy, your adolescent should complete the adolescent booklet of the survey and place it in the other small envelope. Both envelopes should then be placed together in the large, pre-addressed, postage-paid return envelope that came in the packet and be mailed to:

**WTC Health Registry - 116 John Street, Room 800 - New York, NY 10038**

In summary, the steps you should take to complete the survey are as follows:

- Step 1: Read the cover letter and survey instructions.
- Step 2: Read the first page of the Adolescent Booklet.
- Step 3: Complete your Parent or Guardian Booklet.
- Step 4: Place your booklet in the small envelope provided and seal it.
- Step 5: You and your adolescent each put your sealed envelopes into the pre-addressed, postage paid return envelope.
- Step 6: Drop the return envelope into the mail.

If you have any questions about your adolescent's rights as a WTCHR enrollee, please contact the New York City Department of Health and Mental Hygiene (NYC DOHMH) Institutional Review Board Chairperson, Dr. Olivette Burton, at 212-788-4438. If you have any questions about the Registry or the survey, please contact Registry staff at 212-442-1585, 1-866-NYC-WTCR (866-692-9827), or wtchr@health.nyc.gov.

## ADOLESCENT FOLLOW-UP SURVEY 2007 – PARENT/GUARDIAN BOOKLET

Please read the survey instructions on the opposite page. Mark your answers with an "x" or provide a number.

**Today's date:**

□□ / □□ / □□□□  
(Month / Day / Year)

**1 Are you the parent or legal guardian of the adolescent enrolled in the WTC Health Registry?**

- <sub>1</sub> Yes
- <sub>2</sub> No **STOP**. Please give this survey to the adolescent's parent or legal guardian or call 212-442-1585 or toll-free at 866-NYC-WTCR (866-692-9827).

**2 What is YOUR name?** (This information will help us keep track of adults who respond on behalf of their children at each follow-up survey.)

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

**3 What is the name of YOUR ADOLESCENT enrolled in the WTC Health Registry?** (This information will help us keep track of surveys if more than one child or adolescent lives in your household. If you have more than one child or adolescent enrolled in the Registry, you will receive separate surveys for each child.)

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

**4 What is your relationship to the adolescent?** (Check ALL that apply.)

- <sub>1</sub> Mother (biological, step, foster, adoptive)
- <sub>2</sub> Father (biological, step, foster, adoptive)
- <sub>3</sub> Female or male guardian
- <sub>4</sub> Adult sister or brother (biological, step, foster, half, adoptive)
- <sub>5</sub> Aunt or Uncle
- <sub>6</sub> Grandparent
- <sub>7</sub> Other family member
- <sub>8</sub> Other, please specify: \_\_\_\_\_

**5 What is your adolescent's gender?**

- <sub>1</sub> Male
- <sub>2</sub> Female

**6 What is your adolescent's date of birth?**

□□ / □□ / □□□□  
(Month / Day / Year)

**7 The following questions ask about household composition. Answer for the home where your adolescent spends the most time.**

(If your adolescent spends half of his or her time at each of two homes, please answer for the home where the questionnaire arrived.)

**a. How many people does your adolescent live with?**

- Number of adults (18 years old or older)
- Number of children (17 years old or younger)

**b. Which best describes the household where your adolescent spends the most time?**

- <sub>1</sub> Single parent household
- <sub>2</sub> Two parent household
- <sub>3</sub> Other, please specify: \_\_\_\_\_

**8 Approximately how many days per month does your adolescent live in another household?**

(For example, if your adolescent spends two days per week with another parent:

2 days per week X 4 weeks = 8 → enter 08)

- Days per month
- Not applicable, my adolescent lives in one household.

**9 What is the highest level of education reached by your adolescent's parents or guardians?** (Answer for the parents/guardians the adolescent lives with the most.)

- <sub>1</sub> Never attended school or only attended kindergarten
- <sub>2</sub> Grades 1 through 8 (elementary or middle school)
- <sub>3</sub> Grades 9 through 11 (some high school)
- <sub>4</sub> Grade 12 or GED (high school graduate)
- <sub>5</sub> College 1 year to 3 years (some college or technical school)
- <sub>6</sub> College 4 years or more (college graduate)
- <sub>7</sub> Post-graduate degree

**10** Has your adolescent ever gone to see a doctor or other health professional for any of the following symptoms? (Answer as best you can.)

- |   | Yes                      | No                       |
|---|--------------------------|--------------------------|
| a. Severe headaches?  | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Hearing problem or hearing loss?   | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Heartburn, indigestion or reflux?  | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Sinus problems, nose irritation, or postnasal irritation (which occurred when your adolescent did not have a cold or the flu)? | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Skin rash or irritation?   | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Problems with coughing?  | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Problems with breathing such as feeling out of breath or short of breath?  | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Throat irritation?   | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Hoarseness or loss of voice?   | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Wheezing or whistling sound in the chest?  | <input type="checkbox"/> | <input type="checkbox"/> |
| k. Other, please specify:   |                          |                          |

**11** For questions 11a through 11k, how often has your adolescent had each of the following health symptoms in the last 12 months?

(Include symptoms even if your adolescent did not see a doctor. If the symptoms vary throughout the year, base your answer on the seasons when problems are worse.)

**a. Severe headaches?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**b. Hearing problem or loss?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**c. Heartburn, indigestion or reflux?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**d. Sinus problems, nose irritation, or postnasal irritation (which occurred when your adolescent did not have a cold or the flu)?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**e. Skin rash or irritation?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**f. Problems with coughing?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**g. Problems with breathing, such as feeling out of breath or short of breath?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**h. Throat irritation?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**i. Hoarseness or loss of voice?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**j. Wheezing or whistling sound in the chest?**

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**k. Other, please specify:** \_\_\_\_\_

- <sub>1</sub> Never (not in the last 12 months)
- <sub>2</sub> Rarely (less than once a month)
- <sub>3</sub> Sometimes (1-4 times per month)
- <sub>4</sub> Often (more than once a week, but not daily)
- <sub>5</sub> Very often (daily)

**12 The next six questions are about asthma.**

**a. Has a doctor or health professional ever said that your adolescent had asthma?**

- <sub>1</sub> Yes
- <sub>2</sub> No → SKIP to Question 13

**b. How old was your adolescent when the doctor or other health professional first said that he/she had asthma? (Answer as best you can.)**

years old

**c. Did the doctor or other health professional say that your adolescent had asthma before September 11, 2001?**

- <sub>1</sub> Yes
- <sub>2</sub> No

**d. During the last 12 months, has your adolescent had an episode of asthma or an asthma attack?**

- <sub>1</sub> Yes
- <sub>2</sub> No

**e. During the last 12 months, how many times did your adolescent go to an emergency room or urgent care center because of asthma?**

Enter number of visits  OR None

**f. In the last 12 months, did your adolescent use an inhaler or nebulizer prescribed by a doctor for asthma?**

- <sub>1</sub> Yes
- <sub>2</sub> No

**13 About how long has it been since your adolescent last visited a doctor for a routine check-up? A routine check-up is a general physical exam, not an exam for a specific injury, illness, or condition.**

- <sub>1</sub> Within the past year (last 12 months)
- <sub>2</sub> Over a year but less than 2 years ago
- <sub>3</sub> Over 2 years ago but less than 5 years ago
- <sub>4</sub> 5 or more years ago
- <sub>5</sub> Never in my adolescent's life

**14 Was there a time in the last 12 months when your adolescent needed health care, but did not get it?**

- <sub>1</sub> Yes
- <sub>2</sub> No → SKIP to Question 15

**a. What type of health care did your adolescent need, but did not get during the last 12 months? (Check ALL that apply)**

- <sub>1</sub> Routine check-up (e.g. immunizations)
- <sub>2</sub> A specialist (e.g. ear, nose, throat doctor)
- <sub>3</sub> Inpatient care (e.g. hospitalization)
- <sub>4</sub> Diagnostic services (e.g. lab test or x-ray)
- <sub>5</sub> Outpatient care (e.g. seeing a doctor for the flu)
- <sub>6</sub> Prescription medicines
- <sub>7</sub> Mental health care or counseling
- <sub>8</sub> Dental care
- <sub>9</sub> Eye exam
- <sub>10</sub> Other, please specify: \_\_\_\_\_

**b. What prevented your adolescent from getting the health care that he or she needed in the last 12 months? (Check ALL that apply)**

- <sub>1</sub> Lacked money
- <sub>2</sub> Lacked insurance
- <sub>3</sub> Lacked transportation
- <sub>4</sub> Lacked childcare
- <sub>5</sub> Did not know where to go for care
- <sub>6</sub> Was unable to find a provider who could diagnose or treat my adolescent's condition
- <sub>7</sub> Other, please specify: \_\_\_\_\_

**c. Regarding health care that your adolescent did not receive in the last 12 months, were you seeking health care for a problem that may be related to September 11, 2001?**

- <sub>1</sub> Yes
- <sub>2</sub> No
- <sub>3</sub> I don't know

**15** During the last 12 months have you or another parent or guardian talked to a professional about a mental or emotional problem your adolescent might have? (For example, a doctor, psychiatrist, psychologist, counselor, nurse, social worker, other health professional or clergy member.)

- <sub>1</sub> Yes
- <sub>2</sub> No

**16** Questions 16a and 16b ask about the emotional health of your adolescent's parents or guardians. Your answers are confidential.

**a. During the last 12 months, were you told by a health professional that you had any of the following emotional conditions? (Check ALL that apply.)**

- <sub>1</sub> Yes, depression
- <sub>2</sub> Yes, post-traumatic stress disorder (PTSD)
- <sub>3</sub> Yes, an anxiety disorder, other than PTSD
- <sub>4</sub> Yes, another condition. Please specify:  
\_\_\_\_\_
- <sub>5</sub> No

**b. During the last 12 months, was your adolescent's other parent or guardian told by a health professional that he/she had any of the following emotional conditions? (Check ALL that apply.)**

- <sub>1</sub> Yes, depression
- <sub>2</sub> Yes, post-traumatic stress disorder (PTSD)
- <sub>3</sub> Yes, an anxiety disorder, other than PTSD
- <sub>4</sub> Yes, another condition. Please specify:  
\_\_\_\_\_
- <sub>5</sub> No
- <sub>6</sub> I don't know
- <sub>7</sub> Not applicable, my adolescent has one parent or guardian

**17** The next set of questions asks about your adolescent's school experience on September 11, 2001. Please answer as best as you can.

**a. Did your adolescent evacuate from school on September 11, 2001?**

- <sub>1</sub> Yes
- <sub>2</sub> No → SKIP to Question 18

**b. About what time did your adolescent evacuate from school?**

:  AM or  PM

**c. After evacuating from school, about how long did it take your adolescent to get to a safe location such as his or her home or the home of a friend or relative?**

Hours <sub>1-10</sub> AND Minutes <sub>1-59</sub>

**18** The next set of questions asks about your adolescent's home experience on and shortly after September 11, 2001.

**a. Between September 11th and September 18th, 2001, did your adolescent leave his/her primary home for at least 24 hours because of the WTC attack?**

- <sub>1</sub> Yes
- <sub>2</sub> No

**b. If your adolescent did not leave his/her home for at least 24 hours between September 11th and September 18th, 2001, what were some of the reasons?** (Check ALL that apply.)

- <sub>1</sub> It wasn't necessary
- <sub>2</sub> Some family members wanted to stay
- <sub>3</sub> Some family members wanted to stay and help with the recovery
- <sub>4</sub> The family could not afford to leave
- <sub>5</sub> There was nowhere else to go
- <sub>6</sub> Some family members were afraid to leave
- <sub>7</sub> Some family members couldn't because of a disability
- <sub>8</sub> Some family members couldn't because of a pet
- <sub>9</sub> Some family members couldn't leave a loved one
- <sub>10</sub> Other reason: \_\_\_\_\_
- <sub>11</sub> Not applicable, my adolescent left his/her home between September 11th and September 18th, 2001.

**c. What was the condition inside your adolescent's home after the WTC disaster (before any cleanup)?** (Answer for the home where your adolescent spends the most time. Check ALL that apply to at least one room.)

- <sub>1</sub> No damage was done
- <sub>2</sub> Fine coating of dust on surfaces
- <sub>3</sub> Heavy coating of dust on surfaces (so thick you couldn't see what was underneath)
- <sub>4</sub> Broken window(s)
- <sub>5</sub> Damage to home or furnishings
- <sub>6</sub> Debris from the disaster was present
- <sub>7</sub> Other, please specify:  
\_\_\_\_\_

**19** The EPA clean-up program was a voluntary program during 2002 to 2003 for homes south of Canal Street in Manhattan. People had the option of signing up for cleaning and testing or for testing only.

**a. Was your adolescent's home part of the EPA's cleanup program?**

- <sub>1</sub> Yes
- <sub>2</sub> No → SKIP to Question 20
- <sub>3</sub> I don't know

**b. What did the EPA do to your adolescent's home in 2002-2003?**

- <sub>1</sub> Cleaned and tested
- <sub>2</sub> Tested only

**You are nearing the end of the Parent or Guardian Booklet. Questions 20 and 21 are asked to collect information on economic status.**

**20** In 2005, what was the total income before taxes for the household where the adolescent lives? (Answer for the household where the adolescent spends the most time. Answer as best you can.)

- <sub>1</sub> Less than \$25,000
- <sub>2</sub> \$25,000 to less than \$50,000
- <sub>3</sub> \$50,000 to less than \$75,000
- <sub>4</sub> \$75,000 to less than \$100,000
- <sub>5</sub> \$100,000 or more

**21** Approximately how much additional financial support does this household receive per month? (For example, from child support, social security, Medicaid, food stamps. Exclude income reported in Question 20. Answer for the household where the adolescent spends the most time. Answer as best you can.)

- \$, .00 per month
- Not applicable, this household does not receive additional financial support

**22** The following information is needed from you to properly keep track of who is enrolled in the Registry.

What are the last 4 digits of your adolescent's social security number? (This information will remain strictly confidential and will only be used to match information about your adolescent in the registry to other health registries.)

Enter last 4 digits:

**ADOLESCENT FOLLOW-UP SURVEY 2007 – PARENT/GUARDIAN BOOKLET**

**23** What is your current e-mail address? (This information will be used to update our records in order to contact you in the future.)

Enter e-mail address: \_\_\_\_\_

**24** Please let us know if you have any additional health concerns related to your adolescent since September 11, 2001:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**25** We would like to hear about your experiences as a respondent for your adolescent enrolled in the WTC Health Registry. Do you have comments or suggestions about the Registry, or any important questions you felt the survey did not cover?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**THANK YOU** for participating on behalf of your adolescent in the first WTC Health Registry follow-up survey. The WTC Health Registry is an important public health endeavor for the New York City metropolitan area and the nation. Your contribution will help researchers understand the scope of the health effects related to this tragedy. We greatly appreciate your cooperation, the time you took to complete this booklet, and the information you provided.

**This is the end of the Parent or Guardian Booklet.**

Please check one of the boxes below to indicate how the Adolescent Booklet was completed.

- The Adolescent Booklet was completed by the adolescent alone.
- The Adolescent Booklet was completed by the adolescent but with parent/guardian's help.
- The Adolescent Booklet was completed by the adolescent and parent/guardian together.
- The Adolescent Booklet was completed by parent/guardian on behalf of the adolescent.

Please place this booklet in one of the small envelopes provided. Then place it in the large, pre-addressed, postage-paid, return envelope. When both booklets (Parent/Guardian AND Adolescent) are in the large envelope, mail the envelope back to:

**WTC Health Registry, 116 John Street Rm 800, New York, NY 10038**



**LifeNet**

If you or a family member has a mental health emergency or crisis, call

**1-800-LifeNet (1-800-543-3638)**

**1-212-982-5284 (TTY)**

For more information, go online at: [www.nyc.gov/html/doh](http://www.nyc.gov/html/doh)