

Petition for the Addition of a New WTC-Related Health Condition for Coverage under the World Trade Center (WTC) Health Program

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
National Institute for Occupational Safety and Health

General Instructions

Any interested party may petition the WTC Program Administrator to add a condition to the List of WTC-Related Health Conditions (List) in 42 C.F.R. Part 88 (see complete list) for the

Please use this form to petition the Administrator to add a health condition (any recognized medical condition requiring treatment or medication) to the List. Please use a separate form for each health condition.

Use of this petition *form* is voluntary, but any petition must include all of the information identified below, as required by 42 C.F.R. Part 88. Petitions that do not provide the required information will not be considered by the WTC Program Administrator. Additional supporting materials may be submitted and are encouraged.

Please note, however, the petition and all supporting materials submitted to the WTC Health Program are part of the public record and may be subject to public disclosure. Personal information will be redacted prior to public disclosure.

Please TYPE or PRINT all information clearly on the form.

If you need more space to provide the required information, please attach additional pages to this form.

Mail or email this form to: World Trade Center Health Program
395 E. Street, S.W., Suite 9200
Washington, D.C. 20201
WTC@cdc.gov

Public reporting burden of this collection of information is estimated to average 40 hours per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-0929).

A. Interested Party Information

A1. Do you represent an organization (are you submitting this petition on behalf of an organization)? Yes (Go to A2) No (Go to A3)

A2. Organization Information:

Name of organization

A3. Name of Individual Petitioner or Organization Representative:

First name

Last name

Position, if representative of organization

A4. Mailing Address:

Street

City

State

Zip code

A5. Telephone Number: _____

A6. Email Address: _____

B. Proposed WTC-Related Health Condition Information

B1. Health Condition Information:

systemic auto-immune disorders: rheumatoid arthritis, vitiligo, & hepatotoxic injury- fatty liver disease

Name of health condition you wish to petition to add to the List of covered conditions

If the name of the condition is not known, please provide a description of the condition or the name of the diagnosis provided by a physician or other healthcare provider.

C. Basis for Proposing that the Condition Be Added to the List of WTC-Related Health Conditions

C1. Describe the reasons the WTC Program Administrator should consider the addition of this health condition. Explain how the health condition you are proposing relates to the exposures that may have occurred from the September 11, 2001, terrorist attacks. Your explanation must include a medical basis for the relationship/association between the 9/11 exposure and the proposed health condition. The medical basis may be demonstrated by reference to a peer-reviewed, published, epidemiologic study about the health condition among 9/11 exposed populations or to clinical case reports of health conditions in WTC responders or survivors. First-hand accounts or anecdotal evidence may not be sufficient to establish medical basis. If you need more space, please attach additional pages to this form.

The medical basis for consideration of the proposed health conditions should be considered to be linked to the exposure to 9/11 worksite debris. This debris includes several toxic substances/ chemicals such as gasoline, asbestos, metals, construction debris, concrete dust, and others that I may be unaware. I believe these diseases/ disorders should be considered to have direct link in terms of cause in otherwise healthy individuals such as myself. I am an individual who has little to no risk factors for developing these disease and I have no one in my immediate family who has these diseases therefore I doubt that there is any familial link to my illnesses.

I was an RN working at ground zero at the age of 24 and developed my first auto-immune disorder at the age of 28. I am 43 now and have to be on immuno-suppressive therapy to control my auto-immune disorder symptoms as well as be on a restricted diet to control my liver issues. My liver enzymes, despite diet control and exercise, are always elevated. I often struggle daily with basic tasks of living and depend on my immuno-suppressive medications for relief from the joint pain associated with my auto-immune disorders. I have reported my symptoms during my last WTC health program medical evaluation but was told that none of these medical conditions were deemed related to 9/11 exposure. I am surprised and disappointed that by now these conditions have not been linked to the WTC exposure of the many folks who did not know how much they were really sacrificing that day including myself. Although I have been thanked for my service, I ask that those overseeing this program really not forget all that was sacrificed. I feel true appreciation for our efforts will be demonstrated when the validation and recognition of all the chronic medical conditions and/ or diseases are validated as linked to our efforts. At that point the CDC will have realized for those who worked at ground zero, like me, responded without hesitation for what we would endure in the future.

As I am aware, several studies are underway to validate these diseases. These studies include: "Nested Case Control Study of Selected Systemic Autoimmune Diseases in World Trade Center Rescue/ Recovery Workers" by Webber et al (2017), Hepatotoxic Exposures, Progressive Fatty Liver Disease (NASH), and the World Trade Center Health Program General Responder Cohort, (2017) Project #: 1 UoI OH011489-01. It is my hope that these conditions will be added. Thank you.

D. Signature of Petitioner

Sign your name below to indicate that you are petitioning the WTC Program Administrator to consider adding a health condition to the list of WTC-related health conditions identified in 42 C.F.R. Part 88.



11/2/2010
Date

Privacy Act Statement

In accordance with the Privacy Act of 1974, as amended (5 U.S.C. § 552a), you are hereby notified of the following:

Title I of the James Zadroga 9/11 Health and Compensation Act of 2010 amended the Public Health Service Act (PHS Act) to establish the World Trade Center (WTC) Health Program. Sections 3311, 3312, and 3321 of Title XXXIII of the PHS Act require that the WTC Program Administrator develop regulations to implement portions of the WTC Health Program established within the Department of Health and Human Services (HHS). The WTC Health Program is administered by the Director of the National Institute for Occupational Safety and Health (NIOSH), within the Centers for Disease Control and Prevention (CDC). The information provided with this form and supporting documentation will be used by the WTC Program Administrator to consider the disposition of a petitioned-for health condition. Disclosure of this information is voluntary.

Records containing information in identifiable form become part of an existing NIOSH system of records under the Privacy Act, 09-20-0147, "Occupational Health Epidemiological Studies and EEOICPA Program Records and WTC Health Program Records, HHS/CDC/NIOSH." These records are treated in a confidential manner, unless otherwise compelled by law.

Information submitted to WTC Health Program which may be considered "protected health information" pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) (Pub. L. 104-191; 42 U.S.C. § 1320d) and the HIPAA Privacy, Security, Breach Notification, and Enforcement Rules (45 C.F.R. pts. 160, 162, and 164) will be maintained in accordance with all applicable laws.

NIOSH may disclose information in identifiable form only insofar as such disclosure is permitted pursuant to the HIPAA Privacy Rule; this may include disclosure to the WTC Health Program Scientific/Technical Advisory Committee (STAC), which may be asked to consider the petition and issue a recommendation to the WTC Program Administrator. Information in identifiable form will be redacted from submitted petition forms and supporting documentation that become a part of the public record (e.g. in conjunction with STAC consideration or a rulemaking).