

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

Dear World Trade Center Health Registry Enrollee:

You are one of more than 71,000 people who joined the World Trade Center Health Registry (WTCHR). It is important that we regularly contact you for an update on your physical and mental health. This first follow-up survey is your opportunity to do so. Your answers are very important. They will help us understand the long-term health effects of the 9/11 disaster.

**About the Survey.** The survey will take 15 to 30 minutes to complete. Your participation is voluntary. We will link your answers in this follow-up survey to the survey you completed in 2003 or 2004. All information you provide will be kept strictly confidential. Your answers are legally protected by a Federal Certificate of Confidentiality. You will remain in the Registry even if you choose not to 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 based on your survey responses.

A postage-paid envelope is enclosed for you to use to return the survey to us. Please return the survey within **10 days** if possible. If this letter is addressed to a Registry enrollee who is not able to complete the survey, please see the instructions on the other side of this page.

If you prefer, you may complete the survey on-line at **<u>www.wtcsurvey.org</u>** instead of completing this paper survey and mailing it back. If you complete the survey on-line, you can print out a copy of your answers to keep for your records. Please note that the on-line survey is available only in English. To complete the survey on-line, you will need the identification number that is on the sticker on the top right corner of this page.

If you feel emotional distress while answering questions or afterwards, please call LifeNet (1-800-LIFENET), a free and confidential service which provides mental health information and referrals 24 hours a day, 7 days a week. You may also access the "WTCHR Resource Guide: March 2006" at <u>www.wtcregistry.org</u> to obtain information about 9/11-related services and resources.

Thank you for being part of the World Trade Center Health Registry.

Sincerely,

Thomas Turely

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

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

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Mark Farfel, Sc.D. Director, WTCHR

The Registry is an important effort of the NYC DOHMH in partnership with the federal Agency for Toxic Substances and Disease Registry (ATSDR). ORC Macro, 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 an adult enrolled in the WTC Health Registry. The follow-up survey for child enrollees will be sent to their parents or guardians in August 2006. If the adult enrollee is unable to fill out this survey because of a mental or physical disability, someone else may complete the survey on his or her behalf. If the enrollee lives at another address, please forward the survey to the appropriate address. If this survey has been sent to an enrollee who has died, please accept our condolences. We are very sorry for your loss. Please notify us at 212-442-1585.

#### How should I complete the survey?

Mark answers with an X or enter a number where appropriate. Report <u>all</u> 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 health in the "<u>last 12 months</u>", or "<u>last 4 weeks</u>" or "<u>last 30 days</u>".

#### What do I do if more than one adult in my household is enrolled in the WTC Health Registry?

Each adult enrollee should complete a separate survey. Be careful not to mix up the surveys. The adult enrollees in your household may not all receive their follow-up surveys at the same time because the surveys are being sent out in batches.

#### 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?

Place the completed survey in the postage-paid return envelope that came in the packet and mail to: WTC Health Registry - 116 John Street, Room 800 - New York, NY 10038

Thank you for completing this survey. If you have any questions about your rights as a WTCHR enrollee, please contact the NYC DOHMH Institutional Review Board Chair, Dr. Olivette Burton, at 212-788-4483. 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 <a href="https://www.wtchr@health.nyc.gov">wtchr@health.nyc.gov</a>.

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## the mental health association of new york city, inc.

#### 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)

1-866-NYC-WTCR

1-866-692-9827

	se read the survey instructions on the opposite page. c answer with an X or enter a number.	5	What is your date of birth?
	Today's date:		(Month / Day / Year)
	(Month / Day / Year)	a.	What is your current age?
1	For whom are you completing this survey?		
	$\square_1$ Myself $\rightarrow$ SKIP to Question 3	6	Would you say that in general your health is: (Pick <u>only</u> one answer)
	$\square_2$ My spouse or partner		L Excellent
	$\square_3$ My mother or father		□₂ Very good
	☐₄ My adult child		□ <sub>3</sub> Good
	$\square_{\circ}$ My brother or sister		□_₄ Fair
	□ Other, please specify:		□ <sub>5</sub> Poor
2	If you are completing this survey for someone else, what prevented this person from completing the survey on their own?	7	For questions 7a through 7c, please provide answers based on the <u>last 30 days</u> .
	(Check the primary reason)	a.	Thinking about your physical health, which includes physical illness and injury, for how many
	The person was a child (under 18 years of age)		days during the <u>last 30 days</u> was your physical
	A physical disability		health <u>not</u> good?
	□₃ A mental disability		Enter number of days U OR None U
	□₄ The person is deceased*	b.	Thinking about your mental health, which includes
	□₅ A language barrier (Note the primary language of the WTCHR enrollee):		stress, depression, and problems with emotions, for how many days during the <u>last 30 days</u> was your mental health <u>not</u> good?
	The survey was too difficult for the person to read		Enter number of days OR None O
Wor	remaining questions refer to the person <u>enrolled</u> in the Id Trade Center Health Registry. In all questions "you" "your" refers to the enrollee (even when another person	c.	For how many days did poor physical or mental health keep you from doing your usual activities during the <u>last 30 days</u> ?
	iswering questions for the enrollee).		Enter number of days 🔲 🛛 OR None 🗌
3	Name:		
	First Name:		
	Last Name:		
4	What is your gender?		
	□ ₁ Male		
plea	the survey has been sent to an enrollee who has died, se call us at (212) 442-1585. Please do not complete survey. We are very sorry for your loss.		

8	On September 11, 2001, <u>before</u> the attack, did you have any disabilities or medical conditions that were diagnosed by a physician?	11	Have you <u>ever</u> sought care of a doctor or other health professional for any of the following symptoms:
		a.	Frequent severe headaches?
	$\square_2$ No $\rightarrow$ SKIP to Question 9		
a.	On September 11, 2001, <u>before</u> the attack, did any disabilities or medical conditions affect your	h	□ <sub>2</sub> No Hearing problem or loss?
	(Check all that apply)	D.	
	Ll₁ Mobility (e.g. walking)		$\square_2$ No
	Ll₃ Vision	C.	Heartburn, indigestion or reflux?
	Ll₄ Heart		L⊥₁ Yes
	₅ Breathing		□ <sub>2</sub> No
	La_6 Mental Health	d.	Sinus problems, nose irritation, or postnasal
	└┘ <sub>7</sub> Other, please specify:		irritation (which occurred when you did not have a cold or the flu)?
	$\square_{\scriptscriptstyle B}$ None of the above		$\square_1$ Yes
9	Do you <u>currently</u> have a disability or a medical condition that was diagnosed by a physician?		$\square_2$ No
		e.	Skin rash or irritation?
	$\square_2$ No $\rightarrow$ SKIP to Question 10		∐₁ Yes
a.	Do you think any of your <u>current</u> disabilities or medical conditions affect your (Check all that apply)	f.	Shortness of breath? □₁ Yes
	$\square_2$ Hearing		L <sub>2</sub> No
		g.	Throat irritation?
	$\square_4$ Heart		
	□ ₅ Breathing		2 No
	$\square_{6}$ Mental Health	h.	Hoarseness or loss of voice?
	□ <sub>7</sub> Other, please specify:		
b.	Do you think any of these <u>current</u> disabilities or medical conditions are a <u>direct</u> result of the events of September 11, 2001?	1.	Wheezing?
			L <sub>2</sub> No
		j.	Other, please specify:
10	In the <u>last 30 days,</u> have you used an inhaler prescribed by a doctor for any breathing problem?		
	└─_₁ Yes		
	L <sub>2</sub> No		

1-866-NYC-WTCR

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Please answer the next set of questions <b>even if you did</b> <b>not visit a doctor</b> for these symptoms. If Yes, how often have you had this symptom in the <u>last 30 days</u> ?	13 The next set of questions is about persistent cough.
12 Have you experienced any of these symptoms in the <u>last 30 days</u> ?	a. Have you <u>ever</u> sought the care of a doctor or other health professional for a persistent cough?
a. Frequent severe headaches?	
$\Box_1  \text{Yes} \rightarrow  \text{Estimate number of days}  \Box_2 \\ \Box_2  \text{No}$	b. Have you experienced a persistent cough in the <u>last 12 months</u> ?
b. Hearing problem or loss?	
$\Box_1$ Yes $\rightarrow$ Estimate number of days $\Box\Box$	
	c. Have you experienced a persistent cough in the <u>last 30 days</u> ?
c. Heartburn, indigestion or reflux?	
$\Box_1$ Yes $\rightarrow$ Estimate number of days $\Box_2$	$\square_2$ No $\rightarrow$ SKIP to Question 14
Ll₂ No d. Sinus problems, nose irritation, or postnasal	d. How often have you had a persistent cough in the <u>last 30 days</u> ?
irritation (which occurred when you did not have a cold or the flu)?	Estimate number of days:
$\square_1 \text{ Yes } \rightarrow \text{ Estimate number of days } \square_2 \text{ No}$	e. Does your persistent cough occur only when clearing your throat?
e. Skin rash or irritation?	
$\square_1$ Yes $\rightarrow$ Estimate number of days $\square$	
□₂ No	f. Do you usually cough as much as 4 to 6 times a day, 4 or more days out of the week?
f. Shortness of breath?	
$\Box_1$ Yes $\rightarrow$ Estimate number of days $\Box$	
∐₂ No	g. Do you usually cough at all when getting up or first thing in the morning?
g. Throat irritation?	$\square_1$ Yes
$\Box_1$ Yes $\rightarrow$ Estimate number of days $\Box_2$	$\square_2$ No
h. Hoarseness or loss of voice?	h. Do you usually cough at all during the rest of the day or at night?
$\Box_1$ Yes $\rightarrow$ Estimate number of days $\Box_2$	
i. Wheezing?	i. Do you usually cough like this on most days for 3
$\Box_1$ Yes $\rightarrow$ Estimate number of days $\Box_1$	consecutive months or more during the year?
j. Other, please specify:	
$\Box_1$ Yes $\rightarrow$ Estimate number of days $\Box$	j. For how many years have you had this cough?
	Estimate number of years:
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For each of the following health conditions, indicate Yes or No. If Yes, follow the arrows to additional questions in each row.

**14** Have you <u>ever</u> been told by a doctor or other health professional that you had any of these conditions: (Check Yes only if you were diagnosed by a doctor or other health professional)

		What year were you <u>first</u> told by a Were you				
		do		r other health professional	told <u>before</u>	
		_	th	at you had this condition?	9/11/01?	
a.	Hypertension or high blood pressure	∐₁ Yes	$\rightarrow$	Year first told:	∐₁ Yes	
		□_2 <b>No</b>			2 No	
b.	Angina, also called angina pectoris	□₁ Yes	$\rightarrow$	Year first told:	□₁ Yes	
		2 No			□₂ No	
c.	Heart attack or myocardial infarction	□₁ Yes	$\rightarrow$	Year first told:	□₁ Yes	
	-	□_2 <b>No</b>	-			
d.	Other heart disease	□₁ Yes	$\rightarrow$	Year first told:		
		□₂ No	,			
e	Stroke		$\rightarrow$	Year first told:		
•.		$\square_2$ No			$\square_2$ No	
£	Diabetes or sugar diabetes		$\rightarrow$	Year first told:		
	Diabetes of Sugar diabetes		7			
		∐₂ No	•			
g.	Cancer or malignancy, please specify type:	∐₁ Yes	$\rightarrow$	Year first told:	∐₁ Yes	
		∐₂ No			₂ No	
h.	Depression	∐₁ Yes	$\rightarrow$	Year first told:	∐₁ Yes	
		L <sub>2</sub> No			₂ No	
i.	Post-traumatic stress disorder or PTSD	∐₁ Yes	$\rightarrow$	Year first told:	∐₁ Yes	
		□ ₂ No			2 No	
j.	Anxiety disorder, other than PTSD	L ₁ Yes	$\rightarrow$	Year first told:	L ₁ Yes	
		□_2 <b>No</b>			□₂ No	
k.	Hay fever or allergic rhinitis	□₁ Yes	$\rightarrow$	Year first told:	□₁ Yes	
		□_2 <b>No</b>			2 No	
I.	Chronic bronchitis	□₁ Yes	$\rightarrow$	Year first told:	□₁ Yes	
		□_2 <b>No</b>			□_2 <b>No</b>	
m.	Emphysema	□₁ Yes	$\rightarrow$	Year first told:	□ <sub>1</sub> Yes	
		□₂ No	,			
n.	Reactive airway disease, also called RADS		$\rightarrow$	Year first told:		
			/		$\square_2$ No	
~	Sarcoidosis		$\rightarrow$	Year first told:		
0.	Sarcoluosis		7			
	Other lung disease (a g nulmenery fibrasis	∐₂ No			Ll <sub>2</sub> No	
р.	Other lung disease (e.g. pulmonary fibrosis,		、	Year first told:	□₁ Yes	
	granulomatous lung disease)	∐₁ Yes	$\rightarrow$		_	
	please specify:					
q.	Other disease (not lung related) please specify:	□₁ Yes	`	Year first told:	□₁ Yes	
	אוכמסב סאברווא		$\rightarrow$			
		L2 No				
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Your answers are confidential.

15	Have you <u>ever</u> been told by a doctor or other health professional that you had asthma?	17	Was there a time when you needed health care, but did not get it during the <u>last 12 months</u> ?
	$\square_2 \text{ No } \rightarrow \text{ SKIP to Question 16}$		$\square_2 \text{ No} \rightarrow \text{SKIP to Question 18}$
a.	What year were you <u>first</u> told by a doctor or other health professional that you had asthma?	a.	What type of health care did you need, but did not get during the last 12 months? (Check all that apply)
c. d.	Year first told:		□       Routine check-up         □       A specialist (e.g. dermatologist or surgeon)         □       Inpatient care (e.g. hospitalization)         □       Diagnostic services (e.g. radiology)         □       Soutpatient care (e.g. seeing a doctor for the flu)         □       -         □       Outpatient care (e.g. seeing a doctor for the flu)         □       -         □       Outpatient care (e.g. seeing a doctor for the flu)         □       -         □       Outpatient care (e.g. seeing a doctor for the flu)         □       -         □       Outpatient care (e.g. seeing a doctor for the flu)         □       -         □       Outpatient care (e.g. seeing a doctor for the flu)         □       -         □       Outpatient care (e.g. seeing a doctor for the flu)         □       -         □       Nental health care or counseling         □       -         □       Nental care         □       -         □       Other, please specify:
			□ I don't know
	· · · · · · · · · · · · · · · · · · ·		

W	WORLD TRADE CENTER HEALTH REGISTRY - ADULT FOLLOW-UP SURVEY 2006			
	ne time the time	19	to a professional for a mental or emotional problem? (e.g. a doctor, psychiatrist, psychologist, counselor, nurse, social worker, other health professional or clergy member) 1 Yes 2 No	
	ne ne time the time the time	use.	<ul> <li>During the last 12 months, have you taken any medication that was prescribed to you to treat a mental or emotional condition?</li> <li> <ul> <li>1</li> <li>Yes</li> <li>2</li> <li>No</li> </ul> </li> <li>ne next set of questions asks about tobacco and alcohol e. Please answer as best you can. Your answers are nfidential.</li> </ul>	
<b>c.</b> Restless or fice $\square_1$ All the tim $\square_2$ Most of the $\square_3$ Some of $\square_4$ A little of $\square_5$ None of the	ne time the time the time	21 a.	<ul> <li>Do you <u>now</u> smoke cigarettes every day, some days, or not at all?</li> <li>□₁ Every day</li> <li>□₂ Some days</li> <li>□₃ Not at all</li> <li>a. About how many cigarettes on average do you smoke per day?</li> </ul>	
<ul> <li>d. Hopeless?</li> <li>1 All the tin</li> <li>2 Most of ti</li> <li>3 Some of</li> <li>4 A little of</li> <li>5 None of ti</li> <li>e. That everythin</li> <li>1 All the tin</li> <li>2 Most of ti</li> </ul>	ne time the time the time he time g was an effort? ne ne time		<ul> <li>of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor.</li> <li>a. During the last 30 days, how many days per week or per month did you have at least one drink of any alcoholic beverage?</li> <li>Days per Days in last week: 30 days:</li> <li>1.7 OR 1.30 OR None</li> </ul>	
$\square_3  \text{Some of}$ $\square_4  \text{A little of}$ $\square_5  \text{None of f}$ <b>f. Worthless?</b> $\square_1  \text{All the tim}$ $\square_2  \text{Most of f}$ $\square_3  \text{Some of}$ $\square_4  \text{A little of}$ $\square_5  \text{None of f}$	the time he time ne time the time the time		<ul> <li>b. On the days when you drank, about how many drinks did you drink on average? Number of drinks:</li> <li> <ul> <li>Image: 1.30</li> <li>Image: OR</li> <li>Image: None</li> </ul> </li> <li>c. Considering all types of alcoholic beverages, how many times during the last 30 days did you have 5 or more drinks on one occasion? Number of times:</li> <li>Image: Image: Image:</li></ul>	
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Below is a list of problems or complaints that people sometimes have in response to stressful experiences like the events of September 11, 2001.

23 How much have you been bothered by the following problems in the <u>last 30 days</u>:

		Extremely	Quite a bit	Moderately	A little bit	Not at all
a.	Repeated, disturbing memories, thoughts, or images of the events of 9/11?			3	4	5
b.	Repeated, disturbing dreams of the events of 9/11?			<b></b> 3	4	5
c.	Suddenly acting or feeling as if the events of 9/11 were happening again (as if you were reliving it)?	1	2	3	4	5
d.	Feeling very upset when something reminded you of the events of 9/11?			3	4	5
e.	Having physical reactions (e.g. heart pounding, trouble breathing, sweating) when something reminded you of the events of 9/11?	1	2	3	4	5
f.	Avoiding thinking about or talking about the events of 9/11 or avoiding having feelings related to it?		2	3	4	5
g.	Avoiding activities or situations because they remind you of the events of 9/11?			<b></b> 3	4	5
h.	Trouble remembering important parts of the events of 9/11?			<b>_</b> 3		5
i.	Loss of interest in activities that you used to enjoy?			<sub>3</sub>	4	5
j.	Feeling distant or cut off from other people?	<b>1</b>	2	3	4	5
k.	Feeling emotionally numb or being unable to have loving feelings for those close to you?			3	4	5
I.	Feeling as if your future will somehow be cut short?			<b>_</b> 3		5
m	. Trouble falling or staying asleep?	1	2	3	4	5
n.	Feeling irritable or having angry outbursts?	<b>1</b>	2	3	4	5
о.	Having difficulty concentrating?			<b></b> 3	4	5
p.	Being "superalert" or watchful or on guard?				4	5
q.	Feeling jumpy or easily startled?		2	3	4	5

Sometimes people exposed to a traumatic event experience symptoms of distress. Some people may continue to suffer emotionally and have impaired functioning even after a significant amount of time has passed. If you or someone you know or love is still experiencing such difficulties, we encourage you to contact a mental health professional or call 800-LIFENET, a toll-free number that you can call 24 hours a day, 7 days a week to get free, confidential mental health information and referrals.

The next series of questions asks about the dust and debris cloud on September 11, 2001. These questions refer to the cloud in Lower Manhattan that resulted from the collapse of the WTC Towers. We asked similar questions during the initial WTCHR interview, but we want to obtain additional information about your dust and debris cloud experience.	<ul> <li>26 Did you experience any of the following situation between September 11, 2001 and December 31, 2001? (Check all that apply)</li> <li>a. I smelled smoke or odors from the fires on most days at</li> </ul>		
<ul> <li>On September 11, 2001, were you in the dust and debris cloud that resulted from the collapse of the WTC Towers?</li> <li>□ 1 Yes</li> <li>□ 2 No → SKIP to Question 26</li> <li>a. On September 11, 2001, when were you first caught in the dust and debris cloud?</li> </ul>	<ul> <li>☐ 1 My residence</li> <li>☐ 2 My work</li> <li>☐ 3 My school</li> <li>☐ 4 On the street</li> <li>☐ 5 Not applicable</li> <li>b. Debris or waste from 9/11 was transported nearby</li> </ul>		
<ul> <li>After the first tower began to collapse but before the collapse of the second tower.</li> <li>Less than 1 hour after the collapse of the second tower.</li> <li>More than 1 hour after the collapse of the second tower.</li> </ul>	$\square_1  \text{My residence}$ $\square_2  \text{My work}$ $\square_3  \text{My school}$ $\square_4  \text{On the street}$		
<ul> <li>25 When you were in the dust and debris cloud on September 11, 2001, which of the following did you experience?</li> <li>a. I could not see more than a couple of feet in front of me.</li> <li> <ul> <li> <li> <li> 1 </li> <li> Yes </li> <li> 2 </li> <li> No </li> </li></li></ul> </li> <li>b. I had trouble walking or finding my way because the dust was so thick. <ul> <li> 1 </li> <li> Yes </li> <li> 2 </li> <li> No </li> <li> C. I had to find shelter like under a car or in a doorway. </li> <li> 1 Yes </li> <li> 2 </li> <li> No </li> <li> d. I was covered from head to toe with dust and debris. </li> </ul></li></ul>	<ul> <li>Not applicable</li> <li>What was the condition inside your primary workplace upon your return after the WTC disaster? (Check all that apply)</li> <li>1 No damage to my workplace</li> <li>2 Fine coating of dust on surfaces</li> <li>3 Heavy coating of dust on surfaces (so thick you couldn't see what was underneath)</li> <li>4 Broken window(s)</li> <li>5 Damage to workplace or furnishings</li> <li>6 Debris from the disaster was present</li> <li>7 Not applicable, I did not have a primary workplace</li> <li>8 Not applicable, I did not return to my primary workplace</li> <li>9 Other, please specify:</li></ul>		
$ \begin{array}{c c} & & & \\ \hline & & \\ 1 & & \\ 2 & & \\ No \end{array} $ <b>e. I could not hear anything.</b> $ \begin{array}{c c} & & \\ \hline & & \\ 1 & & \\ 1 & & \\ 2 & & \\ No \end{array} $			

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The next series of questions asks about loss <u>as a result</u> of September 11, 2001. We sincerely extend our sympathy to all who suffered any loss during or following the WTC disaster. These questions are asked because it is important to understand the emotional impact of the disaster on enrollees.	<ul> <li>This next section is about social support. There are <u>no</u> right or wrong answers. Please answer as best you can, based on your <u>current</u> situation.</li> <li>About how many close friends do you have now? Close friends are people you feel at ease with and</li> </ul>			
<ul> <li>28 Did you think that you might be injured or killed during the WTC disaster on September 11, 2001?</li> <li>□ 1 Yes</li> <li>□ 2 No</li> <li>29 Since September 11, 2001, have you lost your job?</li> <li>□ 1 Yes</li> <li>□ 2 No → SKIP to Question 30</li> <li>a. Was this a result of the events of September 11, 2001?</li> <li>□ 1 Yes</li> <li>□ 2 No</li> <li>□ 2 No</li> <li>□ 3 I don't know</li> </ul>	<ul> <li>can talk with about what is on your mind (You may include relatives)</li> <li>Number of close friends □□1.30 OR None □</li> <li>32 Over the last 12 months, about how often did you get together with friends or relatives, like going out together or visiting each other's homes?</li> <li>□1 Every day</li> <li>2 Several days a week</li> <li>3 About once a week</li> <li>4 2 or 3 times a month</li> <li>5 About once a month</li> <li>6 5 to 10 times a year</li> <li>7 Less than 5 times a year</li> </ul>			
<ul> <li>30 Did anyone you know die on September 11, 2001 as a result of the WTC disaster?</li> <li>□₁ Yes</li> <li>□₂ No → SKIP to Question 31</li> <li>We sincerely extend our sympathy to you for your tragic loss on September 11, 2001.</li> </ul>				
a. Would you please tell us who lost their lives? (Check all that apply)         1       Your spouse         2       Your partner         3       Your child(ren)         4       Your parent(s)         5       Your brother(s) or sister(s)         6       One of your best friends         7       Your co-worker         8       Another family member. What was his/her relationship to you?         9       A friend or acquaintance         10       Other, please specify:				

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33	During the last 30 days about how often have	e.	Attended a religious service?		
	you		□ <sub>1</sub> Every day		
а.	Had friends over to your home? (Do not count relatives)		□₂ Several days a week		
	□₁ Every day		□ 3 About once a week		
	$\square_2$ Several days a week		□₄ 2 or 3 times a month		
	$\square_3$ About once a week		$\Box_{\mathfrak{s}}$ Once in the past month		
	$\square_4$ 2 or 3 times a month		$\square_{6}$ Not at all in the past month		
	$\square_5$ Once in the past month	34	About how many volunteer groups or		
	$\square_6$ Not at all in the past month		organizations do you belong to? (e.g. church groups, clubs, parent groups that you belong to because you want to)		
b.	Visited with friends at their homes? (Do not count relatives)		Number of groups		
	□ <sub>1</sub> Every day	35	How active are you in the affairs of these groups or clubs that you belong to?		
	□₂ Several days a week		$\square_1$ Very active, attend most meetings		
	□₃ About once a week		$\square_2$ Fairly active, attend fairly often		
	□₄ 2 or 3 times a month		$\square_3$ Not active, belong but hardly go		
	$\square_{\mathfrak{s}}$ Once in the past month		$\square_4$ Do not belong to any groups or clubs		
	$\square_{\epsilon}$ Not at all in the past month	36			
c.	Been on the telephone with close friends or	30	6 How many children less than 18 years of age <u>currently</u> live in your household?		
	relatives?		Number of children		
	Ll₁ Every day	37	What is your <u>current</u> marital status?		
	└┘₂ Several days a week		□, Married		
	Ll₃ About once a week		□₂ Not married, but living with a partner		
	└┘₄ 2 or 3 times a month		□ ₃ Widowed		
	└─₁₅ Once in the past month				
	Ll <sub>6</sub> Not at all in the past month		□ ₅ Separated (not living together)		
d.	Written a letter to a friend or relative (sent by mail or email)?		□ Never married		
	□ <sub>1</sub> Every day	38	What was your marital status on September 11, 2001?		
	□₂ Several days a week		□ 1 Married		
	□ ₃ About once a week		$\Box_2$ Not married, but living with a partner		
	□₄ 2 or 3 times a month				
	$\square_{\mathfrak{s}}$ Once in the past month				
	$\square_{6}$ Not at all in the past month		$\Box_{\mathfrak{s}}$ Separated (not living together)		
			□ <sub>6</sub> Never married		

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39	Are you currently: (Check all that apply)	a.	. Which union were you a member of? (Please check
	□ _ Employed for full-time wages		your primary union only)
	□ _₂ Employed for part-time wages		American Federation of Government Employees
	$\Box_{3}$ Unable to work because of disability		Communications Workers of America
	□ ₄ Self-employed		□ Correction Officers' Benevolent Association
	$\square_{\rm 5}$ Out of work for more than 1 year		□ Detective's Endowment Association
	$\square_6$ Out of work for less than 1 year		□ District Council 37 (AFSCME)
	$\square_7$ A homemaker		International Union of Operating Engineers
	$\square_{\circ}$ A student		□ <sub>7</sub> Patrolmen's Benevolent Association
			Sanitation Officer's Association Sergeant's Benevolent Association
	Retired		
	$\square_{10}$ On maternity or parental leave		$\Box_{10}$ Uniformed Firefighters Association (UFA) $\Box_{11}$ Uniformed Fire Officers Association (UFOA)
40	What kind of work are you doing at your main job		$\square_{12}$ Uniformed Sanitationmen's Association
	specialist)	<b>Dusiness?</b> (e.g. construction, mail clerk, computer cialist)	$\square_{12}$ United Federation of Teachers
	□ Occupation:		$\square_{14}$ Other, please specify:
	$\square_2$ Not applicable		$\square_{14}$ Other, please specify
41	What are your most important activities on this job or business? (e.g. sell cars, keep account books, operate printing press)	45	following 9/11-related medical monitoring or treatment programs? (Check all that apply)
	□ Duties:		□ Bellevue Hospital WTC Health Impacts Treatment Program
	□ Not applicable		$\square_2$ Charles B. Wang Community Health Center
42	For how many years have you done this kind of work?		☐₃ FDNY WTC Medical Monitoring and Treatment Programs
	Number of years		□ The WTC Federal Responder Medical Screening Program
	□₂ Not applicable		□ 5 The WTC Health Effects Treatment Program at Mount Sinai
43	Does your <u>current</u> position require you to work at multiple locations?		The WTC Medical Monitoring Program (coordinated by Mount Sinai)*
	∐₁ Yes		□ <sub>7</sub> Other, please specify:
	□₂ No		□ I did not receive services from 9/11-related
	Ll₃ Not applicable		medical monitoring or treatment programs
44	On September 11, 2001, were you a member of a union?	*	<sup>4</sup> This program has a network of providers, including the following: Bellevue Hospital, Mt. Sinai, Nassau University, Queens College Ground Zero Health Watch, St. John's Riverside Hospital, SUNY-Stony Brook, UMDNJ-Robert Wood Johnson University Hospital, and other providers.

During the initial interview, you indicated that on September 11, 2001 you were living in Lower Manhattan. We would like to get a better understanding of your experience as a resident in Lower Manhattan and the methods used to clean the dust and debris from homes of residents in the area surrounding the WTC. Please answer the following questions as accurately as you can recall.         A1       During the period of September 11 to September 18, 2001 did you leave your home for at least 24 hours because of the WTC attack?         □       1       Yes → SKIP to question A2         □       2       No         a.       If you did not leave your home for at least 24 hours between September 11 and September 18, what were some of the reasons?         (Check all that apply)       □       1         □       1       It wasn't necessary         □       1       It ouldn't afford to leave         □       1       It ouldn't afford to leave         □       1       It couldn't because of a pet         □       1       It couldn't because of a pet         □       1       I couldn't leave a loved one         □       0       0       0         □       0       0       1         □       1       1       1         □       1       1       1         ■       1       1       1	<ul> <li>A3 Which of the following were done by you personally to clean your home following September 11, 2001? (Check all that apply)</li> <li>□ I did not personally clean my home</li> <li>□ I cleaned the ventilation ducts</li> <li>□ I cleaned with a damp cloth or wet mop or damp sponge</li> <li>□ I used a vacuum with a High-Efficiency Particulate Air (HEPA)* filter</li> <li>□ I used a vacuum without a High-Efficiency Particulate Air (HEPA)* filter</li> <li>□ I dusted or swept without water</li> <li>A4 Did someone other than yourself clean your home following September 11, 2001? (Check all that apply)</li> <li>□ No</li> <li>□ Yes, a licensed asbestos abatement contractor</li> <li>□ Yes, a professional from the EPA clean-up program</li> <li>□ Yes, a worker hired off the street</li> <li>□ Yes, someone else from another government agency</li> <li>□ Yes, someone else, but I do not know their qualifications</li> <li>A5 Which of the following were done by someone else other than yourself to clean your home following September 11, 2001? (Check all that apply)</li> <li>□ No</li> <li>□ Yes, a worker hired off the street</li> <li>□ Yes, someone else from another government agency</li> <li>□ No the following were done by someone else other than yourself to clean your home following September 11, 2001? (Check all that apply)</li> <li>□ No one else cleaned my home</li> </ul>
$\square_2$ Fine coating of dust on surfaces	$\square_2$ Someone else cleaned the ventilation ducts
<ul> <li>Heavy coating of dust on surfaces</li> <li>Heavy coating of dust on surfaces</li> <li>(so thick you couldn't see what was underneath)</li> </ul>	□ Someone else cleaned with a damp cloth or wet mop or damp sponge
□ 4 Broken window(s)	□₄ Someone else used a vacuum with a
□ <sub>5</sub> Damage to home or furnishings	High-Efficiency Particulate Air (HEPA)* filter
$\square_6$ Debris from the disaster was present	Someone else used a vacuum without a
□ <sub>7</sub> Other, please specify:	High-Efficiency Particulate Air (HEPA)* filter
* A HEPA filter is a specially constructed filter membrane that allows a high volume of air flow and stops small particles from passing through.	$\square_6$ Someone dusted or swept without water $\square_7$ I don't know

A6 A7	Were any of the following replaced in your home because of September 11, 2001? (Check all that apply to at least one room) I I did not have anything replaced Carpet or rugs I Furniture (replaced or re-upholstered) I Drapes, blinds or curtains S Air conditioners 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. Was your home part of the EPA's clean-up program? I Yes I No I don't know What did the EPA do to your home in 2002-2003? I Cleaned and tested I 2 Tested only	from 200 <sup>7</sup> build like	ng the initial interview, you indicated you evacuated a building in Lower Manhattan on September 11, 1. The building you evacuated from was on a list of dings destroyed or damaged in the attacks. We would to get a better understanding of your experience. Ise answer the following questions the best you can. <b>How did you evacuate the building?</b> (Check all that apply)
		<b>B</b> 4	<ul> <li>I was overwhelmed by feelings of fear or panic</li> <li>I encountered many flights of stairs (was exhausted)</li> </ul>

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During your initial interview, you informed us that you were involved in the WTC rescue, recovery, and cleanup as a worker
or volunteer. We would like to learn more about your experience with personal protective equipment, such as availability and
training, during that time.

Directions: As you answer these quest	tions, please refer to the pictures o	of respirators and masks shown o	on the opposite page.
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<b>C1</b>	Before September 11, 2001, such as at your usual job or volunteer work, did you receive training in the use of
	respirators or masks? (You may check more than one)

- └┘₁ Yes, respirator(s) such as Types 1 or 2 shown on the opposite page
  - <sup>2</sup> Yes, mask(s) such as Types 3 or 4 shown on the opposite page
  - No
- C2 During your WTC-related work, did you ever receive training in the use of respirators or masks? (You may check more than one)
  - └└₁ Yes, respirator(s) such as Types 1 or 2 shown on the opposite page
    - <sup>2</sup> Yes, mask(s) such as Types 3 or 4 shown on the opposite page
  - \_₃ No
- C3 The next set of questions are about types of masks you used during WTC-related work. Please refer to the pictures of respirators and masks shown on the opposite page.

	Type1	Type2	ТуреЗ	Type4	Other	None	Not appli- cable
a. On September 11, 2001, which type of mask or respirator did you wear the most? (Check one)		2	3	4	5	6	7
b. From September 12 to December 31, 2001, which type of mask or respirator did you wear the most? (Check one)	<b>1</b>		3	4	5	6	7
<ul> <li>c. From January 1, 2002 onward, which type of mask or respirator did you wear the most? (Check one)</li> </ul>	<b>1</b>	2	3	4	5	6	7

C4 During your WTC-related work, on the days you wore a Type 1 or Type 2 respirator....

	All of the time	Most of the time	Some of the time	None of the time	Don't know	Not appli- cable
a. How often did it fit you well (form a seal to your face)?		2	3	4	5	
b. How often was it cleaned before you wore it?		2	3	4	5	6
c. How often were the cartridges (filters) replaced before you wore it?		2	<b></b> 3	4	5	6

## C5 During your WTC-related work, did you have a fit-test\* for at least one of the Type 1 or Type 2 respirator(s) you used on or after September 11, 2001?

- \_₁ Yes
- ]<sub>2</sub> No

**Type 1: Full-Face Respirator** 

<sup>3</sup> Not applicable, I did not wear a Type 1 or Type 2 respirator.

\* Fit Test: There are several types of fit-tests which require you to do short exercises such as talking or moving your head side-to-side while wearing the respirator. One type involves comparing dust levels inside and outside the respirator after the exercises. Another type involves spraying a test solution (such as banana oil or saccharine) under a hood while you wear the respirator to see if you can smell or taste the test solution.

#### **Examples of Respirators and Masks**

**Type 2: Half-Face Respirator** 

## Shield covers whole face Shield covers nose and mouth Replaceable filter / chemical cartridges Replaceable filter / Chemical cartridges: or clean-air supply (SCBA) or powered air purification (PAPR) Type 3: Disposable Masks with N95 to P100 Rating Nose clip -Most have two straps MUST HAVE N95 to P100 Rating Valve (left) and Non-Valve (right) Type 4: Other Disposable Masks (nuisance dust masks, surgical masks) Some have nose clip May only have 1 strap Does NOT have N95 to P100 Rating

15 Your answers are confidential. 1-866-692-9827

You are nearing the end of this survey.

D1 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 social security number? This information will remain strictly confidential and will only be used to match your responses to those in the baseline interview and to other health registries.

Enter last 4 digits:	
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D2 What is your current email address?

We are requesting this information so that we can better stay in touch with you.

D3 Please let us know below if you have any additional health concerns since September 11, 2001:

D4 We would like to hear about your experiences as an enrollee in the WTC Health Registry. Do you have any comments or suggestions about the Registry, or are there any important questions you felt the survey did not cover?

#### THANK YOU

Thank you for participating in the first WTC Health Registry follow-up survey. The WTCHR 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 health effects related to this tragedy. We greatly appreciate your cooperation, the time that you took to complete the survey, and the information you provided.

#### **REMINDER:**

The latest updated version of the Registry's "Resource Guide: March 2006" is online as well as other updated WTCHR reports and publications. Please visit **www.wtcregistry.org** to obtain copies.

Please return your completed survey in the envelope provided to:

WTC Health Registry 116 John St. Rm 800 New York, NY 10038



If you are interested in receiving regular health updates and information via email from the NYC Department of Health and Mental Hygiene, visit <u>www.nyc.gov/html/doh</u>.

On the home page, click on the box "**Sign up for Health Emails**" (located in the top right corner). This will open the "Email Update" page. Under "Step 1: Select Categories," check those health topics for which you wish to receive updates (e.g. diabetes, smoking & tobacco, depression). Select "WTC Health Registry" to receive updates about the Registry.

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## Ten Steps to Improve Your Health are:



- 1. Have a Regular Doctor or Other Health Care Provider
- 2. Be Tobacco Free
- 3. Keep Your Heart Healthy
- 4. Know Your HIV Status
- 5. Get Help for Depression
- 6. Live Free of Dependence on Alcohol and Drugs
- 7. Get Checked for Cancer
- 8. Get the Immunizations You Need
- 9. Make Your Home Safe and Healthy
- 10. Have a Healthy Baby

For more information, go online at: www.nyc.gov/html/doh