HEALTH PROGRAM

Member Handbook





"The World Trade Center Health Program saved my life."

-Stanley, responder

Purpose of this Handbook

The purpose of this handbook is to provide you with information on the World Trade **Center (WTC) Health Program** (the Program).

The handbook includes:

- Information on member benefits:
- Important contact information;
- Details on certified conditions:
- Health information privacy policies;
- Member responsibilities.

This handbook is available online at www.cdc.gov/wtc/handbook.html or by scanning this QR code with your mobile device:



Disclaimer: This handbook is not a legal document. The purpose of this handbook is to provide general Program information in a way that is easy for you to use and understand.

Important Contact Information

If you are experiencing a medical emergency, call 911 immediately.

If you are in distress, call the National Suicide Prevention Lifeline at 1-800-273-8255

WTC Health Program Call Center: 1-888-982-4748 (toll-free)

(Monday-Friday, 9 am-5 pm Eastern)

Email: WTC@cdc.gov (for general inquiries only) Website: www.cdc.gov/wtc

Call your clinic directly to schedule appointments and for specific questions **about your care and treatment.** See pages 7-10 for Clinical Center for Excellence and Nationwide Provider Network contact information.

Social Media

Follow us on Facebook and Twitter for important Program information, health tips,



facebook.com/wtchealthprogram



twitter.com/wtchealthprgm

Reminder: The WTC Health Program is administered by the National Institute for Occupational Safety and Health (NIOSH), part of the Centers for Disease Control and Prevention (CDC) in the U.S. Department of Health and Human Services (HHS). The Clinical Centers of Excellence and Nationwide Provider Network provide medical care on behalf of NIOSH.

Definitions of the words **highlighted in blue** can be found in the glossary beginning on page 57.

A Message from the Administrator

It is my pleasure to present you with the World Trade Center (WTC) Health Program Member Handbook. I hope this handbook helps you find Program information quickly and easily, and that it makes Program benefits and policies easier to understand.

In addition to this handbook, we continually add and improve information on our website, including:

- A Member Resources page that contains quick links to important member-specific information at www.cdc.gov/wtc/memberresources.html,
- Frequently Asked Questions (FAQs) in easy-to-understand categories at www.cdc.gov/wtc/faq.html, and
- A How to Apply section that helps those you know who are interested in applying to the Program better understand who is eligible and what is needed to apply at www.cdc.gov/wtc/apply.html.

We know that you depend on the WTC Health Program for high-quality, compassionate care for your WTC-related health care needs. Your trust, satisfaction, and success in the Program is very important to us.

Please feel free to call our call center at 1-888-982-4748 if you have any questions or concerns. You can also view or download this handbook online at www.cdc.gov/wtc/handbook.html.

Sincerely.

John Howard, MD

Administrator, World Trade Center Health Program

About the Administrator

Harris

John Howard, MD, MPH, JD, LLM, MBA, is board-certified in internal medicine and occupational medicine. He is admitted to the practice of medicine and law in the State of California and in the District of Columbia, and is a member of the U.S. Supreme Court bar.

In addition to serving as the Administrator of the WTC Health Program, he also serves as Director of the National Institute for Occupational Safety and Health (NIOSH).

Learn more about Dr. Howard at www.cdc.gov/about/leadership/leaders/niosh.html



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"Coming into the health program has provided me hope. They can understand my symptoms and they can understand what I'm going through."

-Alex, responder

Overview of the WTC Health Program

The World Trade Center (WTC) Health Program provides no-cost health care for certified WTC-related health conditions at multiple Clinical Center of Excellence (CCE) locations throughout the New York (NY) metropolitan area. The Nationwide Provider Network (NPN) provides care for members who live outside the NY metropolitan area.

The Program's medical and mental health providers are 9/11 health experts with special skills in the diagnosis and treatment of WTC-related health conditions. The Program offers a safe space to talk about what happened on 9/11 and how it might still affect you, your family, and your work.

The James Zadroga 9/11 Health and Compensation Act

On January 2, 2011, President Obama signed the **James Zadroga 9/11 Health and Compensation Act of 2010 (Zadroga Act)** into law (Public Law 111-347). The Zadroga Act modified the Public Health Service Act to extend and improve protections and services to individuals directly impacted by September 11, 2001.

The Zadroga Act established or reauthorized the following three programs that help those directly affected by the September 11, 2001, attacks:

- The WTC Health Program;
- The September 11th Victim Compensation Fund (VCF); and
- The WTC Health Registry.

On December 18, 2015, President Obama signed legislation to reauthorize the Zadroga Act. The law extended the WTC Health Program until 2090. In 2019, legislation was signed into law increasing the number of individuals who can be newly enrolled in the WTC Health Program.

See pages 2-3 for more information on the VCF and WTC Health Registry.

About the WTC Health Program

Through the Zadroga Act and its implementing regulations, the WTC Health Program is able to provide WTC-related medical and mental health services at no cost to you.

This means access to high-quality, compassionate care without having to pay any copayments, deductibles, or other out-of-pocket expenses for **medically necessary treatment** of certified WTC-related health conditions.

The WTC Health Program is authorized by the Zadroga Act to provide benefits to these categories of individuals:

WTC Responders: workers or volunteers who provided rescue, recovery, debris
cleanup, and related support services on or in the aftermath of the September 11,
2001, attacks for certain amounts of time during the period between September 11,
2001, and July 31, 2002. There are three types of responders: FDNY Responders, NYC
General Responders (including NYPD), and Pentagon and Shanksville, PA, Responders.

2. WTC Survivors: individuals who were present in the New York City (NYC) Disaster Area in the dust or dust cloud on September 11, 2001; who worked, resided, or attended school, childcare, or adult daycare in the NYC Disaster Area from September 11, 2001, to July 31, 2002; who were eligible for certain residential grants or whose place of employment was eligible for certain grants following the September 11, 2001, attacks.

As a limited health care benefits program, the WTC Health Program provides the following services to members:

Enrolled Responders receive:

• Annual monitoring exams.

Enrolled Screening-Eligible Survivors receive:

A one-time initial health evaluation.*

*If the initial health evaluation does not result in any **certifications** and the Survivor later feels a new health problem may be WTC-related, he or she can pay out of pocket or use primary health insurance for an additional health evaluation by a Program doctor.

Enrolled Responders and **Certified-Eligible Survivors** (survivors with a certified health condition) receive:

- Annual monitoring exams;
- Medical and mental health treatment for covered WTC-related health conditions;
- Cancer screening (when indicated in the U.S. Preventive Services Task Force (USPSTF) guidelines); and
- Benefits counseling services.

This handbook will provide you with detailed information about these services as well as your benefits, rights, and responsibilities as a member of the Program.

Other September 11th Programs

September 11th Victim Compensation Fund

The September 11th Victim Compensation Fund (VCF) is a separate program from the WTC Health Program and is administered by the U.S. Department of Justice.

The VCF provides financial compensation to individuals (or a personal representative of a deceased individual) who were present at the World Trade Center or in the NYC Exposure Zone (see www.vcf.gov/nyc-map-exposure-zone); the Pentagon crash site; or the Shanksville, Pennsylvania, crash site, at some point between September 11, 2001, and May 30, 2002, and who have since been diagnosed with a 9/11-related physical illness.

The VCF does not compensate for mental health conditions and does not distinguish between responders and survivors.

To be eligible to file a claim now or in the future, you <u>must</u> register with the VCF by the following deadlines:

- Those with a WTC-related physical health condition certified by the WTC Health Program <u>before</u> July 29, 2019, must register with the VCF by **July 29, 2021**.
- Those who are certified with a WTC-related physical health condition <u>after July</u> 29, 2019, must register two years after the latest date of such a certification.

You can register now, even if you are not sick and do not have any WTC-related physical health conditions certified by the Program. Registration simply preserves your right to file a claim if you become sick. You will not lose legal rights by registering. The VCF can accept claims through October 1, 2090.

For more information about the VCF, including everything needed to register, file, and monitor the status of a claim, visit www.vcf.gov or contact the VCF directly at 1-855-885-1555.

Enrollment in the WTC Health Program does <u>not</u> automatically register you or file a claim with the VCF.

WTC Health Registry

The Zadroga Act also extended the WTC Health Registry (the Registry). The Registry was developed to document and evaluate the long-term physical and mental health effects of the 9/11 attacks. To date, the Registry is the largest effort in the U.S. to monitor the health of people exposed to a large-scale disaster.

Enrollment in the Registry occurred in 2003-2004 through voluntary responses to a survey and is now closed.

If you are enrolled with the Registry, you received a first survey and now receive periodic follow-up surveys from them. The results of these surveys help determine to what extent physical and mental health conditions have persisted in 9/11-exposed populations, and whether any new symptoms and conditions have emerged. Another important goal of the Registry is to identify and help address gaps in physical and mental health treatment in these populations.

For more information about the Registry, please contact them directly at wtchr@health.nyc.gov. You can also visit www.nyc.gov/9-11health or call 1-866-692-9827.

Workers' Compensation

WTC Health Program members whose certified WTC-related health condition(s) are also work-related may be eligible to file for **workers' compensation** benefits. Even if you are a Program member and receiving medical treatment for your certified WTC-related health condition(s) at no cost to you, it can be beneficial to file a workers' compensation claim. This is because workers' compensation may also provide a financial award for lost wages related to your WTC-related health condition(s).

New York State Workers' Compensation Law

Workers and volunteers who performed rescue, recovery, and clean-up of the World Trade Center and other impacted sites can register with the New York State Workers' Compensation Board. This registration preserves the right to file for workers' compensation benefits through the State of New York should you need them in the future.

New York State passed legislation (Amendment S7797-A) on September 7, 2018, extending the deadline until September 11, 2022, for filing the Registration of Participation in World Trade Center Rescue, Recovery and/or Clean-up Operations form (Form WTC-12).

For information on eligibility, to download Form WTC-12, and for any questions about this program, please see the "Preserve Your Rights - WTC Registry" section on the New York State Workers' Compensation Board World Trade Center Assistance site at www.wcb.ny.gov/WTC/wtc-assistance.jsp or call 1-877-632-4996. Workers can also obtain Form WTC-12 from any New York State Workers' Compensation Board office.

WTC Health Program Coverage

The Program covers initial health evaluations, annual monitoring exams, and medically necessary medical and mental health treatment for certified WTC-related health conditions. For the **List of WTC-Related Health Conditions**, see covered conditions on pages 25-27.

Health Insurance Requirement

The WTC Health Program does not replace your primary health insurance.

The Zadroga Act requires all Program members to have qualifying health insurance unless they meet one of the exceptions in the Affordable Care Act.

If you do not have health insurance, your CCE or the NPN will refer you to a staff person who can help you determine if you might be eligible for public health insurance programs like **Medicaid** or **Medicare**. If not, a staff person can help you to get the care you need at a **Federally Qualified Health Center** or other community health center that offers more affordable care options for you.

The Program covers the cost of treatment for certified WTC-related health conditions <u>only</u>. You must use your primary health insurance or pay out of pocket for any treatment related to a health condition not certified by the Program. Your CCE or the NPN can advise you on how to find care for any health conditions not certified by the Program.

Program Coverage and Workers' Compensation

If you already have an established workers' compensation case for a certified WTC-related health condition(s) that is not funded by New York City, the Program will bill your workers' compensation insurance carrier for the cost of the treatment of those conditions. This is known as recoupment.

If you are waiting for your case to be established, the Program will continue to pay for any medically necessary services needed to treat your certified WTC-related health condition(s) until the case is established. If your workers' compensation case is denied, then the WTC Health Program will directly cover the cost for the medically necessary treatment of your certified WTC-related health condition(s).

For more information about the Program's workers' compensation recoupment policy, refer to the Policy and Procedures for Recoupment: Lump-Sum Workers' Compensation Settlements online at www.cdc.gov/wtc/policies.html or the frequently asked questions about workers' compensation recoupment at www.cdc.gov/wtc/faq.html.

Workers' Compensation Settlements

Some workers decide to settle their workers' compensation claims. The worker enters into a settlement agreement, called a Section 32 waiver agreement, with the workers' compensation insurance carrier. The insurance carrier gives the worker a lump sum of money to close the case forever. Sometimes, Section 32 agreements release the insurance carrier from having to pay any future medical costs for the worker's injury or illness.

Any Section 32 agreement entered into between a Program member and an insurance carrier must protect the WTC Health Program's interests. In some cases, the Program will require that money from a Section 32 agreement be set aside to cover future medical expenses that should have been paid by workers' compensation, like the costs of medical treatment and medications for certified WTC-related health condition(s).

If you consider entering into a Section 32 agreement, you must ask the Program to review the proposed settlement. This review determines if the proposed settlement amount is enough to cover future medical costs for your certified WTC-related health condition(s).

Coordination of Benefits

Coordination of Benefits is a process that helps determine who pays a medical bill first when there is more than one potential payer. The Zadroga Act sets the order in which these payers are responsible for paying for monitoring and treatment of a certified WTC-related health condition.

For Responders

The Program directly pays for all monitoring, treatment, and medication costs of a certified WTC-related health condition for Responders with one exception. If a Responder has a workers' compensation claim for the certified condition, then workers' compensation is the primary payer and the Program pays the remainder of the costs. However, to facilitate processing in such cases, the Program will pay initially and then seek recoupment from either the workers' compensation carrier or the settlement, where applicable.

For Survivors

The Program directly pays for the one-time initial health evaluation for **Screening-Eligible Survivors** and for annual monitoring exams for **Certified-Eligible Survivors**.

For treatment and medication costs of a certified WTC-related health condition, the Program covers what is left after your **primary health insurance** pays its share.

The Program bills your private health insurance first. The Program then bills any public health insurance, like Medicare or Medicaid, you may have. Once your other health insurance providers have paid, the Program pays any remaining amount.

This leaves no out-of-pocket cost to you. You are not responsible for paying any co-insurance charges, copayments, or deductibles for care of your certified WTC-related health conditions so long as that care is received from a Program provider.

Please note: If a Survivor's certified condition is work-related and they have a workers' compensation claim for the condition, then workers' compensation is the primary payer. However, to facilitate processing in such cases, the Program will pay initially and then seek recoupment from either the workers' compensation carrier or the settlement, where applicable.

Survivors must share their primary health insurance information when visiting a CCE or an NPN- or CCE-affiliated provider. This may include both private and public insurance information.

Billing

In most cases, the billing of medical claims for both Responders and Survivors is handled by the CCE or NPN and no action is needed by you.

However, Survivors who receive treatment at an affiliated provider not located at a CCE should let the provider staff know that the visit is for a certified WTC-related health condition. This will help make sure that the visit is billed properly.

For Survivors who get medications at a pharmacy, please tell your pharmacy to bill your primary insurance first and the WTC Health Program last. Visit www.cdc.gov/wtc/cob.html for more information on how to help your pharmacist bill your prescription correctly.

If you receive a bill for WTC-related care, please call your CCE, the NPN, or the Program call center so that the issue can be addressed.

WTC Health Program Clinical Centers of Excellence

Various Clinical Centers of Excellence (CCEs) are available to you in the NY metropolitan area based on your category of membership in the WTC Health Program.

Below is a list of the CCEs, including contact information, based on the membership category served by each clinic. CCEs in the NY metropolitan area are centers with physicians, nurses, case managers, and other health care providers from multiple disciplines on site.

Visit www.cdc.gov/wtc/clinics.html for additional contact information and links to individual clinic websites.

Fire Department - City of New York Clinical Centers of Excellence

CCE	Location	Phone
FDNY Headquarters	9 Metro Tech Center Brooklyn, NY 11201	1-718-999-1858
Brentwood, Suffolk County, Long Island	1001 Crooked Hill Road Brentwood, NY 11717	1-718-999-1858
Commack, Suffolk County, Long Island (Physical Health Services Only)	66 Commack Rd Suite 200 Commack, NY 11725	1-718-999-1858
Fort Totten, Queens	Fort Totten, Building 413B Bayside, NY 11359	1-718-999-1858
Manhattan (Mental Health Services Only)	251 Lafayette St. New York, NY 10012	1-212-570-1693
Middletown, Orange County	2279 Goshen Turnpike Middletown, NY 10940	1-718-999-1858
Staten Island	1688 Victory Boulevard Suite 101A Staten Island, NY 10314	1-718-999-1858

WTC General Responder Clinical Centers of Excellence

CCE	Location	Phone
Icahn School of Medicine at Mount Sinai Selikoff Centers for Occupational Health;	<i>Manhattan</i> 1468 Madison Ave, 3rd Floor New York, NY 10029	1-212-241-1554
WTC Health Program Clinical Center of Excellence at Mount Sinai	Staten Island 2052 Richmond Road, Suite 2A Staten Island, NY 10306	1-212-241-1554
	Rockland County 222 Route 59 Suffern, NY 10901	1-212-241-1554
New York University Grossman School of Medicine NYUSOM WTC Health Program Clinical Center of Excellence	Manhattan 650 First Ave, 7th Floor, WTC Suite New York, NY 10016	1-212-263-7335
Northwell Health Northwell WTC Clinical Center	<i>Queens</i> 97-77 Queens Blvd, 9th Floor Rego Park, NY 11374	1-718-267-2420
Rutgers, The State University of New Jersey Environmental & Occupational Health Sciences Institute; World Trade Center Health Program at Rutgers	New Jersey 170 Frelinghuysen Road Piscataway, NJ 08854	1-848-445-0123
State University of New York (SUNY), Stony Brook Stony Brook Medicine	Suffolk County (Main Clinic) 500 Commack Road, Suite 160 Commack, NY 11725	1-631-855-1200
Stony Brook WTC Health and Wellness Program	Nassau County (Satellite Clinic) 173 Mineola Blvd, Suite 302 Mineola, NY 11501	1-631-855-1200

WTC Survivor Clinical Centers of Excellence

CCE	Location	Phone
NYC Health + Hospitals System WTC Environmental Health Center	Manhattan NYC Health + Hospitals/Bellevue 462 First Ave (at 27th St.) New York, NY 10016	1-877-982-0107
	Manhattan NYC Health + Hospitals/ Gouverneur 227 Madison St (at Clinton St.) New York, NY 10002	1-212-238-7400
	Queens NYC Health + Hospitals/Elmhurst 79-01 Broadway RM D1-24 Elmhurst, NY 11373 Main Building, First Floor Entrance located on 80th St. & 41st Avenue	1-877-982-0107
William Street Clinic* Operated by Logistics Health Incorporated	Manhattan 156 William Street, Suite 401 New York, NY 10038	1-800-714-7426

^{*}Performs initial health evaluations, monitoring exams, and coordinates ongoing treatment services using the WTC Health Program Provider Network.

How to Make an Appointment with a CCE

Current Members: Contact your CCE directly for medical appointment scheduling and any questions or issues related to your care. The WTC Health Program call center cannot schedule or change appointments.

New Members: Your Program enrollment welcome letter contains specific information on how to schedule an initial health evaluation/baseline monitoring exam at one of the CCEs or through the NPN. If you have questions, please call the WTC Health Program call center at 1-888-982-4748.

If you need to cancel or reschedule an appointment, be sure to call the CCE within 24 hours of your scheduled appointment time so that the appointment can be offered to another member. If you receive paperwork from your CCE before your appointment, be sure to complete it.

Nationwide Provider Network

You are eligible to receive care through the Nationwide Provider Network (NPN) if you reside outside of the NY metropolitan area. The NPN is operated by **Logistics Health Incorporated (LHI)**. They have a network of providers that are located in every state and centrally manage care for members assigned to the NPN.

Since the NPN is made up of individual doctors with their own specialties, you may need to go to more than one provider to receive care for each of your certified WTC-related health conditions.

If you live in an urban area, the NPN will try to find you care within 30 miles of your residence. If you live in a rural area, the NPN will try to find you care within 75 miles of your residence. If you would like to learn more about the location of local providers available to you through the NPN, please contact the NPN directly.

Members outside the NY metropolitan area

Name	Location	Phone
Nationwide Provider Network (NPN) Operated by Logistics Health Incorporated (LHI)	LHI Headquarters 328 Front Street South La Crosse, WI 54601	1-877-498-2911 Fax: 1-608-783-7532

How to Make an Appointment with the NPN

Current Members: Contact LHI directly at 1-877-498-2911 for issues related to your care. If you have been assigned a local provider, contact that provider directly to schedule appointments. You can also get comprehensive information about your appointments and care through LHI.Care at https://lhi.care/start.

New Members: Shortly after you receive your Program welcome letter, you will receive a new member packet from LHI. This will include instructions on finding a local WTC Health Program provider. It also will contain information on how to sign up for LHI.Care.

Travel Expenses (For NPN Members Only)

Travel expenses are available on a limited basis under the Program for members of the NPN. Transportation and lodging expenses for medically necessary care within the U.S. may be allowed on a case-by-case basis. In order for reimbursement to be considered, certain criteria (such as the need to travel over 250 miles for necessary medical care) must be met and approved in advance of any travel. Please speak to your NPN case manager for additional information.

Transferring Clinics

WTC Health Program members are allowed to change their clinic **once a year**.

In some limited circumstances, you can transfer your care to a new CCE even if it has been less than a year since you began care at your current CCE. For example, if you move within the NY metropolitan area, you can transfer to a CCE that is closer to your new residence, or if you have not yet had your initial health evaluation.

- If you move out of the NY metropolitan area, you can transfer to the NPN. Through the NPN you receive the same benefits that you received at your CCE, except you may have to travel to multiple specialists instead of a central clinic;
- General, Pentagon, or Shanksville Responders may transfer between any Responder
 CCE or the NPN. Responders cannot transfer to Survivor clinics;
- FDNY Responders may transfer between the FDNY CCE and the NPN. For retired FDNY Responders, transfers can be made between the FDNY CCE, any General Responder CCE, and the NPN; and
- Survivors can only transfer between a Survivor CCE and the NPN. Survivors cannot transfer to the Responder clinics.

You can request a transfer by informing your current CCE or NPN by phone or in person that you would like to transfer to a different CCE or another doctor in the NPN.

For more detailed information on the process of transferring clinics and how long it takes, visit www.cdc.gov/wtc/clinic_transfer.html.

Join the Research Program

The WTC Health Program research program plays a vital role in the treatment of your condition and the Program's ability to add a condition to the List of WTC-Related Health Conditions.

For members in the NY metropolitan area, when you come in for an exam, you will be asked if the CCE can add your medical information to the data which researchers are using to understand 9/11 health effects.

Participation is optional and any information collected is maintained in accordance with strict requirements for privacy and confidentiality. You will receive your exam and continue to receive treatment, even if you do not agree to share medical information for research purposes.

"There's no other program like this where workers or responders or anybody that lives in this area where they can get help so specific to this problem, to 9/11."

-Lainie, survivor

Enrollment in the WTC Health Program

How to Apply

If you are not yet a **member** of the **World Trade Center (WTC) Health Program**, follow these steps to complete an application. If you are not sure if you are already member or need help with any part of the application process, call the Program call center at 1-888-982-4748.

Step 1: Review the eligible groups

The WTC Health Program serves **four** groups of people affected by the 9/11 attacks:

- Fire Department City of New York (FDNY) Responders;
- WTC General Responders;
- WTC Survivors (lived, worked, or went to school in NYC Disaster Area); and
- Pentagon/Shanksville Responders.

Review the activity, location, time period, and hours requirements for each group. If you satisfy the requirements for a group, you may be eligible for the Program and should move to step 2.

Step 2: Gather your supporting documentation

In order to have a complete application, your activity, location, time period, and hours requirements must be reflected in your supporting documentation. Each eligible group has different requirements and types of required supporting documentation that can be submitted. Gather this information before moving on to step 3 to complete the application.

Step 3: Apply

Once you've determined your eligibility and gathered your documentation, the next step is to apply. You can apply online or submit a paper application by mail or fax. Application details can be found on page 17.

For more detailed information on eligible groups, supporting documentation, and the application process, visit www.cdc.gov/wtc/apply.html.

Designated Representative

During the application process, you may wish to have a **designated representative**, a person that you choose to represent your interests in the Program. Go to page 45 or visit www.cdc. gov/wtc/designated_representative.html to learn more about designating a representative.

If you have already applied to the Program and are a current member, you do not need to apply again.

Eligible Groups

To be eligible for the Program, you must meet all of the required criteria for one of the four eligible groups: FDNY Responders, WTC General Responders, Pentagon/Shanksville Responders, or WTC Survivors.

Requirement criteria includes the activity performed, location, time period, and minimum hours. Before applying to the Program, ensure that you meet the criteria for the category that best describes your 9/11 experience.

For more information on the eligible groups for the Program, including detailed requirement criteria for each group, visit www.cdc.gov/wtc/eligiblegroups.html.

Fire Department - City of New York (FDNY) Responders

You are eligible as an FDNY Responder if you were an active or retired FDNY firefighter or EMS worker and participated for at least one day in the rescue and recovery effort at any of the former WTC sites between September 11, 2001 and July 31, 2002. FDNY Responders receive Program services through the FDNY Clinical Center of Excellence (CCE). Retired FDNY Responders can receive care through the FDNY CCE, the General Responder CCEs, or the Nationwide Provider Network (NPN).

Surviving FDNY Family Members

A surviving immediate family member of an individual in the FDNY (whether fire or emergency personnel, active or retired) who was killed at Ground Zero on September 11, 2001, is eligible for **mental health treatment** if the family member received any treatment for a WTC-related mental health condition on or before September 1, 2008.

WTC General Responders

You are eligible as a General Responder if you worked or volunteered on-site in rescue, recovery, debris clean-up, or related support services at various sites involved in 9/11 events. These sites include Ground Zero, lower Manhattan (south of Canal Street), the Staten Island Landfill, the barge loading piers, PATH tunnels, and the NYC Chief Medical Examiner's Office, for certain specified durations during specified time periods between September 11, 2001 and July 31, 2002.

In addition, Responders identified as eligible for monitoring through Mount Sinai Hospital or FDNY prior to the Zadroga Act and establishment of the WTC Health Program may be enrolled as **WTC Responders** in the Program.

Pentagon and Shanksville, PA Responders

You are eligible as a Pentagon or Shanksville, PA Responder if you were an active or retired member of a fire or police department (fire or emergency personnel); if you worked for a recovery or cleanup contractor; or if you were a volunteer that performed rescue, recovery,

demolition, debris cleanup, or other related services for at least one day at either the Pentagon site during the period between September 11 and November 19, 2001, or at the Shanksville, PA site during the period between September 11 and October 3, 2001. Pentagon and Shanksville Responders receive Program services through the General Responder CCEs or the NPN.

WTC Survivors

You are eligible as a **WTC Survivor** if you were present in the dust or dust cloud in the New York City (NYC) Disaster Area on September 11, 2001; if you worked, resided, or attended school, childcare or adult daycare in the NYC Disaster Area during specified time periods after September 11, 2001; if you were eligible for certain residential grants following the September 11, 2001 attacks; or if your place of employment was eligible for certain grants following the September 11, 2001 attacks. WTC Survivors receive Program services through a Survivor CCE or the NPN.

In addition, Survivors identified as eligible for medical treatment and monitoring by the WTC Environmental Health Center prior to the Zadroga Act and establishment of the WTC Health Program may be enrolled as WTC Survivors in the Program.

Required Supporting Documentation

Each eligible group has different eligibility requirements that must be reflected in your supporting documentation. Your application and supporting documentation must include the appropriate activity, location, time period, hours requirement, and covered activities as described in the eligibility criteria.

Responders should provide copies of documents that must include the following information:

- The type of work you performed (activity);
- The address and/or street name of where you worked (location);
- The time period you worked at each location; and
- The number of hours per day you worked at each location.

Survivors should provide copies of documents that include **one or more** of the following:

- Address of your home, workplace, school, daycare center, or adult daycare center and dates of residence or attendance:
- Proof of presence within the NYC Disaster Area and confirmation of exposure to the dust or dust cloud on September 11, 2001; or
- Proof of eligibility to receive a grant from Lower Manhattan Development Corporation (LMDC) Residential Grant Program or proof of your employer receiving a LMDC grant.

Please note: You may need to submit multiple documents to fully verify your eligibility.

First-Party and Third-Party Attestations

We understand that you may have difficulty obtaining documentation.

If you cannot find official supporting documentation, you can submit a letter written by someone who can confirm your eligibility details (known as a third-party attestation).

For Responders, the third-party attestation must describe:

- Type of work you performed (activity);
- Address or street name of where you worked (location);
- Time period you worked at each location; and
- Hours worked per day.

For Survivors, the third-party attestation must include the address of your home, workplace, school, daycare, or adult daycare center; or describe your exposure to the dust or dust cloud.

If you cannot find official supporting documentation or someone to write a third-party attestation, you can personally write a letter that includes the required eligibility information listed above (known as a first-party attestation). Along with the first-party attestation you must also include details about:

- What you did to try to get copies of your documentation; and
- Why you can't include it.

Both types of attestations must contain the required specific information and be **hand signed** by the writer as truthful under penalty of law. **Electronic signatures are not accepted.**

Tips for your supporting documentation:

- Try to find documentation that includes as much detail as possible.
- Make sure the supporting documentation contains your full name.
- If you have a different name now than what is demonstrated on your supporting documentation (due to marriage or divorce), then you will need to submit additional documentation demonstrating the name change (such as a marriage certificate).
- Make sure the supporting documentation is consistent with the information you
 provided on your application. For example, the hours or days in your supporting
 documentation must be consistent with the hours or days in your application. If it is
 not, please provide an explanation.

Application

The final step to apply to the WTC Health Program is to complete the application and send it in with your supporting documentation. You can either apply online using the online system or print a paper application and send through mail or fax.

Apply online: Apply and upload documentation at https://oasis.cdc.gov (available in English only)

Apply by mail or fax: Download a paper application at www.cdc.gov/wtc/application.html (available in English, Español, Polskie, and 中文)

Mail or fax the signed application to:

WTC Health Program P.O. Box 7000 Rensselaer, NY 12144 Fax Number: 1-877-646-5308

Applicants should only apply once by using either the online system or by printing the application and submitting via mail or fax. If you do not have access to a computer, please call the WTC Health Program call center at 1-888-982-4748 to have an application mailed to you.

Supporting documentation should be included when submitting your application. If you do not include your supporting documentation at the time of your application submission, you should mail or fax a copy of your supporting documents or your attestation(s).

Please make sure your application includes your full legal name and date of birth.

A complete application is one that is signed with all pages filled out and all required supporting documentation included. Before submitting your application, please make sure to make a copy of the application and all documentation to keep for your records.

Enrollment

If your application is approved and you are enrolled in the Program, you will receive a welcome letter in the mail with details about setting up your **initial health evaluation**.

For members living in the New York (NY) metropolitan area:

- **FDNY Responders** will receive a letter with details on how to schedule your initial health evaluation at an FDNY clinic.
- WTC General Responders will receive a letter and a clinic selection postcard. Once you make a clinic selection and return the postcard, you will be contacted by that clinic to schedule your initial health evaluation. If the Program does not receive your card within 30 days, you will automatically be assigned to the clinic location nearest the home address you have provided.
- **WTC Survivors** will receive a letter with your clinic assignment. This letter will provide you with details on how to schedule your initial health evaluation.

For members who live outside of the NY metropolitan area, regardless of eligibility category, you will receive a welcome packet from the Nationwide Provider Network (NPN) administrator Logistics Health Incorporated (LHI) shortly after receiving your welcome letter from the Program. The welcome packet will include instructions on how to schedule your initial health evaluation through LHI.

If your application is denied, you will receive a letter that states why you are not eligible and how you can **appeal** the decision. Learn more about appeals on page 46.

Disenrollment

The Program may disensoll members if it is found that the Program mistakenly enrolled a person who does not meet eligibility requirements or did not provide the required proof of eligibility. The Program may also disensoll a Program member if the member's enrollment was based on incorrect or fraudulent information.

In the event of a disenrollment, the Program will send a letter to the disenrolled member that documents the disenrollment decision, provides an explanation for the decision, and informs the person how to appeal the decision. For more information on appeals, see page 46.

A disenrolled individual may try to re-enroll in the Program using the standard application and enrollment procedures if the new application is supported by new information.

A Program member may request to be removed from the Program at any time.

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"When I got that letter that I was certified it was this great sense of relief ... a big burden was lifted off our shoulders."

-Reggie, responder

Certifications and Covered Conditions

Initial Health Evaluations

Initial health evaluations are given to each new **member** of the **World Trade Center (WTC) Health Program** at no cost to you. If you are deemed eligible for the Program and enrolled as either a Responder or Survivor, you will receive an initial health evaluation.

The purpose of the initial health evaluation is to find out if you have any conditions related to your 9/11 exposures that are covered by the Program. Only Program doctors may conduct an initial health evaluation.

An initial health evaluation may include the following services:

- 9/11 exposure assessment;
- Medical history and mental health questionnaires;
- Physical examination;
- Spirometry/Pulmonary function testing (breathing test);
- Vital signs (blood pressure, pulse);
- Blood tests;
- Chest X-ray, if medically necessary;
- **EKG** (heart test), if medically necessary; and
- Urinalysis.

Responders: Your initial health evaluation may also be called a baseline monitoring exam. These terms are used interchangeably. The Program provides Responders yearly follow-up exams called **annual monitoring exams**, whether you are sick or not. Only Program doctors may conduct an initial health evaluation or annual monitoring exam.

Survivors: New Survivor enrollees in the Program are called **Screening-Eligible Survivors**. The Program offers a one-time initial health evaluation to all Screening-Eligible Survivors. The **Zadroga Act** allows only one initial health evaluation to be paid for by the Program. Therefore, Survivors should have symptoms of a **WTC-related health condition** before applying to the Program. See examples of WTC-related health conditions on pages 25-27.

As a Survivor, if you are certified as having a WTC-related health condition, then your status is changed to a **Certified-Eligible Survivor**. You are then eligible for yearly follow-up exams called annual monitoring exams, as well as cancer screenings and other benefits.

Tips for getting the most out of your initial health evaluation:

- Review this handbook and the Program website (www.cdc.gov/wtc) to learn about your Program benefits, rights, and responsibilities;
- Complete any paperwork provided by your Program clinic prior to your first visit;
- Write down a list of symptoms you are experiencing, even those that you think might not be related to your 9/11 exposures. Symptoms may include trouble sleeping, persistent cough, runny nose, etc.;
- Write down a list of questions you would like to ask the doctor, mental health provider, or **benefits counselor**;
- Write down a list of any medications you are currently taking;
- Bring your medical records and any workers' compensation or line-of-duty injury paperwork with you; and
- Be prepared to talk about your exposure, work history (if applicable), and your current symptoms.
- **Survivors:** present your primary insurance card at ALL appointments.

Annual Monitoring Exams

Responders and Certified-Eligible Survivors receive annual monitoring exams in the Program. Annual monitoring exams help track your health over time and allow Program doctors to evaluate any new symptoms to determine if a WTC-related health condition(s) or health condition medically associated to your WTC-related health condition(s) has developed.

Your annual monitoring exam may include:

- Blood tests;
- Medical history and mental health questionnaires;
- Physical examination;
- Urinalysis (urine test);
- Vital signs (blood pressure, pulse);
- Chest X-ray, if medically necessary;
- EKG (heart test), if medically necessary; and
- Spirometry/Pulmonary function testing (breathing test)

Program members should contact their Clinical Center of Excellence (CCE) or Nationwide Provider Network (NPN) provider directly to schedule an annual monitoring exam.

Cancer Diagnostic and Screening Services

The Program covers diagnostic services, such as blood work, imaging studies, biopsies, and specialty consults that your Program doctor needs to determine if you have a cancer that is covered by the Program.

The Program covers cancer screenings for Responders and Certified-Eligible Survivors when you meet age and risk-factor criteria indicated in the **U.S. Preventive Services Task Force** (**USPSTF**) cancer screening guidelines. The criteria for each type of screening is listed below.

Cancer screening benefits may change based on new guidelines issued by USPSTF. The Program may offer additional screening tests in the future based on the recommendations for cancer screenings by the USPSTF.

Please note: The Program may cover earlier or more frequent screenings if you have a higher risk, such as a family history or previous cancer diagnosis.

Breast Cancer Screening/Mammograms

If you are a woman between the ages of 50 and 74, you may receive a **mammogram** once every other year. The Program will also cover an additional mammogram if you receive a positive test result from a mammogram.

Cervical Cancer Screening

Most female members between the ages of 21 and 65 are eligible to receive cervical cancer screening covered by the Program. Female members between the ages of 21 and 65 may receive a Pap smear every three years. Female members between the ages of 30 and 65 who wish to lengthen the screening interval may choose to receive a Pap smear in combination with HPV testing every five years.

Colon Cancer Screening

In most cases, the Program provides colon cancer screening for members between the ages of 50 and 75.

Lung Cancer Screening

Low-dose computed tomography (also called a low-dose CT scan, or LDCT) is the main test used to screen for lung cancer. Program members who are at high risk for lung cancer are eligible for annual lung cancer screening. This includes members who are between the ages of 55 and 80 years old and are current smokers; or members between 55 and 80 years old who are former smokers who have quit smoking within the past 15 years and have a smoking history of at least 30 pack years (i.e., 1 pack a day for 30 years; 2 packs a day for 15 years).

For more information on cancer screening, consult the Program fact sheets at www.cdc.gov/wtc/cancerfactsheets.html.

Your Exam Outcome

An initial health evaluation or baseline monitoring exam is the first step in determining if you have a WTC-related health condition that is eligible for **certification**.

Your exam can result in 3 different outcomes.

For Responders:

- Come back in 1 year: If you do not have any symptoms that are related to your 9/11 exposures, return in 1 year for an annual monitoring exam. Annual monitoring exams track your health over time, may help catch new conditions or diseases early, and contribute to the overall understanding of how 9/11 is affecting Responders' health.
- Set up a follow-up appointment: If you have symptoms that could be related to your 9/11 exposures but more information is needed, then you will be advised on what follow-up medical appointments, testing, or procedures are required. Your clinic will then advise you on the next steps in the process, find any necessary specialty providers, and schedule an appointment to find out if you have a WTC-related health condition.
- Get your condition certified: Your WTC Health Program doctor will request certification of your health condition by the Program if your doctor determines that

 (1) you have a health condition that is on the List of WTC-Related Health Conditions,
 (2) that your 9/11 exposures are substantially likely to have been a significant factor in aggravating, contributing to, or causing your health condition, and (3) your health condition and 9/11 exposures meet Program policies and criteria for certification, such as maximum time intervals, minimum latency requirements, or any additional requirements. For more details on certifications, see page 27.

For Survivors:

- Monitor your own health: If your WTC Health Program doctor does not find a condition related to your 9/11 exposures, then you will not receive additional services from the Program at this time. However, you remain a member of the Program. If you develop symptoms in the future that you believe may be associated with your 9/11 exposures, you may request an additional health evaluation from a Program doctor at your own expense.
- Set up a follow-up appointment: If you have symptoms that could be related to
 your 9/11 exposures, but more information is needed, then you will be advised on
 what follow-up medical appointments, testing, or procedures are required. Your case
 manager will then advise you on the next steps in the process, find any necessary
 specialty providers, and schedule an appointment to find out if you have a WTCrelated health condition.

• **Get your condition certified:** Your WTC Health Program doctor will request certification of your health condition by the Program if your doctor determines that (1) you have a health condition that is on the List of WTC-Related Health Conditions, (2) that your 9/11 exposures are substantially likely to have been a significant factor in aggravating, contributing to, or causing your health condition, <u>and</u> (3) your health condition and 9/11 exposures meet Program policies and criteria for certification, such as maximum time intervals, minimum latency requirements, or any additional requirements. For more details on certifications, see page 27.

If your health condition is certified by the Program, you are then referred to as a Certified-Eligible Survivor. As a Certified-Eligible Survivor, you are eligible to receive annual monitoring exams from the Program as well as **medically necessary treatment** for your certified WTC-related health conditions.

WTC-Related Health Conditions Covered by the Program

The WTC Health Program provides medically necessary monitoring and treatment for certified WTC-related conditions. The Program also covers **medically associated health conditions**, which are conditions that result from the treatment or progression of a certified condition. For more information on certification of WTC-related conditions, see page 27.

The following categories are outlined by the Zadroga Act and include examples of conditions within each category.

Note: The list below is not exhaustive. It has been adapted from the List of WTC-Related Health Conditions in the Zadroga Act and the Program's regulations for ease of use. The full list of covered conditions can be found at www.cdc.gov/wtc/regulations2.html.

Acute Traumatic Injuries

Acute traumatic injuries are characterized by physical damage to your body caused by hazards or adverse conditions. **Examples include:**

- Burn
- Complex sprain
- Eye injury
- Fracture

- Head trauma
- Tendon tear
- Other

Airway and Digestive Disorders

Airway and digestive disorders, also known as aerodigestive disorders, are a group of conditions that affect breathing airways, such as your sinuses or lungs, or upper digestive tract, such as your esophagus. **Examples include:**

- Asthma
- Chronic cough syndrome
- Chronic laryngitis
- Chronic nasopharyngitis
- Chronic respiratory disorder-fumes and vapors
- Chronic rhinosinusitis
- Gastroesophageal reflux disorder (GERD)

- Interstitial lung disease
- New-onset, and WTC-exacerbated chronic obstructive pulmonary disease (COPD)
- Reactive airway dysfunction syndrome (RADS)
- Sleep apnea (medically associated to another airway or digestive disorder)
- Upper airways hyperreactivity

Cancers

Cancer may be defined as the uncontrolled growth and spread of cells. It may occur at any place in the body, and it makes it difficult for the body to function normally. **Examples include:**

- Blood and lymphoid tissue (including lymphoma, myeloma, and leukemia)
- Breast
- Childhood cancers
- Digestive system (including colon and rectum)
- Eye and orbit
- Ovary
- Head and neck (oropharynx and tonsil)
- Prostate

- Mesothelioma
- Rare cancers
- Respiratory system (including lung and bronchus)
- Skin (melanoma, non-melanoma and carcinoma in situ)
- Soft tissue
- Thyroid
- Urinary system (including kidney and bladder)

Mental Health Conditions

Mental health conditions include a wide range of conditions that affect your mood, thinking, and behavior. **Examples include:**

- Acute stress disorder
- Adjustment disorder
- Anxiety disorders
- Depression
- Dysthymic disorder

- Generalized anxiety disorder
- Major depressive disorder
- Panic disorder
- Post-traumatic stress disorder (PTSD)
- Substance use disorder

Musculoskeletal Disorders (for WTC Responders ONLY)

Musculoskeletal disorders are chronic or recurring disorders of the musculoskeletal system caused by heavy lifting or repetitive strain on the joints. **Examples include:**

- Carpal tunnel syndrome (CTS)
- Low back pain
- Other musculoskeletal disorders

For more information on covered conditions, visit www.cdc.gov/wtc/conditions.html.

Certification of Covered Conditions

The WTC Health Program will pay for medically necessary treatment of certified conditions. Your condition can be certified by the Program if:

- Your health condition is included on the List of WTC-Related Health Conditions:
- Your health condition and 9/11 exposures meet WTC Health Program policies and criteria for certification, such as maximum time intervals, minimum latency requirements, or any additional requirements; and
- Your 9/11 exposures are substantially likely to have been a significant factor in aggravating, contributing to, or causing the health condition.

If your WTC Health Program doctor determines that you have a health condition that meets all of the criteria above, your CCE or the NPN will complete paperwork signed by your Program doctor (called the WTC-3 Certification Package) to request that the Program certify your health condition.

The Program **Administrator** and medical staff will review the WTC-3 Certification Package submitted by your CCE or the NPN to decide if your health condition can be certified. The Program will certify your health condition if it finds that your health condition and exposure meet the above criteria. The Program will notify you in writing and will also communicate the decision to your CCE or the NPN. You can be certified for more than one condition.

Please note: Your WTC Health Program doctor may only submit a request for certification to the Program when all of the criteria listed above are met. Requests for certification that do not meet these criteria will not be accepted by the Program and will not be eligible for **appeal**.

More information on WTC Health Program policies and certification criteria are available at www.cdc.gov/wtc/policies.html and www.cdc.gov/wtc/ppm.html#certification.

In some circumstances, a certified condition may be decertified. For information on decertification, see page 32.

Certification of Medically Associated Health Conditions

In addition to the health conditions on the List of WTC-Related Health Conditions, the Program may also certify health conditions that result from either the treatment of your certified WTC-related health condition or the progression of your certified WTC-related health condition. These conditions are called medically associated health condition(s).

Your medically associated health condition will be eligible for treatment in the Program if the Program finds it is the direct result of the treatment or progression of your certified WTC-related health condition and the relationship between the two conditions is supported in the scientific literature. Medically associated conditions must be certified.

To certify a medically associated health condition, your CCE or NPN doctor must explain how the health condition results from either treatment or progression of the underlying certified WTC-related health condition. The Program will review your CCE or NPN doctor's explanation and determine whether the relationship linking the medically associated health condition with your certified WTC-related health condition is appropriate for coverage.

In some circumstances, a certified condition may be decertified. For information on decertification, see page 32.

Maximum Time Intervals for Aerodigestive Disorders

For an aerodigestive disorder, an additional requirement known as **maximum time interval** must be met for the health condition to be certified by the Program. The maximum time interval is the maximum amount of time that could have gone by between the last date of your 9/11 exposures and the initial onset of symptoms of your aerodigestive disorder. Your symptoms of the aerodigestive disorder must have started during that time frame in order for it to be certified by the Program.

The Administrator divided aerodigestive disorders into 6 categories and set a maximum time interval for each category. The time intervals are based on the best available published science and the Program's clinical expertise.

If you have questions about the maximum time interval for your aerodigestive disorder, speak to your Program doctor. For more information about maximum time intervals, you can refer to the Program policies at www.cdc.gov/wtc/policies.html.

CERTIFICATIONS/CONDITIONS

The 6 categories of aerodigestive disorders and the maximum time interval for each are as follows:

Category	Types of Diseases	Conditions Included	Maximum Time Interval
1	Chronic Obstructive Pulmonary Disease (COPD)	COPD (both WTC-exacerbated and new onset)	No maximum time interval
2	Other Obstructive Airways Diseases (does not include COPD-see above)	Asthma Chronic cough syndrome Chronic respiratory disorder Reactive Airways Dysfunction Syndrome (RADS)	5 years
3	Upper Respiratory Diseases	Chronic laryngitis Chronic nasopharyngitis Chronic rhinosinusitis Upper airway hyperreactivity	5 years
4	Interstitial Lung Diseases	All types of interstitial lung diseases	No maximum time interval
5	Co-occurring GERD	GERD in combination with a 5 years condition in Categories 1, 2, 3, or 4	
6	Isolated GERD	GERD with no other diagnosed WTC-related health condition	1 year

Cancer Latency

Minimum latency requirements must be met in order for your cancer to be certified by the Program. In most cases, cancer does not develop until some time has passed after exposure to a cancer-causing agent. Latency is the amount of time that has passed between your initial 9/11 exposures and the date you were first diagnosed with cancer. As a result, the Program has set minimum latency requirements based on well-established scientific literature.

The following table outlines the minimum latency requirements for cancers covered by the Program:

Type of Cancer	Minimum Latency Requirement	
All types of blood cancers	0.4 years (146 days)	
All types of childhood cancers	1 year	
All types of thyroid cancer	2.5 years	
All types of mesothelioma	11 years	
All other types of covered solid cancers	4 years	

Please note: the WTC Health Program will not consider any exceptions to the latency period. Members may not request a secondary medical review when their cancer does not meet the minimum latency period and may not appeal this decision.

If you have questions about latency requirements for certification of your cancer, speak to your Program doctor. For more information about latency requirements, you can refer to the Program policies at www.cdc.gov/wtc/policies.html.

Acute Traumatic Injury and Musculoskeletal Disorder Criteria

In order for your Acute Traumatic Injury (ATI) or Musculoskeletal Disorder (MSD) to be certified by the Program, the injury must be directly related to your 9/11 exposures and activities. The Zadroga Act only allows coverage of MSDs for WTC Responders with a chronic or recurrent disorder of the musculoskeletal system caused by heavy lifting or repetitive strain during rescue or recovery efforts in the **New York City Disaster Area**. Therefore, Survivors and Pentagon and Shanksville, PA, Responders cannot be certified for an MSD.

However, all categories of Program members (except FDNY family members) can be certified for an ATI. For both ATIs and MSDs, there must be evidence that you received medical treatment for the ATI or MSD injury between September 11, 2001 and September 11, 2003.

If you have questions about ATI or MSD criteria, speak to your Program doctor. For examples of acute traumatic injuries and musculoskeletal disorders, see page 25-27.

Secondary Medical Review

If your WTC Health Program provider does not submit your condition to the Program for certification, you may be eligible for a secondary medical review. A secondary medical review is a review of your case by the CCE/NPN Clinical Director or a designee. This designee may be a WTC Health Program doctor at another CCE.

Examples of when you may request a secondary medical review include, but are not limited to, when you disagree with the CCE/NPN doctor regarding the characterization of your exposure, diagnosis, onset of symptoms dates, or intensity of exposure in relation to aggravating, contributing to, or causing your health condition.

You may <u>not</u> request a secondary medical review when your health condition does not meet Program policy. Disagreement with Program policy is not a valid reason for secondary review.

Your CCE or the NPN will advise you if you may be eligible for a secondary medical review. To initiate the process, you must send a letter to the CCE/NPN Clinical Director or designee which clearly indicates your request to obtain a secondary medical review.

How to Add a Condition to the List of WTC-Related Health Conditions

The Program only provides treatment for the specific conditions on the **List of WTC-Related Health Conditions** established by the Zadroga Act and Program regulations. However, the Administrator may add new health conditions to the List through the rulemaking process.

For example, a condition may be added if the Administrator finds there is enough scientific evidence to link a health condition to 9/11 exposures. This might happen if research shows that a health condition is more likely to occur in individuals with 9/11 exposure than in individuals without 9/11 exposure.

You may have a condition that you believe is the result of your 9/11 exposure but is not included on the List. If this is the case, you may **petition** the Administrator to add a health condition to the List. In order to be considered, a petition must be sent in writing to the Administrator, and include the following:

- An explicit statement of an intent to petition the Administrator to add a health condition to the List of WTC-Related Health Conditions:
- Name, contact information, and signature of the interested party submitting the petition;
- Name and description of the health conditions(s) to be added; and
- Reasons for adding the health conditions(s), including the medical basis for the association between 9/11 exposure and the health condition(s) to be added.

The petition form can be found at www.cdc.gov/wtc/petitions.html. For more information on how the Program considers petitions to add health conditions to the List of WTC-Related Health Conditions, you may review the applicable three policies and procedures at www.cdc.gov/wtc/policies.html. These include:

- Policy and Procedures for Handling Submissions and Petitions to Add a Health Condition to the List of WTC-Related Health Conditions;
- Policy and Procedures for Adding Non-Cancer Condition to the List of WTC-Related Health Conditions; and
- Policy and Procedures for Adding Types of Cancer to the List of WTC-Related Health Conditions.

Decertification

The Program may decertify your WTC-related or medically associated health condition in the following circumstances:

- The Program finds that your 9/11 exposures do not meet the Program requirements;
- The Program finds that your certified health condition was certified in error or mistakenly considered to have been aggravated, contributed to, or caused by exposure to airborne toxins, any other hazard, or any other adverse condition resulting from the September 11, 2001 attacks; or
- The Program finds that your health condition was mistakenly found to be medically associated with a WTC-related health condition.

The Program will notify you in writing if the certification has been withdrawn and your health condition has been decertified. The letter will explain why your condition was decertified and provide you with information about how to appeal the decision if you would like to do so.

For more information on how to appeal a decertification, see the appeals section on page 46.

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"I know that my healthcare is under control, that my symptoms are under control."

-Florence, survivor

Treatment in the WTC Health Program

The World Trade Center (WTC) Health Program pays for all medically necessary treatment for your certified WTC-related health condition(s), as well any certified medically associated health conditions, as long as the treatment is provided by a WTC Health Program affiliated provider.

Affiliated Providers

In order for your treatment to be covered by the Program, you must receive the treatment from a WTC Health Program affiliated provider. Affiliated providers are health care providers (individuals or groups) that are associated with your **Clinical Center of Excellence (CCE)** or the **National Provider Network (NPN)** to provide care covered by the Program.

Each CCE has established a health care provider **network** to serve all Program **members** assigned to the CCE. Some affiliated providers work directly for the CCE or the medical institution that hosts the CCE. Some affiliated providers do not work directly for the CCE but are contracted by the CCE to provide medical and/or mental health services to members of the CCE.

The NPN is a network of affiliated providers that are located all over the country to serve Program members that reside outside of the **New York (NY) metropolitan area**. The NPN is operated by **Logistics Health Incorporated (LHI)**.

Your CCE and the NPN ensure all affiliated health care providers are qualified to provide care to Program members. For CCE locations and contact information, or for NPN contact information, see pages 7-10.

Treatment and Authorizations

The Program only provides treatment for your certified WTC-related health condition or medically associated health condition. All Program treatment services must be authorized by your Program provider, and in some cases the CCE or NPN Clinical Director and the Program. Treatment must follow Program guidelines and be medically necessary to treat your certified health condition.

In order to access the treatment services for your certified WTC-related or medically associated health conditions, you will need your current Program identification (ID) number. Your Program ID number is included on your Program welcome letter from the time of your enrollment, your condition **certification** letter from the Program, and on your Optum or NPN treatment card, if applicable.

Your Program provider will help coordinate care of <u>only</u> your certified WTC-related health conditions. Members should always maintain their own primary care provider for health conditions not covered in the Program. If your Program provider thinks that you need to see a specialist to diagnose or treat a certified WTC-related health condition, she or he will refer you to a specialist that is affiliated with the Program.

For example, if you have asthma, your Program provider might refer you to a pulmonologist who is affiliated with the Program. Your Program provider and the specialist will communicate about medically necessary treatment for your certified WTC-related health condition(s).

Level 1 Authorization

Your WTC Health Program provider authorizes your treatment to ensure it is medically necessary for your condition and meets Program policy. This is called a **Level 1 Authorization**.

Level 2 and Level 3 Prior Authorizations

In some cases, your Program provider or specialist needs additional authorization from your CCE or NPN Clinical Director (Level 2 Prior Authorization) or the WTC Health Program administration (Level 3 Prior Authorization) before a medically necessary treatment service can be covered by the Program. If you need treatment services that require a Level 2 or Level 3 Prior Authorization, your Program provider will request the authorization for you.

Medical Treatment Guidelines

The following treatments are examples of the medically necessary treatments you may receive for your certified WTC-related health condition(s).

Please note: The WTC Health Program reserves the right to not cover any of the following services at any time if they are determined not to be medically necessary or do not meet Program policies or coverage guidelines.

Program published medical policies are available at www.cdc.gov/wtc/policies.html and www.cdc.gov/wtc/ppm.html. Please refer to these links for the most current medical coverage guidelines, as guidelines may change based on the latest medical research and recommendations.

Cancer Treatment Services

The Program will cover all medically necessary cancer treatment for your certified WTC-related cancer. This includes doctor visits, medications, cancer therapies, surgeries, and other services.

The Program will cover these services if both of the following conditions are met:

- Your cancer specialist is an affiliated provider of the Program and has been approved to provide services to Program members; and
- The cancer treatment you receive follows the National Comprehensive Cancer Network (NCCN) guidelines on treatment for your type of cancer.

Please coordinate cancer treatment services with your CCE or the NPN. Learn more about NCCN guidelines at www.nccn.org/patients/guidelines/cancers.aspx.

Durable Medical Equipment

Durable Medical Equipment (DME) is medical equipment used in the home, such as hospital beds, wheelchairs, nebulizers, CPAP machines, and other types of equipment. If DME is medically necessary to treat your certified WTC-related health condition(s), then the rental or purchase of DME is covered by the Program and supplied by a preferred Program provider whenever possible.

Family Therapy and/or Marital Counseling

In certain circumstances, psychotherapy services for a member's family may be covered as part of the treatment of the member's certified WTC-related health condition. Marital counseling for a member and his or her spouse may also be covered in certain circumstances. If you are interested in learning more about this, consult your Program provider or case manager.

Home Health Services

Home health services are a wide range of health care services provided in a member's home to treat a certified WTC-related health condition(s). Home health services may be covered for a limited period of time for members who are homebound and require medically necessary home health care services. These services must be authorized by your CCE or the NPN Clinical Director or by the Program.

Hospice Care

The Program may cover hospice services when treatment for your certified WTC-related health condition is no longer controlling the illness and the member has a life expectancy of six months or less if the illness runs its normal course. **Hospice care** may be provided in the member's home or a hospice facility when it is recommended by your Program doctor. Hospice care typically lasts 6 months but may be continued longer if your CCE or the NPN Clinical Director confirms care is needed for a longer period of time.

Inpatient Care Services

The Program covers inpatient treatment and services if those services are medically necessary to treat your certified WTC-related health condition(s). **Inpatient care** covers hospital services, including semiprivate rooms, meals, general nursing, and prescription drugs as part of your inpatient treatment, and other hospital services and supplies. This includes the care you get in acute care hospitals, critical access hospitals, and mental health care in a hospital setting.

In order for inpatient services to be covered, your CCE or the NPN Clinical Director must authorize the services before you are hospitalized or admitted to an inpatient facility. It is important to work closely with your CCE or NPN case management team if inpatient care is needed so that the services can be appropriately authorized by your CCE, the NPN Clinical Director, or the Program.

Inpatient Rehabilitation Services

The Program may cover inpatient rehabilitation services for members with intensive physical rehabilitation needs due to their certified WTC-related health condition. Inpatient rehabilitation services may be covered when the member requires a team approach to care that cannot be provided in an outpatient setting. These services must be authorized by the Program.

Long-Term Care Hospital

A long-term care hospital provides care to members with medically complex problems that require an extended stay. In order for a stay at a long-term care hospital to be covered, the Program must confirm these services are medically necessary for your certified WTC-related health condition(s) and authorize your treatment.

Mental Health Services

The Program covers mental health treatment services for certified WTC-related mental health conditions. Mental health treatment services include services of psychiatrists and other mental health providers, such as psychologists, social workers, counselors; in addition to treatment services such as prescription drugs, counseling/psychotherapy, hospitalization, and other services in special circumstances. The Program does not cover residential treatment for mental health care.

At some CCEs, the mental health treatment services are provided in-house by a mental health provider employed directly by the CCE. At other CCEs, these services are provided by affiliated external mental health providers who are part of the CCE's network of credentialed health care providers. The NPN also includes affiliated and credentialed mental health care providers.

FDNY Family Members' Mental Health Treatment

Family members of deceased FDNY personnel may receive mental health treatment under the following conditions:

- You are a surviving immediate family member of an FDNY Responder who was killed at the WTC site on September 11, 2001; and
- You received treatment for a mental health condition included on the List of WTC-Related Health Conditions on or before September 1, 2008; and
- You are enrolled in the Program and your mental health condition has been certified by the Program.

Non-Emergency General and Medical Transport

Non-emergency medical transportation, such as via an ambulance or ambulette, may be provided to you if you are receiving medically necessary care for a certified WTC-related health condition and it is determined that such transportation is necessary.

Non-medical, general transportation is only available to NPN members who live a certain distance away from a Program provider. All non-emergency transportation services must be authorized by the Program or your CCE or the NPN Clinical Director before using the service.

Organ Transplants

The Program may cover organ transplants if specific circumstances are met. If you are interested in learning more about coverage for organ transplants, speak to your Program doctor or NPN case manager.

Outpatient Rehabilitation Services

The Program may cover physical rehabilitative care for a certified WTC-related health condition in a Comprehensive Outpatient Rehabilitation Facility. This facility provides outpatient services such as physical therapy, physician services, and social or psychological services. Your CCE or NPN Clinical Director must review your rehabilitative care plan and authorize your treatment.

Skilled Nursing Facility Services

The Program may cover medically necessary services in a **skilled nursing facility** that provides around-the-clock nursing or rehabilitation services after a member has been hospitalized for a certified WTC-related health condition(s). Multiple criteria must be met in order for these services to be covered, and the services must be authorized by your CCE or the NPN Clinical Director. If you are interested in learning more about skilled nursing facility services, consult your Program provider or NPN case manager.

Smoking Cessation Therapy

The WTC Health Program provides smoking cessation therapy for:

- Members with at least one certified WTC-related health condition; or
- Eligible members who are current smokers and are referred based on the results of lung cancer screening.

Examples of smoking cessation therapy include non-nicotine medications that reduce cravings and nicotine replacement products such as patches, gum, and lozenges.

Substance Use Disorder Treatment Programs

In certain circumstances, the Program may cover substance use disorder treatment. This may include acute hospitalization services and specialty outpatient treatment to treat certified mental health and substance use disorders. Residential treatment for substance use disorder is not covered by the Program. To learn more about available treatment for substance use disorder, speak to your WTC Health Program provider.

Vaccine Coverage

The Program covers certain vaccines for all eligible enrolled members (except for FDNY family members). Members may be eligible for vaccines recommended by the CDC Advisory Committee on Immunization Practices (ACIP) when the member meets requirements regarding age, timing of doses, and specific precautions. The Program also covers the flu shot for all members. Talk to your CCE or the NPN to learn more about vaccine coverage.

Medical Emergencies

In the event of a **medical emergency**, call 911 or go to the nearest emergency room.

A medical crisis can occur unexpectedly and after normal office hours. As a member of the Program you have access to **urgent care** and emergency room services for your certified WTC-related health condition(s) in your local area and when travelling outside of your local area. You should seek immediate treatment for any illness or injury that would be considered an emergency.

You do not need to call your CCE or the NPN before receiving emergency medical care. However, in all emergencies, you must notify your CCE or the NPN within 24 hours. This allows the Program to coordinate your ongoing care and ensure you receive proper authorization.

When seeking emergency care, please note that the Program <u>only</u> covers emergency care services that are related to your certified WTC-related health condition(s).

Urgent Care (After Hours)

Urgent care services are for medically necessary treatment of an urgent medical condition which is not considered to be an emergency, but is an illness or injury that must be addressed within 12 hours to avoid the likely onset of a medical emergency. The Program provides payment for certain types of urgent care visits for your certified WTC-related health condition(s).

Emergency Care Services

The Program defines a medical emergency as a serious medical condition with symptoms so severe that the health of the member would be at risk without immediate medical attention. The Program may cover emergency care services that are necessary to prevent death or serious impairment to the member as a result of a certified WTC-related health condition(s).

The Program does not cover non-emergency visits to the emergency department. Members should follow up with their CCE or NPN for non-emergency care.

Pharmacy Benefits

Pharmacy Benefit Manager

The Program has partnered with Managed Care Advisors (MCA) and Optum to provide prescription benefits for members with certified WTC-related health condition(s). This national pharmacy network includes 65,000 retail pharmacy network locations. If you have a certified condition, you may also use the home delivery option to have your medications mailed directly to your home.

Members with certified conditions will receive an Optum pharmacy card. If you did not receive an Optum card, or have questions about your pharmacy benefits, please call Optum at 1-855-640-0005 or contact your CCE.

For members in the NPN, pharmacy information is printed on the NPN cards sent by **LHI**. However, only those NPN members with a certified WTC-related health condition(s) receive NPN cards. If you have questions about NPN member cards, please call LHI at 1-877-498-2911 or contact them through the LHI.Care Member Portal.

Prescription Drugs

The Program covers prescription drugs used to treat a certified WTC-related health condition. Your Program doctor or specialist will prescribe medication for you using the Program's **formulary**, a list of drugs approved by the Program.

On occasion, you may need a medication that is not on the approved formulary. Your Program doctor can submit a request to the Program for approval to prescribe a drug for you that is not on the Program's formulary.

Program medical staff will review the request from your Program doctor and decide if the drug should be approved. If the drug is approved, the medication will be covered by the Program at no cost to you. Non-formulary drugs can be approved for up to 1 year.

If the drug is not approved but you would like to continue using it, you will have to use a different form of payment such as your primary insurance or pay out of pocket for the drug.

Generic Drugs

The Program requires that WTC-related prescriptions for medications that come in generic form must be filled using the generic medication. Generic drugs contain the same active ingredients as brand name drugs, and are the same in dosage, safety, stability, strength, purity, quality, and administration. However, the cost of a generic drug is significantly lower than brand name drugs.

For some drugs, there are no approved generics. In these cases, the Program reviews the available medications to compare effectiveness and cost. The Program then decides to cover a specific medication based on the one that provides a reasonable treatment at the best cost. This practice is known as **preferred medications** and is common with government health programs and private insurance companies.

For more information on generic drugs, talk to your CCE or NPN provider.

Filling Prescriptions

You may fill medications in two ways:

- 1. **Home Delivery (Mail Order)** Through Optum's home delivery service, you can get up to a 90-day supply of medications delivered to your home. To register for mail order services through Optum, please visit https://wtchomedelivery.optum.com/ or call 1-855-640-0005, Option 2.
- 2. **Retail** You can get up to a 30-day supply of drugs through a pharmacy of your choice. To locate the retail pharmacy closest to you, visit https://workcompauto.optum.com/content/owca/owca/en/pharmacy-locator.html.

Effective October 2019, the WTC Health Program only allows up to a 30-day supply of medication for each fill at a retail or community pharmacy. For any medication fills above 30 days and up to 90 days, you must use Optum's home delivery service. All members receiving medications taken on a regular or on-going basis are encouraged to enroll in home delivery when possible.

Please note: The 30-day supply limit at retail and community-based pharmacy policy was suspended in April 2020 in response to the COVID-19 pandemic. This suspension is temporary and the new quantity must be approved by your Program provider. The 30-day limit will be reinstated at a later date. Visit www.cdc.gov/wtc/covid19.html for more information.

If a retail pharmacy is having trouble filling a prescription, please ask the pharmacist to call Optum at 1-855-640-0005 to resolve the issue.

For Survivors, the **Zadroga Act** requires that your primary, individual health insurance (private and/or public) pays their share of the cost first and the Program pays the rest. This is known as **Coordination of Benefits** and is a process required by the Zadroga Act. Learn more about this process on page 5. For more information on how to ensure your prescriptions are billed correctly at a retail pharmacy, visit www.cdc.gov/wtc/cob.html.

More Program pharmacy benefit information is available at www.cdc.gov/wtc/pharmacy.html.

Benefits Counseling

As a member of the Program, you are eligible for **benefits counseling** from a case manager, social worker, benefits counselor, or other designated staff person at your CCE or the NPN. Benefits counselors can help identify benefits you may be eligible for and explain how you can apply for those benefits. Benefits counselors may also refer you to external benefits experts to help you access benefits available outside the Program, if needed.

As part of each visit, a CCE or NPN Program representative will work with you to complete a short benefits assessment questionnaire. The questionnaire helps the Program representative identify specific benefits for which you might be eligible. Then, you can work with your Program representative to learn more about those benefits, seek assistance applying for benefits, and/or be referred to a benefits expert for help.

The WTC Health Program offers various types of benefits counseling, including:

Workers' Compensation Counseling

Educates you about available **workers' compensation** benefits, how to access them, and how they interact with WTC Health Program benefits. More information on how Workers' Compensation works with the Program is available on pages 3-5.

September 11th Victim Compensation Fund Assistance

Informs you about the **September 11th Victim Compensation Fund (VCF)**, how to register and file a claim, and the relationship between the VCF and the WTC Health Program. Your WTC Health Program doctor may conduct a VCF disability evaluation as needed and appropriate. More information about the VCF is available on page 2.

External Work-Related and Disability Benefits Counseling

Helps you identify external (non-WTC Health Program) benefits you might be eligible for and educating you on how to access them (i.e., LODI, 3/4 WTC Disability Pension, SSD, CVB).

Social Services Assistance

Helps you access needed social services, such as food, utility, housing, transportation, or other basic needs assistance.

Cancer Care Assistance

Helps members with cancer identify and access Program cancer-related benefits and services, as well as other resources needed for cancer treatment and/or in response to the financial, psychosocial, legal, or occupational impact of cancer on the member and the member's family. Coordinates with oncology social workers as needed.

Non-Covered Conditions Assistance

Helps you identify appropriate care for medical and mental health conditions or medications not covered by the Program.

For benefits counseling assistance, contact your CCE or the NPN.

Case Management

The goal of case management is to share resources that allow you to return to your maximum health and well-being. Case managers can help you understand your available care options while developing a plan of care specific to your individual needs. This may include helping identify providers, locate healthcare facilities, address pharmacy concerns, assist with billing inquiries, and obtain authorizations for specialty care.

At each CCE, your Program provider may refer you to the case management team at the CCE for extra help navigating your care. A case management team is made up of the many individuals involved in a member's care. This could include doctors, nurse practitioners, nurses, social workers, care coordinators, and CCE support staff.

In the NPN, if you need treatment, you will be connected with a nurse case manager and/ or care coordinator. This team will coordinate with you, your health care providers, and social services resources. How often you interact with your nurse case manager and the care coordinator will depend on your treatment needs. It is very important that you work closely with the case management team because they will be coordinating your care and should be your first level of contact if an issue arises. For any questions, call the NPN case management helpline at 1-877-498-2911.

"The Program really is about giving one hope."

-Morris, responder

Program Support

Designated Representatives

A **designated representative** is someone you appoint and authorize to act on your behalf and represent your administrative interests in the **World Trade Center (WTC) Health Program.** However, this person may not make medical care (e.g., treatment) decisions for you.

When you designate a representative, you must also authorize the WTC Health Program to disclose your personal health information to the representative under the **Health Insurance Portability and Accountability Act of 1996 (HIPAA)**. The designated representative will then be authorized to do the following:

- Serve as your representative in all matters pertaining to your membership in the WTC Health Program, including enrollment, certification, and any other administrative issues; and
- Receive and/or provide information pertaining to your membership and participation in the WTC Health Program, including copies of factual and medical evidence contained in your records for the Program.

Please note: Any requirement of the WTC Health Program to notify you in writing is fully satisfied if sent to the designated representative.

You may only have one designated representative at a time. This individual can be someone such as an attorney, family member, advocate, or friend, unless that individual's service as a representative would violate any applicable provision of law. An entire organization or group of people—such as a law firm or multiple family members—is not permitted.

If a **member** is a minor, a parent or guardian may act on the member's behalf. If a member is a mentally incompetent adult, the person authorized under state or other applicable law to act on the member's behalf may act as his or her designated representative in the Program.

How to Designate a Representative

To designate a representative, you must notify the Program in writing using the Designated Representative forms available at www.cdc.gov/wtc/designated_representative.html.

If you have additional questions, contact the Program call center at 1-888-982-4748.

Please note: Your **Clinical Center of Excellence (CCE)** or the **Nationwide Provider Network (NPN)** may have additional requirements and forms for medical records to be released to your designated representative.

Appeals

You or your designated representative may **appeal** the following 3 types of decisions made by the Program:

- 1. Enrollment denial includes denial of enrollment in the Program or disenrollment
- Certification denial includes denial of certification as a WTC-related health condition, denial of certification of a health condition as medically associated health condition, or decertification of a WTC-related health condition
- 3. Treatment denial includes denial of treatment authorization for certified health condition based on a finding that the treatment is not medically necessary

Requesting an Appeal

If you would like to appeal one of the above decisions, you must mail or fax a written letter requesting an appeal to the Program's appeals coordinator postmarked within **120 calendar days** from the date of your denial/disenrollment/decertification letter from the **Administrator**.

Your appeal letter must:

- Be made in writing and signed;
- Identify the name, address, and contact information of the member and designated representative (if applicable);
- Describe the decision being appealed and state the reasons why you believe the decision was incorrect and should be reversed; and
- Provide a basis for the appeal that is sufficiently detailed and supported by information to permit a review of the appeal. An appeal request may include relevant new information not previously considered by the WTC Health Program.

The description may include:

- Scientific or medical information correcting factual errors that may have been submitted to the Program by the CCE or NPN;
- Information showing that the Program did not correctly follow or apply relevant Program policies or procedures;
- Any information showing that the Program's decision was not reasonable given the facts of the case; or
- A request to designate a representative.

Your appeal letter should be mailed or faxed to:

Appeals Coordinator WTC Health Program P.O. Box 7000 Rensselaer, NY 12144

Fax: 1-877-646-5308

For certification denial, decertification, or treatment authorization denial appeals, your appeal request may also include a request for you or your designated representative to make a 15-minute oral statement by telephone.

Scope of Appeals

Not all appeal requests can be considered. An appeal will be considered invalid if it challenges:

- Enrollment criteria established by the James Zadroga 9/11 Health and Compensation
 Act (Zadroga Act) or WTC Health Program regulations;
- Certification requirements established by the Zadroga Act;
- A WTC Health Program policy that has been established by the Administrator and is applicable to all Program applications and/or members; or
- The exclusion or absence of a health condition from the **List of WTC-Related Health Conditions (List)**.

Criteria and requirements in the Zadroga Act are established by law and may only be changed by the U.S. Congress amending the Act. Criteria within the WTC Health Program's regulations are established through rulemaking and may only be changed by the Program revising the regulations. Health conditions may only be added to the List through a **petition** process (see page 31).

Your appeal may, however, challenge the Program's application of enrollment, certification, or treatment authorization criteria to your individual enrollment, certification, or treatment decision. For example, an appeal request could argue that the Program incorrectly determined the number of hours the individual worked or volunteered during a covered time period.

More information on what may and may not be appealed is available at www.cdc.gov/wtc/appeals.html.

Appeal Process

When the Program receives your appeal, the Administrator will appoint a Federal Official independent of the Program to review your appeal.

The Federal Official will review all available records, including any oral statement made by you or your designated representative (**please note:** oral statements are not available for enrollment denial or disenrollment appeals), relevant to the Program's decision to assess whether your appeal should be granted. This review would include any relevant new information submitted by you.

The Federal Official may also consult one or more qualified experts to review the Program's decision and any additional information provided by you.

Based on the review, the Federal Official makes a recommendation to the Administrator regarding whether or not your appeal should be granted.

More information on the appeal process is available at www.cdc.gov/wtc/appeals.html.

Final Appeal Decision and Notification of the Outcome

The Administrator reviews the Federal Official's recommendation and any relevant information and makes a final decision on your appeal. You will be notified in writing of the following:

- 1. The recommendation and findings made by the Federal Official;
- 2. The Administrator's final decision on your appeal;
- 3. An explanation of the Administrator's final decision; and
- 4. Any actions taken by the Program in response to the Administrator's final decision.

Once the Administrator has made a decision on your appeal, it is final. The Administrator's decision may not be appealed further.

Your Rights and Responsibilities

Your Rights as a WTC Health Program Member

- Be assured of privacy and confidentiality: Your personal and medical information
 will be handled in a manner that preserves and protects your confidentiality. This
 includes, but is not limited to, the maintenance of medical records in a secure
 environment and the education of Program staff regarding confidentiality. The
 Program will not release medical information without authorization, except as
 required or permitted by law to administer benefits, comply with government
 requirements, or if you consent to participate in research or education.
- Have access to treatment: You have the right to receive medically necessary
 treatment for a certified WTC-related health condition(s) if the condition(s) are
 certified by the Program. In addition, you have the right to be informed about the risks
 and benefits of treatment and to refuse care.
- **Appeal decisions:** You have a right to appeal certain decisions by the Program, including an enrollment denial, disenrollment, and certification denial. Learn more about what can and cannot be appealed on page 46.
- Voice complaints/grievances related to the Program: You have the right to voice
 your concerns and receive a prompt and fair review of any complaints you may have
 about the Program. For more information about the complaints procedure, please see
 Complaints Procedure section on page 54.
- Receive considerate, respectful care: In the Program, we strive to treat all members
 equally and with respect and dignity, regardless of race, religion, sex, sexual
 orientation, national origin, age, disability, or income. If you have any concerns about
 how you are being treated, please contact the Program's call center at 1-888-9824748.

Your Responsibilities as a WTC Health Program Member

- Knowing the extent and limitations of the Program's services: This handbook provides information about the Program to help you better understand the Program's benefits and services. Visit the Program website at www.cdc.gov/wtc or contact the Program's call center 1-888-982-4748 if you have questions.
- **Keeping appointments:** You have a responsibility to keep your appointments. If you are unable to keep your appointment, notify your Program CCE or NPN case manager within 24 hours of your appointment so that your appointment time can be given to another member.
- **Providing accurate and complete information:** You are responsible for providing accurate and complete information about your present and past medical conditions to the Program. You are also responsible for submitting appropriate signed medical release forms so that the Program can obtain medical records as needed. Survivors must share primary insurance information when receiving care for certified WTC-related health conditions at a CCE and at an external provider.
- Active participation in your care: You have a responsibility to participate in your care by asking questions to understand your certified WTC-related health condition(s), following the recommended treatment plan, managing your medications, and making healthy lifestyle choices to try to maintain your health and prevent illness.
- Fulfilling financial obligations: Treatment of your certified WTC-related health conditions will be provided at no cost to you as long as the provider is affiliated with the Program and the services are appropriately authorized. Depending on the type of treatment services you need, services must be authorized by your WTC Health Program doctor or NPN case manager, your CCE or the NPN Medical Director, or the Program's Medical Benefits team.
- Showing consideration and respect: You have a responsibility to show consideration and respect to Program providers and staff at all times. Disruptive, abusive, or threatening behavior may impact the Program's ability to provide benefits to you in a timely manner.

Disruptive and Abusive Behavior

The WTC Health Program believes that all individuals have a right to a safe working environment. Disruptive or abusive behavior by a WTC Health Program applicant or member at or directed towards a facility or personnel affiliated with the Program (e.g., a Clinical Center of Excellence (CCE), the Nationwide Provider Network (NPN), providers, or staff) will **not** be tolerated.

Continued on next page

These types of behavior include, but are not limited to:

- Acts of violence or threats against staff or other patients, including verbal or physical abuse;
- Rude or vulgar language, including cursing or shouting;
- Throwing and striking objects;
- Harassing or stalking;
- Concealing or using a weapon; and
- Engaging in criminal behavior.

Depending on the particular circumstances, members who engage in such behaviors:

- May have their care suspended by their CCE or NPN provider;
- May be required to sign a behavioral agreement outlining what will be expected of them in order to receive care from their provider;
- May be required to transfer to another CCE or NPN provider; or
- May be subject to other appropriate actions, including involvement of law enforcement authorities as necessary.

The Program strives to provide high-quality, compassionate care for members' WTC-related health needs. Disruptive or abusive behavior, however, may impact the Program's ability to provide benefits in a timely manner.

Notice Regarding HIPAA Privacy Practices in the WTC Health Program

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT CAREFULLY.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) requires the World Trade Center (WTC) Health Program to maintain the privacy and security of your personal health information and to provide you with notice of its legal duties and privacy practices with respect to how your personal health information is held, used, and disclosed by the WTC Health Program.

How Do We Use and Share Your Personal Health Information?

The WTC Health Program must use and share your personal health information to provide information:

- To you, someone you name to receive your personal health information, or someone
 who has the legal right to act for you (the WTC Health Program will make sure that the
 person has the proper authority before taking any action);
- To the Secretary of the Department of Health and Human Services (HHS), if necessary, to make sure your privacy is protected and that the HIPAA requirements are being followed; and
- Where required by law.

How Else Do We Use and Share Your Personal Health Information?

The WTC Health Program may use and share your personal health information to provide you with treatment, to pay for your health care, and to operate the WTC Health Program. For example, the WTC Health Program may use or share your personal health information in the following ways:

- The WTC Health Program will collect and use your personal health information to decide if you meet the necessary requirements for coverage of your health condition(s) under the WTC Health Program. Conditions which meet these requirements are then "certified" by the WTC Health Program.
- The WTC Health Program will collect and use your personal health information to determine your diagnosis and any medically necessary treatment for your "certified" health conditions.
- The WTC Health Program will disclose your personal health information to the Centers for Medicare and Medicaid Services (CMS) Office of Financial Management to pay providers for eligible health care services you received.
- The WTC Health Program will review and use your personal health information to make sure you are receiving quality healthcare.

Under limited circumstances, the WTC Health Program may use or share your personal health information for the following purposes:

- To other federal and state agencies, where allowed by federal law, that need WTC Health Program health data for their program operations;
- For public health activities conducted by public health authorities (such as reporting disease outbreaks);
- For health care oversight activities (such as fraud and abuse investigations);
- For judicial and administrative proceedings (such as in response to a court order);
- For law enforcement purposes
- To avoid a serious and imminent threat to health or safety;
- For purposes of reporting information to a government authority about victims of abuse, neglect, or domestic violence;
- To report information about deceased individuals to a coroner, medical examiner, or funeral director;
- To organ procurement organizations for organ or tissue donation and transplantation purposes;
- For research purposes, under certain conditions;
- For workers' compensation purposes; or
- To contact you about new or changed coverage under the WTC Health Program.

What Are Your Rights When It Comes To Your Personal Health Information?

When it comes to your personal health information, you have certain rights. By law, you have the right to:

- Receive a paper copy of this privacy notice. You can ask for a paper copy of this
 notice even if you have already received an electronic copy (for example, by email).
 We will provide you with a paper copy promptly upon request.
- Receive a list that shows with whom we have shared your personal health information. You can ask for a list (accounting) of the times we have shared your personal health information for six years prior to the date you ask. The list shows whom we shared it with, when, and why. The list does not include information about treatment, payment, health care operations, and certain other disclosures (such as any you asked us to make). We will provide one free accounting a year but will charge a reasonable, cost-based fee if you ask for another one within 12 months.
- Receive a copy your personal health information. You can ask to see or get a copy of your health and claims records and other health information that we have about you. You can contact us by using the information included in the last page of this notice. We will provide a copy or a summary of your health and claims records, usually within 30 days of your request. We may charge a reasonable, cost-based fee to send your health and claims records.
- Ask us to change ("amend") your personal health information. You can request to change your records if you believe that your personal health information is wrong or that information is missing. Please note that we may deny your request to change your personal health information if we believe the information in your records is accurate and complete. If your request is denied, we will provide you with a written explanation of the denial within 60 days of the date we received your request. You may have a statement added to your personal health records to reflect your disagreement.
- Request confidential communications. You may request that we communicate your personal health information in a private ("confidential") way. You may ask that we contact you in a specific way (for example, home or office phone) or to send mail to a different address.
- Ask us to limit how we use and share your personal health information. You can
 ask us not to use or share certain health information. We are not required to agree to
 the limits you request, except under certain circumstances.
- Choose someone to act for you. If you have given someone medical power of attorney or if someone is your legal guardian, that person can exercise your rights and make choices about your personal health information. We will make sure the person has this authority and can act for you before we take any action.
- **Receive breach notification.** You can expect to be informed of and receive notification if a breach occurs that may have compromised the privacy or security of your information.

When Do We Require Your Written Permission?

By law, the WTC Health Program must have your written permission (authorization) to use or share your personal health information for any purpose that is not set out in this notice, including certain uses or disclosures of psychotherapy notes. In addition, the WTC Health Program will not sell or market your personal health information without your written permission.

You may take back (revoke) your written permission anytime, except in cases where the WTC Health Program has already acted on your permission. If you take back your written permission, please provide that to the WTC Health Program in writing.

The WTC Health Program is prohibited from using or sharing your personal genetic health information (i.e., your genetic tests, the genetic tests of your family members, and your family medical history) to determine your eligibility and enrollment into the WTC Health Program (i.e. underwriting).

What Are the Responsibilities of the WTC Health Program?

The WTC Health Program is required by law to abide by the terms of this privacy notice. The WTC Health Program has the right to change this privacy notice and the changes will apply to all the information that we have about you. If we make any significant changes to this notice, a copy of the revised notice will be made electronically available on the WTC Health Program website and you will receive the new notice by mail or email within 60 days. You may also request to receive a copy of the notice at any time.

How Can You Contact the WTC Health Program?

You can call 1-888-982-4748 to get further information about matters covered by this notice. Ask to speak to a customer service representative about the WTC Health Program's HIPAA privacy notice. To view an electronic copy of the WTC Health Program's HIPAA privacy notice, you can visit the WTC Health Program's website at www.cdc.gov/wtc/privacy.html.

How Can You File a Complaint?

If you believe that your privacy rights have been violated, you may file a complaint with the WTC Health Program by calling 1-888-982-4748 or by sending a letter to P.O. Box 7000 Rensselaer, NY 12144 **ATTN:** WTC Health Program, HIPAA Complaint. Filing a complaint will not affect your coverage under the Program.

You may also file a complaint with the HHS Office for Civil Rights by sending a letter to 200 Independence Avenue, SW, Washington, DC 20201, calling 1-877-696-6775, or visiting www.hhs.gov/ocr/privacy/hipaa/complaints/. TTY users should call 1-800-537-7697.

This Notice of Privacy Practices for the WTC Health Program is effective September 23, 2020.

Complaint Procedure

All Program health care providers and staff share responsibility for assuring member satisfaction. If you have a problem or concern about the services you receive, please ask for help. Each CCE and the NPN has an administrator who is able to assist you with your concerns and complaints.

If you have a problem with any aspect of the service you have received at your CCE, call or visit the administrative office at that facility.

If you have a problem with the service you have received with the NPN, you may call the NPN at 1-877-498-2911 or visit https://lhi.care/wtcfeedback. The NPN has an administrator or director who is responsible for addressing concerns involving the facility or provider **network**.

If you are not satisfied with the way your complaint was handled, you can contact the Program's call center at 1-888-982-4748. A Member Services Associate will assist you in addressing your concern as best as possible.

Be sure to provide complete information regarding the nature of your complaint, including names, dates, and any other specific information. The Member Services Associate will forward the complaint to the appropriate Program staff. We will make every effort to respond to your request as quickly and effectively as possible.

Fraud and Abuse

Fraud is the intentional deception or misrepresentation that an individual or entity makes knowing that the misrepresentation could result in some unauthorized benefit to the individual, or the entity, or to some other third party.

The Program will closely monitor any fraudulent activity including the submission of fraudulent information in support of a claim of eligibility or for necessary and covered services, fraudulent misuse of the Program by health care providers participating in the Program, and submission of claims for services not provided or needed as claimed.

The Program will report fraudulent conduct to Federal law enforcement agencies and violators may be subject to criminal, civil, or administrative penalties.

Information concerning suspected fraud related to the Program by contractors, grantees, health care providers, or individual recipients should be reported to the U.S. Department of Health and Human Services, Office of Inspector General by phone at 1-800-HHS-TIPS (1-800-447-8477), online at https://oig.hhs.gov/fraud/report-fraud/ or in writing to the following address:

U.S. Department of Health and Human Services Office of Inspector General ATTN: OIG HOTLINE OPERATIONS P.O. Box 23489 Washington, DC 20026 THIS PAGE LEFT INTENTIONALLY BLANK

"It's been a really good experience for me. It's a lot easier to see doctors who are able to understand how things have gotten serious. They know what kind of treatments are working for other people who had the same type of exposure."

-Lila, survivor

Glossary

Please Note: Many of the terms here are formally defined in the Zadroga Act and Program regulations. The definitions below are provided solely for purposes of this Member Handbook to provide general Program information in a way that is easy to understand for members. The definitions below are not legally binding.

Administrator (the Administrator of the WTC Health Program): The Director of the National Institute for Occupational Safety and Health (NIOSH), part of the Centers for Disease Control and Prevention (CDC) in the Department of Health and Human Services (HHS), or his or her designee. The Administrator is the person responsible for overseeing and administering the Program.

Affiliated Provider: Outside providers must be associated with a CCE or the NPN in order to provide care covered by the Program.

Annual Monitoring Exam: Also called Medical Monitoring Exam; Detailed yearly health exam of a WTC Responder or Certified-Eligible Survivor that looks for WTC-related physical and mental health conditions. Findings help determine whether a member has a condition that can be certified (approved) for treatment in the WTC Health Program.

Appeal: To formally challenge a decision made by the Program to not enroll an applicant or to disenroll a member, to not certify a health condition or to decertify a health condition, or to not cover a treatment.

Benefits Counseling: A service available to members where a WTC Health Program staff person informs you about various benefits outside of the Program that you might be eligible for and assists you to apply for those benefits.

Centers for Medicare and Medicaid Services (CMS): The Federal agency that administers the Medicare and Medicaid programs; CMS assists the WTC Health Program with payment functions.

Certification: A decision by the WTC Health Program that your health condition is included on the List of WTC-Related Health Conditions, that your health condition and 9/11 exposures meet Program policies, and that your 9/11 exposures are substantially likely to have been a significant factor in aggravating, contributing to, or causing the health condition.

Certified: A certified WTC-related health condition (or medically associated health condition) is one that has been approved for coverage by the Program based on the approval of a certification request for that condition.

Certified-Eligible Survivor: A Survivor with a certified WTC-related health condition(s). These members are eligible for annual monitoring exams and treatment for certified WTC-related and medically associated health condition(s).

Clinical Center of Excellence (CCE): A medical center under contract with the WTC Health Program to provide WTC-related health services to members.

Coordination of Benefits: A process that helps determine who pays a medical bill first when there is more than one potential payer.

Designated Representative: A person that you choose to represent your interests in the Program. They can represent your interests in Program administrative processes, including during an appeal.

Durable Medical Equipment (DME): Medical equipment used in a member's home, such as CPAP machines and wheelchairs.

EKG: Abbreviation for electrocardiogram. An electrocardiogram is a medical test used to look at and record the electrical activity of your heart.

Federally Qualified Health Center (FQHC):

Community-based organizations that provide medical, dental, and mental health/substance abuse services to persons of all ages, regardless of their ability to pay or health insurance status.

Formulary: A list of prescription drugs covered by the Program. The CCEs and the NPN are given updated lists periodically.

Fraud: Intentional deception or misrepresentation by an individual or entity with knowledge that the misrepresentation could result in an unauthorized benefit to the individual, the entity, or some other third party.

Health Insurance Portability and Accountability Act of 1996 (HIPAA): A

federal law that established national privacy standards for the protection of personal health information (called "protected health information" or PHI under HIPAA) given to and used by health care entities such as health plans, hospitals, clinics, and doctors. The law outlines how your PHI can be disclosed to other entities and when your consent is required. Learn more about your rights under HIPAA at www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index. html.

Home Health Services: Healthcare services you receive in your home. These services are delivered according to a plan written by your healthcare provider.

Hospice Care: Special services provided to an individual with a terminal illness. Hospice care addresses the medical, physical, social, emotional, and spiritual needs of a terminally ill person. Hospice also provides care and rest services to caregivers and family members.

Initial Health Evaluation: Also called a baseline monitoring exam for Responders; Assessment of one or more symptoms that may be associated with a WTC-related health condition to evaluate whether a new member has a WTC-related health condition and is eligible for treatment under the Program. This exam includes a medical and exposure history, a physical examination, and additional medical testing as needed.

Inpatient Care: Healthcare you get when you are admitted to a health care facility, like a hospital or skilled nursing facility.

James Zadroga 9/11 Health and Compensation Act of 2010 (Zadroga Act):

Public Law 111-347 passed by the U.S. Congress in 2010 that created the WTC Health Program. The Zadroga Act provided funding for monitoring, medical and mental health treatment, and research for WTC Responders and Survivors. The Zadroga Act also reopened the September 11th Victim Compensation Fund (VCF).

Level 1 Authorization: When your WTC Health Program provider can decide that your needed treatment or medical service can be covered by the Program without having to seek permission from anyone else in the Program.

Level 2 Prior Authorization: When your WTC Health Program provider must request permission from your CCE or the NPN Medical Director for your needed treatment or medical services to be covered by the Program.

Level 3 Prior Authorization: When your WTC Health Program provider must request permission from the WTC Health Program administration for your needed treatment or medical services to be covered by the Program.

List of WTC-Related Health Conditions:

Mental and physical health conditions eligible for coverage in the WTC Health Program identified in the Zadroga Act and Program regulations at 42 C.F.R. § 88.15.

Logistics Health Incorporated (LHI): The organization that manages the Nationwide Provider Network and manages Program health care for members who live outside of the NY metropolitan area.

Mammogram: An X-ray of the breast.

Maximum Time Interval: For certain aerodigestive health conditions, the maximum amount of time that could have gone by between your last 9/11 exposure and the onset of symptoms of your WTC-related health condition.

Medicaid: A joint Federal/state public health insurance program that covers medical costs for some people with low incomes and/or disabilities.

Medical Emergency: A serious physical or mental health condition for which immediate treatment is necessary (it would result in a threat to life, limb, or sight, or when a person is at immediate risk to self or others).

Medically Associated Health Condition: A health condition that results from treatment of a certified WTC-related health condition or results from the progression of a certified WTC-related health condition. A medically associated health condition must be certified as WTC-related by the Program in order to be eligible for coverage.

Medically Necessary Treatment: Services by physicians and other health care providers, including diagnostic and laboratory tests, prescription drugs, inpatient and outpatient hospital services, and other care that is appropriate to manage, improve, or cure a certified WTC-related health condition or a medically associated health condition.

Medicare: A Federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with end stage renal disease.

Member: A WTC Responder or WTC Survivor who has been found eligible for the Program and enrolled.

Minimum Latency Requirement: The shortest amount of time that could have passed between your earliest 9/11 exposure and the date you were first diagnosed with a cancer in order for your cancer to be covered by the Program.

National Institute for Occupational Safety and Health (NIOSH): The federal agency that administers the WTC Health Program. NIOSH is part of the Centers for Disease Control and Prevention (CDC), in the U.S. Department of Health and Human Services (HHS).

Nationwide Provider Network (NPN): A nationwide network of health care providers across the country under contract with the Program to provide WTC-related health care for Program members who live outside the NY metropolitan area and want to receive their WTC-related health care locally.

Network: The health care providers, facilities, and pharmacies the Program has contracted with to provide you with health care services covered by the Program.

New York City (NYC) Disaster Area: The area within New York City that is the area of Manhattan south of Houston Street, and any block in Brooklyn wholly or partially contained within a 1.5 mile radius of the former WTC complex.

New York (NY) Metropolitan Area: An area specified by the Administrator to include portions of New York, New Jersey, Connecticut, and Pennsylvania; Program members residing within the area may access CCEs for their WTC-related health care.

Petition: A formal written request to the Administrator to add a health condition to the List of WTC-Related Health Conditions.

Preferred Medication: An available brand name drug chosen by healthcare experts to be most effective in treating a condition at the lowest cost. Preferred medications are used when a generic version of a drug is unavailable.

Primary Health Insurance: Whatever private or public health insurance you have. Private insurance may include employer-sponsored health insurance or insurance purchased from the health insurance marketplace. Public insurance may include Medicare or Medicaid coverage. Some individuals may have a mix of both private and public insurance. The WTC Health Program is a limited health care benefits program that provides monitoring and treatment for certified WTC-related health conditions only. The Zadroga Act requires all members to maintain minimum essential health insurance coverage outside of the Program.

Screening-Eligible Survivor: An individual who meets the WTC Survivor eligibility criteria and has symptoms of a WTC-related health condition. Upon enrollment in the Program, a Screening-Eligible Survivor is eligible for a one-time, initial health evaluation paid for by the Program.

September 11th Victim Compensation Fund (VCF): A Program administered by the U.S. Department of Justice that provides compensation for economic and non-economic loss to individuals who were physically injured, or made physically ill, or relatives of deceased individuals who were killed, as a result of the terrorist-related aircraft crashes on September 11, 2001. Learn more at www.vcf.gov or 1-855-885-1555.

Skilled Nursing Facility: A nursing facility with the staff and equipment needed to provide skilled nursing care.

Urgent Care: Medically necessary services required for an illness or injury that would not result in further disability or death if not treated immediately but requires professional attention within 24 hours.

U.S. Preventive Services Task Force (USPSTF): An independent, volunteer panel of national experts in disease prevention and evidence-based medicine. The USPSTF works to improve the health of all Americans by making evidence-based recommendations about clinical preventive services. Learn more at www.uspreventiveservicestaskforce.org.

Workers' Compensation: An insurance plan that employers are required to have to cover workers who get sick or injured on the job. It can provide injured or ill workers with medical and compensation benefits.

World Trade Center (WTC) Health Program:

The Program established by Title XXXIII of the Public Health Service Act as amended, 42 U.S.C. §§ 300mm through 300mm– 61 (codifying Title I of the James Zadroga 9/11 Health and Compensation Act of 2010 (Pub.L. 111–347, as amended by Pub. L.114-113)),to provide medical monitoring and treatment benefits for eligible responders and survivors of the September 11, 2001, terrorist attacks.

WTC-3 Certification Package: Paperwork completed by your Program doctor to request certification of your WTC-related health conditions by the Program. It includes information about you, your health condition(s), and your 9/11 work and exposures.

WTC Health Registry: A study run by the New York City Department of Health and Mental Hygiene to document and evaluate the long-term physical and mental health effects of 9/11. Learn more at www1.nyc.gov/site/911health/about/wtc-health-registry.page.

WTC-Related Health Condition: An illness or health condition for which exposure to airborne toxins, any other hazard, or any other adverse condition resulting from the September 11, 2001, attacks, based on an examination by a medical professional with expertise in treating or diagnosing the health conditions in the List of WTC-Related Health Conditions, is substantially likely to be a significant factor in aggravating, contributing to, or causing the illness or health condition or mental health condition. Only those conditions on the List of WTC-Related Health Conditions codified in 42 C.F.R. § 88.15 may be considered WTC-related health conditions and a health condition must be certified by the Program to be eligible for coverage.

WTC Responder: Workers or volunteers who provided rescue, recovery, debris cleanup, and related support services on or in the aftermath of the September 11, 2001 attacks for certain amounts of time during the period between September 11, 2001 and July 31, 2002. There are three groups of Responders in the WTC Health Program: FDNY Responders (and surviving FDNY family members); WTC General Responders (including NYPD); and Pentagon and Shanksville, PA Responders. Learn more at www.cdc.gov/wtc/eligiblegroups.html.

WTC Survivor: Also known as NYC Survivors; Includes individuals who were present in NYC Disaster Area in the dust or dust cloud on September 11, 2001; individuals who lived, worked or went to school or childcare, or adult child care in the NYC Disaster area for a certain amount of time during the period between September 11, 2001 and July 31, 2002; certain cleanup and maintenance workers; and certain individuals eligible (or whose place of employment was eligible) to receive certain grants from the Lower Manhattan Development Corporation. Learn more at www.cdc.gov/wtc/eligiblegroups. html.

NOTES





www.cdc.gov/wtc

The World Trade Center Health Program is administered by the National Institute for Occupational Safety and Health, part of the Centers for Disease Control and Prevention in the U.S. Department of Health and Human Services.