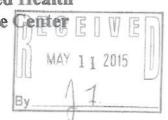
### Petition for the Addition of a New WTC-Related Health

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 <a href="http://www.cdc.gov/wtc/faq.html#hlthcond">http://www.cdc.gov/wtc/faq.html#hlthcond</a> for the complete list).

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 <u>form</u> 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 your Yes (Go to A2) In No (Go to A3)	you submitting this petition on behalf	of an organization)?
A2. Organization Information:		
Name of organization		-
A3. Name of Individual Petitioner or Organ	nization Representative:	
Fust name	Last ńame	
Position, if representative of organization	*	
A4. Mailing Address:		
Street		
City	State	Zip code
A5. Telephone Number:	and A Bostonia and Annual Annu	
A6. Email Address:		
B. Pronosed WTC-Related Health Conditi	ion Information	
B1. Health Condition Information:  AUTS Immune Disease  Name of health condition you wish to petition	- Eucephalitis Of on to add to the List of covered condition	
If the name of the condition is not known, plediagnosis provided by a physician or other h	nealthcare provider.	
4010 - mmore Di	sease-Encephalitis	Of the skeen

C. Bas	sis for P	roposi	ng that t	he Condi	tion Be A	dded to	the List	of WTC-I	Related	Health C	onditions
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Basis for Proposing that the Condition be Added to the List of WTC-Related Health Issues:

Re: (Auto Immune Disease, Encephalitis of the Brain)

I was a responder to the 911 WTC attack. At the time I was a American Red Cross employee in

September 2001. I checked in and worked for a little over . I was provided a Green pass, but generally stayed within the immediate area of the attack. For the first few days, we did not have masks, and when we got them we gave them to the men who were digging on the mound. Altho they were not the best, within a week we finally got masks that were a little better, which we used and also passed out to the people digging. For a while I stayed at the mound and helped talk with first responders as they came off to rest, held them when they cried, got them water and listened to them. I also had fliers translated into many languages where ARC assistance stations and walked the area handing out and posting fliers so people could find assistance. I worked 12 to 16 hours a day some days in the immediate area and close by. For a couple of days,

We found people who had not been evacuated and needed assistance.

. I also worked doing , which were outside, for those who

lived in the area and had lost their home or job. I did many other things i.e.,

I went back to the hotel every night with black dust covering my eyes, ears, face, nose, mouth.

By the time I returned home, I had a bad cough, and was told it was the WTC cough.

Later I was diagnosed with , and the most serious is a relatively rare autoimmune disease – Encephalitis of the Brain. I was sent to a neurologist to figure it out. I
had to go through a spinal tap to ensure that was the diagnosis.

. It's not the most common autoimmune disease and it is probable that the toxins and dust may have caused it. I am enrolled in the WTC Health Program for a yearly physical, which is all that is provided.

I respectfully request that auto-immune diseases be added to the medical list. I know

there are many others with auto-immune diseases. Mine has been diagnosed through a spinal tap and my neurologist. I am typing this as I am shaky and my handwriting is illegible most of the time.

I hope you will add this to the list as there seem to be many responders wwith auto immune diseases. Thank you for your consideration.

5-9-15

D. Signature of Petitioner	
Sign your name below to indicate that y a health condition to the list of WTC-rel	ou are petitioning the WTC Program Administrator to consider adding lated health conditions identified in 42 C.F.R. Part 88.
	5-9-15
Signature	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).

### 9/11 firefighters hit by autoimmune diseases

- 25 March 2015 by <u>Clare Wilson</u>
- Magazine issue 3014. Subscribe and save

THE attack on the World Trade Center changed the world 13 years ago. We're now beginning to understand the long-lasting impact it had on the health of emergency workers who cleared up the site.

Nearly 16,000 firefighters and other emergency crew worked on the site over a period of 10 months after the attack. As well as higher rates of cancer and respiratory problems, it now seems these people are more likely to suffer from autoimmune diseases, such as rheumatoid arthritis and lupus.

When the twin towers fell in 2001, they created an enormous amount of airborne dust that included pulverised cement, glass, silica, asbestos, lead and dioxins. Fires continued to burn for three months afterwards.

"Unlike ordinary building sites, there were unprecedented amounts of aerosolised dust and fumes," says Mayris Webber of the Albert Einstein College of Medicine in New York. Face masks and respirators were available, but there was not always enough to go round, and some people didn't like using them for long periods, says Webber. "They were not consistently worn."

The health problems soon began. More than 70 per cent of firefighters developed a breathing problem in the first year, from coughing to asthma. Since then, they have also been <u>diagnosed with higher than average rates of certain cancers</u>.

Some of the chemicals in the World Trade Center dust have been linked with autoimmune diseases, so Webber's team decided to look for evidence in the workers' health records, kept as part of the fire department's monitoring programme.

Although the number was small – only 216 self-reported cases – Webber points out that you would normally expect very low rates of autoimmune disease in this group of particularly fit and healthy people. So instead of comparing the firefighters with average New Yorkers, they analysed 59 medically confirmed cases alongside firefighters in the monitoring programme who had not developed any autoimmune disorders.

They found that those affected were likely to have worked on the site for longer. The rate of cases was three times higher in those who worked for the full 10 months than in who stayed only one month. On average it took five years to develop the disease.

The workers were exposed to such a complex mix of chemicals it may not be possible to identify the culprits. However, we know that breathing compounds such as asbestos and silica into the lungs seems to make the immune system more reactive, says <u>Jean Pfau</u> of Idaho State University.

Publicising the effects of these chemicals on workers at the world's most famous demolition site could help those in the construction industry. They often come in contact with materials like silica so should be more aware of the dangers and the need for protective gear. "This is a powerful paper describing the phenomenon," says Pfau.

## By Amy Norton HealthDayMarch 19, 2015, 3:55 PMNew health worry for 9/11 recovery workers



Firefighters search through the rubble of the World Trade Center in lower Manhattan following the attacks of Sept. 11, 2001. DOUG KANTER/AFP/Getty Images

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Recovery workers who toiled at the World Trade Center disaster site may face a heightened risk of rheumatoid arthritis and similar autoimmune diseases, a new study suggests.

The findings, reported online March 16 in the journal Arthritis & Rheumatology, add to the <u>list of potential health effects</u> seen among responders to the Sept. 11, 2001, attacks in New York City.

Past studies have found increased rates of respiratory diseases, such as asthma and chronic bronchitis, as well as <u>some forms of cancer</u>. The new study is the first to find an increased risk of certain autoimmune disorders, the researchers say.

Autoimmune diseases arise when the immune system launches an abnormal attack on the body's own tissue. The conditions seen in this study -- which also included lupus and systemic sclerosis -- affect joints, muscles and connective tissue throughout the body.

The diseases were not common. In the 12 years following 9/11, the researchers found 59 new cases of autoimmune conditions among more than 13,600 firefighters and other recovery workers who were potentially at risk.

But their odds of getting such a diagnosis rose 13 percent for each month they spent at the Twin Towers site, the findings showed. And workers who spent 10 months there had a threefold higher risk than those who were on-site for one month.

#### Ground Zero health crisis

It's known that Ground Zero workers were exposed to toxins in the dust and debris left behind by the towers' collapse, including lead, asbestos, glass fibers and silica.

It's not clear which particular toxins might account for the higher risk of autoimmune diseases, said Mayris Webber, the lead researcher on the study and a professor at Montefiore Medical Center/Albert Einstein College of Medicine in New York City.

According to Webber, it's likely that some workers had a genetic predisposition to autoimmune disease, and exposure to one or more toxins at Ground Zero helped trigger the abnormal immune reaction. That's in keeping with the general theory on how autoimmune diseases arise.

Webber said the bottom line for former 9/11 workers is to see a doctor if they develop possible symptoms of the diseases found in this study.

The same advice goes for people who lived near Ground Zero in the months after the attacks, she said.

The most common diagnosis was rheumatoid arthritis, which affected 37 percent of workers with autoimmune diseases. People with rheumatoid arthritis typically have periodic symptom flare-ups, including fatigue and warm, swollen, stiff joints on both sides of the body.

The second most common diagnosis was psoriatic arthritis, which is associated with the skin condition psoriasis. It causes joint stiffness, fatigue, back pain and tender spots where ligaments or muscles attach to bone, especially in the heel or sole of the foot, according to the Arthritis Foundation.

Dr. Michael Crane directs the World Trade Center Health Program at Mount Sinai Medical Center in New York City, which offers free health monitoring and treatment to eligible Ground Zero workers and volunteers.

He said the center has seen cases of autoimmune disease "here and there." The new study, he noted, sheds light on the bigger picture: While the conditions are uncommon, recovery workers with the most intense exposure are at relatively greater risk.

"This is a very important study," Crane said. "These are rare diseases, and without this ongoing monitoring (of recovery workers), these cases would've been lost in the crowd."He agreed that 9/11 responders and residents near the disaster site should get potential symptoms checked out.

"That doesn't mean you should be alarmed any time you have knee pain," Crane said. But because rheumatoid arthritis and similar conditions are so debilitating, it's vital to diagnose them earlyIn the wider context, Crane said, the findings underscore the importance of continuing to monitor recovery workers' health, since some medical conditions take years to surface.

#### March 21, 2015

### Autoimmune diseases rising in 9/11 worker

The list of ailments afflicting the World Trade Center first responders has grown to include systemic autoimmune diseases...

The conditional odds ratio for autoimmune diseases rose by 13% for each month individuals spent working at the site...according to Mayris P. Webber, DPH, Montefiore Medical Center in New York City, and colleagues.

And for those who spent 10 months working at the site the risk tripled the researchers reported... "The terrorist attacks on the World Trade Center buildings and the subsequent building collapses and fires exposed rescue/recovery workers to aerosolized WTC dust, an amalgam of pulverized cement, glass fibers, silica, asbestos, lead, polycyclic aromatic hydrocarbons, polychlorinated biphenyls, and polychlorinated furans and dioxins," they noted.

The result has been the development of various respiratory and other diseases including asthma, gastroesophageal reflux, and cancer in up to 70% of the exposed New York City fire department members, but the entire range of potential health effects is not yet known and may take decades to fully manifest.

Autoimmune diseases have been linked with multiple environmental exposures, including silica, hydrocarbons, and particulates.

These autoimmune conditions include rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), dermatomyositis, vasculitis, and Sjogren's syndrome, and most often have been reported after many years of exposure and predominantly among women.

The finding of an increase in autoimmune disease among WTC responders was "unexpected and highlights the need for increased clinician awareness of the possibility of these and perhaps other autoimmune disorders in their WTC-exposed male patients..."

The authors concluded that workers and residents should be closely monitored for these conditions. "The stakes are high because enhanced surveillance can lead to early detection and treatment, which has been shown to improve quality of life and reduce or delay organ damage including erosive joint destruction, kidney failure, pulmonary fibrosis, and hypertension."

And so it goes. Disease and disability caused by industrial material and chemical can surface many years later. I hope, in this case, our government, the powers that have responsibility for support in unusual circumstances will respond with more pace and thought than they did to the <u>ailments</u> incurred by first responders.

## **Autoimmune Study for Sick 9/11 First Responders**

The World Trade Center (WTC) Health Program is reviewing a <u>study</u> to be published in a forthcoming issue of the American College of Rheumatology's Journal, Arthritis & Rheumatology, and currently available online, regarding the risk of new-onset autoimmune disease in individuals with exposures related to the September 11, 2001, terrorist attacks at the World Trade Center. The authors conclude that prolonged WTC-site work post-9/11 (more than 2 months) may be an important predictor of systemic autoimmune disease. Depending on the results of this and on-going studies, there may be evidence to add new conditions to the list of WTC-related health conditions covered for treatment within the WTC health program, as well as compensation from the Zadroga Victim Compensation Fund.

By Michael Barasch | Published March 26, 2015 | Posted in WTC Victims | Tagged autoimmune disease, autoimmune study, WTC Health Program

- See more at: http://www.personalinjuryjustice.com/2015/03/26/autoimmune-study-for-sick-911-first-responders/#sthash.ozWiakF7.dpuf

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By Michael Barasch | Published March 26, 2015 | Posted in 9/11 Injuries, Health Programs | Tagged autoimmune disease, autoimmune study, WTC Health Program

## WTC firefighters suffer from autoimmune disease

The long tail of **Epidemiology** 

The March 28, 2015, issue of *New Scientist* describes the results of a study by Mayris Webber of the Albert Einstein of Medicine of New York.

Some of the chemicals in the World Trade Center dust have been linked to autoimmune diseases. These autoimmune conditions include rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), dermatomyositis, vasculitis, and Sjogren's syndrome.

Professor Webber's team looked for evidence of autoimmune disease in the FDNY-WTC Health

#### Program.

There were 216 self-reported cases from the 13,617 records. Webber's team looked at 59 firefighters with medically confirmed cases along side firefighters in the FDNT-WTC Health Program with no autoimmune disorders.

#### Time exposed = level of disease

The conditional <u>odds ratio</u> for autoimmune diseases rose by 13% for each month individuals spent working at the site. The risk tripled for those who spent 10 months working at the site.

The finding of an increase in autoimmune disease among WTC responders was "unexpected and highlights the need for increased clinician awareness of the possibility of these and perhaps other autoimmune disorders in their WTC-exposed male patients."

"To the best of our knowledge, acute and chronic WTC exposures have been associated with respiratory conditions like asthma and PTSD, but not with the new onset of systemic autoimmune diseases other than sarcoidosis."

read more:

#### **Uniformed Firefighters Association**

Source article:

Nested Case-Control Study of Selected Systemic Autoimmune Diseases in World Trade Center Rescue/Recovery Workers. *Arthritis & rheumatology* (Hoboken, N.J.)03/2015; DOI: 10.1002/art.39059

### Studies on the Health Impacts of 9/11 Updated March 2010

	Author	Year	Peer Reviewed Journal	Findings:
1	Rom, W	2002	American Journal of Respiratory and Critical Care Medicine	38 year old firefighter with eosinophilic pneumonia. Washings of his airways showed fly ash, degraded glass, metal, and asbestos fibers
2	Prezant, D	2002	New England Journal of Medicine	90% of FDNY firefighters working at the WTC site had a cough, nasal congestion, chest tightness and chest burning; 87% had new onset GERD (gastroesophageal reflux disease). Increased bronchial reactivity was present and worsened over time in many firefighters.
3	Trout, D	2002	Journal of Occupational and Environmental Medicine	Federal workers working near the WTC site were far more likely to have symptoms to shortness of breath, chest tightness and eye irritation, compared to workers in Dallas. Rates of depression and PTSD symptoms were also significantly higher.
4	Galea, S	2002	New England Journal of Medicine	Rescue workers at the site were far more likely to have PTSD and depression than NYC residents who did not do this type of work.
5	CDC	2002	Morbidity and Mortality Weekly Report	82% of the adult population surveyed in neighborhoods surrounding the WTC two months after the event had persistent respiratory symptoms that developed or worsened after the WTC attack, and 39% had symptoms suggestive of PTSD.
6	Das, D	2003	Journal of Urban Health	Individuals within two miles of the WTC site were significantly more likely to visit an Emergency Department for smoke inhalation, trauma, asthma or anxiety compared to those outside a two-mile radius
7	CDC	2003	Morbidity and Mortality Weekly Report	High school and college staff present near the WTC at the time of the collapse had increased rates of eye, nose and throat irritation, cough, and shortness of breath compared to similar workers five miles away.
8	Berkowitz, GS	2003	The Journal of the American Medical Association	Women pregnant and present in lower Manhattan on 9/11/01 and in the three weeks after 9/11 were more likely to have babies with intrauterine growth retardation (smaller babies at birth).
9	Fireman, EM	2004	Environmental Health Perspectives	Sputum (phlegm) induced in firefighters (FDNY) showed WTC dust and particles with a high pH more than eight months after the attack, as well as signs of inflammation

Synopsis of Peer-Reviewed Literature - Human Health Effects related to the WTC Disaster

Page 1 of 17

10	Salzman, SH	2004	Journal of Occupational and Environmental Medicine	78% of police officers at the WTC site developed respiratory symptoms, and 29% of participants had abnormal breathing tests. The study was conducted in December 2001.
11	Skloot, G	2004	Chest	A study of ironworkers working at the site from September 11-15, 2001 had one or more respiratory symptom five months after the attack. Fifty-three percent had evidence of lung function abnormalities.
12	Lederman, S	2004	Environmental Health Perspectives	Birth outcomes for women living within two miles of the WTC had smaller babies than those living farther away, after controlling for other factors.
13	Lin, S	2005	American Journal of Epidemiology	Residents living near the WTC site were significantly more likely to have new-onset respiratory symptoms, compared to residents 6 miles away.
14	Tapp, LC	2005	American Journal of Industrial Medicine	Transit workers evaluated seven months after 9/11/01 with dust cloud exposure had more symptoms of PTSD and depression compared to those without these exposures.
15	Mann, JM	2005	American Journal of Industrial Medicine	A 42 year old highway patrol officer who arrived on September 11 <sup>th</sup> and was in the dust cloud developed severe respiratory symptoms and was found to have interstitial lung disease on open lung biopsy.
16	Reibman, J	2005	Environmental Health Perspectives	56% of residents surveyed in lower Manhattan had new onset lower respiratory symptoms. 26% of the residents had persistent new-onset respiratory symptoms.
17	Banauch GI	2005	Critical Care Medicine	One year post-collapse, 23% of FDNY responders who had been heavily exposed to WTC dust had persistent lung dysfunction, as compared with only 11% of moderately exposed and 4% of unexposed firefighters.
18	Banauch. G	2006	American Journal of Respiratory and Critical Care Medicine	Pulmonary function was compared before and after September 11 <sup>th</sup> . A significant decline in pulmonary function was noted in FDNY personnel who were present at the WTC from September 11-13, 2001, about 12 times more than would be expected from normal aging.
19	Herbert, R	2006	Environmental Health Perspectives	Over 9000 WTC responders were examined over 2.5 year period from July 2002 to April 2004. 69% reported new or worsened respiratory upper and lower symptoms while performing WTC work. Symptoms persisted to the time of examination in 59% of these workers. 28% of responders had abnormal breathing tests.

20	Mauer, MP	2007	Journal of Occupational and Environmental Medicine	Nearly half of NY State personnel (1,400) responding to the WTC had lower and upper respiratory symptoms, and one third reported psychological symptoms. Participants were evaluated from May 2002 – November 2003.
21	Buyantseva, LV	2007	Journal of Occupational and Environmental Medicine	44% of police officers surveyed at one month and 19 months after September 11 <sup>th</sup> had persistent cough, and other respiratory symptoms. Rates of lower respiratory symptoms increased significantly from 2001 to 2003.
22	Izbicki, G	2007	Chest	26 firefighters (FDNY) developed sarcoidosis in the five years after September 11, 2001. The incidence of sarcoidosis was significantly (nearly 8 times) increased when compared to the years before September 11 <sup>th</sup> .
23	Mendelson, D	2007	Journal of Occupational and Environmental Medicine	25 World Trade Center workers with lower respiratory symptoms had chest imaging revealing air trapping. Air trapping in these workers may be a result of disease of the small airways in the lungs.
24	Wheeler, K	2007	Environmental Health Perspectives	WTC rescue, recovery and clean-up workers were surveyed in the WTC Health Registry and found elevated rates of newly diagnosed asthma.
25	Brackbill, RM	2007	Morbidity and Mortality Weekly Report.	Data from the New York City Dept of Health Registry show that, two to three years after 9/11, survivors of buildings that collapsed or that were damaged as a result of the WTC attack reported substantial physical and mental health problems. The long-term effects require followup.
26	Perrin, MA	2007	American Journal of Psychiatry	This NYC DOH Registry study compared the rates of posttraumatic stress disorder (PTSD) across different occupations involved in rescue/recovery work at the WTC site and found that PTSD was significantly higher among those who performed tasks not common for their occupation.
27	Tao, XG	2007	Journal of Occupational and Environmental Medicine	Respiratory health among cleanup workers at the WTC disaster site was evaluated approximately 20 months after the initial exposure; compared with those never at the site, WTC workers were more than three times as likely to report lower respiratory symptoms.

28	Perera, FP	2007	Environmental Health Perspectives	Exposure of pregnant women to the WTC dust cloud may have contributed to a reduction in cognitive development of their children at age 3.
29	DiGrande, L	2008	Journal of Traumatic Stress	NYC DOH Registry surveyed 11,037 adults who had lived south of Canal Street in New York City on 9/11, and found that that posttraumatic stress disorder (PTSD) is a continued health problem in the local community.
30	Farfel, M	2008	Journal of Urban Health	NYC DOH Registry data estimate that between 3,800 and 12,600 adults experienced newly diagnosed asthma and 34,600–70,200 adults experienced PTSD following the attacks, suggesting extensive and continuing health impacts.
31	De la Hoz, RE	2008	International Archives of Occupational and Environmental Health	In a cohort of World Trade Center workers, five categories of disease were predominant: upper airway disease (78%), gastroesophageal reflux disease (58%), lower airway disease (49%), psychological (42%) and chronic musculoskeletal illness (18%).
32	De La Hoz, RE	2008	American Journal of Industrial Medicine	In addition to upper and lower airway disorders, vocal cord dysfunction has been found in World Trade Center workers.
33	Moline, JM	2008	Mount Sinai Journal of Medicine	Clinicians at Mount Sinai developed a medical screening program to evaluate the health status of workers and volunteers who sustained exposure at the WTC disaster site. The program has successfully recruited nearly 22,000 responders, and serves as a model for the rapid development of programs to assess the health of others exposed to similar hazards.
34	Savitz, D	2008	Mount Sinai Journal of Medicine	Comparison of the experience at the World Trade Center disaster with 4 past incidents of chemical and radiation releases at Seveso, Italy; Bhopal, India; Chernobyl, Ukraine; and Three Mile Island, USA, provided useful contrasts and insights.
35	Szeinuk, J	2008	Mount Sinai Journal of Medicine	Diffuse parenchymal lung diseases (DPLDs) appear to be associated with heavy or extended exposure to the toxins released at the WTC disaster site. This suggests the need for continued long-term clinical follow-up of this population.

36	Bills, C	2008	Mount Sinai Journal of Medicine	The mental health needs of workers exposed to the events of September 11 <sup>th</sup> varied widely. These findings suggest the need for future programs for disaster workers to include accessible mental health treatment services as well as comprehensive post-disaster surveillance.
37	Enright, P	2008	Mount Sinai Journal of Medicine	This article describes the approach used to standardize lung function testing for the consortium of institutions providing medical monitoring examinations to WTC responders.
38	Landrigan, P	2008	Mount Sinai Journal of Medicine	To assess effects on children's health associated with the attacks on the WTC, research teams at the Mount Sinai School of Medicine and other academic health centers in New York City launched a series of clinical and epidemiologic studies. They found medical, developmental and mental health problems.
39	Reissman, D	2008	Mount Sinai Journal of Medicine	This article reviews lessons learned about managing the safety and health of workers who were involved in the WTC disaster, including the ongoing responder health burdens, and the changes in federal infrastructure, response planning, and resources for protection of response and recovery personnel.
40	Stellman, J	2008	Environmental Health Perspectives	Working in 9/11 recovery operations is associated with chronic impairment of mental health and social functioning, which greatly exceed population norms. Surveillance and treatment programs continue to be needed.
41	Prezant DJ	2008	Lung	This paper describes treatment recommendations for the main respiratory health consequence from the collapse of the WTC, which has been called "WTC Cough Syndrome", and includes chronic sinusitis, asthma, and/or bronchitis, often complicated by gastroesophageal reflux dysfunction (GERD).
42	Prezant DJ	2008	Mount Sinai Journal of Medicine	This paper reviews several respiratory consequences of occupational and environmental disasters and uses the WTC disaster to illustrate the consequences of chronic upper and lower respiratory tract inflammation.

43	De La Hoz, RE	2008	Journal of Occupational and Environmental Medicine	A variety of gastroesophageal reflux symptoms and disorders is found in WTC responders and seems to be related to the presence of lung disease.
44	De La Hoz, RE	2008	Journal of Occupational and Environmental Medicine	The WTC experience of immigrant responders demonstrates that their health burden is exacerbated by limitations in access to appropriate health care, disability and compensation benefits, and vocational rehabilitation services.
45	Thomas, PA	2008	Environmental Health Perspectives	Asthma prevalence after 9/11 among WTC Health Registry enrollees under 5 years of age was higher than national estimates, and new asthma diagnosis was associated with dust cloud exposure in all age groups. Severity of asthma and persistence of other respiratory symptoms will be determined on follow-up surveys.
46	Daly, ES	2008	Journal of Trauma and Stress	Disaster relief workers may experience an increase in stress symptoms at the anniversary of their traumatic exposure.
47	Tao, L	2008	Environmental Science and Technology	WTC responders were exposed to airborne pollutants through inhalation of dust and smoke released during and after the collapse of the WTC. The potential health implications of these results need more follow up.
48	Jayasinghe, N	2008	Journal of Nervous and Mental Disease	The purpose of this study was to conduct a 1-year follow-up to assess the role of anger in maintaining PTSD. Disaster workers responding to the WTC attacks who developed PTSD continued to report more severe anger than those without; there were statistically significant associations between changes in anger, PTSD severity, depression, and psychiatric distress.
49	Skloot, G	2009	Chest	Lung function abnormalities remain evident more than 5 years after the disaster in many exposed individuals, indicating the need for longer term monitoring of WTC responders.
50	Katz, CL	2009	Psychiatric Bulletin	Ironworkers at Ground Zero tend to have significant psychiatric symptoms likely associated with the traumatic experience of working there during the clean-up operation.

Page 6 of 17

51	Moline, JM	2009	Journal of Occupational and Environmental Medicine	This is a report on 8 cases of multiple myeloma (MM) observed in WTC responders registered in the WTC Medical Program, which underscores the importance of maintaining surveillance for cancer and other emerging diseases in this highly exposed population.
52	Chandran, SK	2009	Ear Nose Throat Journal	Many persons who were exposed to the Ground Zero site have otolaryngologic (Ear Nose and Throat) conditions that are common in persons who were not so exposed. Therefore, otolaryngologists involved in the care of such patients should be cautious about assigning a diagnosis of "WTC syndrome" without a comprehensive examination to look for other possible etiologies.
53	RM	2009	JAMA	Acute and prolonged exposures at the WTC site were both associated with a large burden of asthma and posttraumatic stress symptoms 5 to 6 years after the September 11 WTC attack.
54	Bills, CB	2009	Psychiatric Quarterly	These findings personalize the symptom reports and diagnoses that have resulted from the 9/11 responders' exposure to Ground Zero, yielding richer information than would otherwise be available for addressing the psychological dimensions of disasters and show that large scale qualitative surveillance of trauma-exposed populations is both relevant and feasible.
55	Weiden, MD	2009	CHEST	Airways obstruction was the predominant physiology underlying the reduction in lung function post-9/11/01 in FDNY-WTC rescue workers presenting for pulmonary evaluation.
56	Szema, AM	2009	Allergy Asthma Proc.	Chinatown asthma rates remain higher than among other groups (29% versus the NYC reference rate of 13%). It is possible that exposure to toxins on September 11, 2001 accentuated the effect of subsequent exposure to air pollution.

57	De la Hoz, RE	2009	Journal of Occupational and Environmental Medicine	In 136 former WTC workers and volunteers, atopy (the genetic tendency to develop allergic diseases) seemed to be a risk factor for presumably WTC-related upper airway disease, but not for lower airway disease.
58	Stamell, EF	2009	The Journal of Trauma	This review discusses issues in pediatric disaster preparedness to hopefully foster discussion for future strategies.
59	Webber, MP	2009	Environmental Health Perspectives	Protracted work exposures at the WTC site increased the odds of respiratory and gastro-esophageal reflux disease (GERD) symptoms 4 years later; these data strongly suggest the need to minimize additional exposures during recovery and cleanup phases.
60	Chiu, S	2009	Journal of Affective Disorders	This study evaluated the performance of a modified Center of Epidemiologic Studies Depression Scale (CES-D-m), which captured symptoms in the past month, in comparison to the Diagnostic Interview Schedule (DIS) in identification of major depressive disorder in WTC-exposed retired Fire Department, City of New York (FDNY) firefighters and found that the CES-D-m performed well in identifying those at elevated risk.
61	Yehuda, R	2009	Psychoneuroendocrinology	This study looked at levels of stress hormones in 28 survivors of the World Trade Center attacks on September 11, 2001 who received psychological treatment for PTSD symptoms and their relationship to outcome of treatment.
62	Yehuda, R	2009	Biological Psychiatry	This study found that several genes involved in stress hormone signaling are differentially expressed among those with current PTSD.
63	Evans, S	2009	Journal of Clinical Psychology	Eight hundred forty-two disaster relief workers who had been deployed to the World Trade Center (WTC) following September 11, 2001 completed a battery of comprehensive tests measuring PTSD and social and occupational functioning. Workers with PTSD were more likely to have a history of trauma, panic disorder, and depression.

Page 8 of 17

64	Reibman, J	2009	Journal of Occupational and Environmental Medicine	Residents and local workers as well as those with work- associated exposure to WTC dust have new and persistent respiratory symptoms with lung function abnormalities 5 or more years after the WTC destruction.
65	Chemtob, CM	2009	Disasters	The relationship between exposure to the WTC attacks, increased substance use, functional impairment and mental health service use was assessed through an in-school survey of directly exposed students (N = 1040) attending the five middle and five high schools nearest the WTC. Students with one WTC exposure risk factor had a five-fold increase in substance use, while those with three or more exposure risks had a nearly 19-fold increase.
66	Hoven, CW	2009	Clinical Child and Family Psychology Review	The "Children of First Responder and WTC Evacuee Study"—a two-site longitudinal study—is currently underway in the United States (New York City) and in Israel (Tel Aviv area) in an effort to understand the impact of different patterns of mass violence on the children of responders.
67	Giosan, C	2009	Journal of Anxiety Disorders	This study examined the relationships between memories for a single incident traumatic event - the 9/11 attack on the WTC and posttraumatic stress disorder (PTSD) in 2641 disaster restoration workers deployed at the WTC site in the aftermath of the attack.
68	Mauer, MP	2009	Lung	This study found that sophisticated breathing tests called impulse oscillometry revealed signs of respiratory disease in NYS WTC responders in comparison with unexposed NYS employees.
69	Corrigan, M	2009	Am J Public Health	A short computerized, screening questionnaire effectively identified elevated PTSD risk, higher Counseling Services Unit use, and functional impairment among firefighters and therefore may be useful in allocating scarce postdisaster mental health resources.

Page 9 of 17

70	Laumbach, RJ	2009	Am J Epidemiol	The authors investigated the occurrence of respiratory symptoms among persons living outside of Lower Manhattan in areas affected by the WTC particulate matter plume and found the plume was not strongly associated with respiratory symptoms outside of Lower Manhattan.
71	Bern, AM	2009	Environ Sci Technol	This paper describes the development of a procedure for screening urban background dust for the presence of WTC dust.
72	Boscarino, JA	2009	Psychiatry Res	This study looked at the relationship between a peritraumatic panic attack during a traumatic event and later mental health status.
73	Boscarino, JA	2009	Soc Psychiatry Psychiatr Epidemiol	This study attempted to identify common risk factors associated with PTSD onset and its course.
74	Lowers, HA	2009	J Expo Sci Environ Epidemiol	Slag wool can be used as a signature marker to identify areas that contain potential residual WTC dust contamination at concentrations that are less than average background levels for the material.
75	Franz, VA	2009	Clinical Psychology Review	This article reviews research on the impact of the September 11th terrorist attacks on psychiatric patients.
76	Adler, JM	2009	Journal of Personality	In this study, a nationally representative sample of 395 adults wrote accounts about the 9/11 terrorist attacks approximately 2 months after 9/11.
77	Baschnagel, JS	2009	Journal of Anxiety Disorders	In this study, 308 undergraduates were assessed for coping prior to the 9/11 WTC attack and for PTSD symptomatology at one and three-months post-9/11.
78	DiMaggio, C	2009	Substance Use and Misuse	In analyses controlling for age, gender, median household income, and employment-related exposure to the terrorist attacks, this study found that each two mile increment in distance away from the WTC site was associated with 18% more substance use related diagnoses in the population studied.

Page 10 of 17

79	Pfeffer, CR	2009	International Journal of Psychiatry in Medicine	After September 11, 2001, bereaved (those who lost a loved one) compared to nonbereaved had significantly higher rates of posttraumatic stress disorder (PTSD; 68.1% versus 0%) and major depressive disorder (45.5% versus 9.5%), and bereaved had significantly different levels of certain hormones.
80	Richman, JA	2009	Substance Use and Misuse	This study examined the prevalence of negative beliefs related to terrorism and whether these beliefs were related to distress and drinking.
81	Endara, SM	2009	BMC Public Health	The findings from this large population-based study suggest that women who were pregnant during the terrorist attacks of September 11, 2001 had no increased risk of adverse infant health outcomes.
82	Lin, S	2010	International Journal of Occupational and Environmental Health	Residents living within one mile of the WTC surveyed after 9/11 responding two and four years later to follow-up surveys that asked about lower respiratory symptoms (LRS), medical history, psychological stress, and indoor environmental characteristics were found to have a continuing burden of symptoms associated with LRS.
83	Lin, S	2010	Arch Environ Occup Health	This study found that after 9/11/2001 there was an immediate increase in hospital admissions for respiratory problems after the disaster and a delayed increase in cardiovascular and cerebrovascular admissions.
84	Dimaggio, C	2010	Psychiatry Res	Mathematical models were used to show that, in the months following the attack, each 2-mile increment in distance closer to the WTC site was associated with a 7% increase in anxiety-related diagnoses in the population.
85	Bowers, B	2010	J Clin Rheumatol	This paper describes 2 rescue workers with significant exposure from the WTC collapse, one who presented with joint pain and one with eye problems; both ultimately turned out to have sarcoidosis.

Page 11 of 17

86	Rosen, CS	2010	Psychiatr Serv	This study analyzed community survey data to identify subgroups of children who were at highest risk of posttraumatic stress disorder (PTSD) after the September 11 attacks, and showed that the risks were higher among 4th graders and among children who had a friend or family member directly exposed to the attacks.
87	De la Hoz, RE	2010	J Occup Environ Med	This study examined the association of WTC exposure and findings on nocturnal polysomnogram (sleep studies), as well as known predictors of obstructive sleep apnea (OSA) in 100 responders and found that OSA was associated with obesity and male sex, but not with occupational WTC exposure indicators in those studied.
88	Mauer, MP	2010	Occup Med (Lond).	This paper found that, even in a moderately exposed responder population, lower respiratory effects were a persistent problem 5 years post-9/11, indicating that some WTC responders require ongoing monitoring.
89	Mauer, MP	2010	Int Arch Occup Environ Health	This study found that moderately exposed New York State employees who responded to the WTC disaster experienced health impacts from exposures 2 years post-9/11 and that exposure to smoke may have had a greater lower respiratory impact than resuspended dust.
90	Chiu, S	2010	J Affect Disord	FDNY investigators evaluated the performance of a modified Center of Epidemiologic Studies Depression Scale (CES-D-m), which captured symptoms in the past month, in comparison to the Diagnostic Interview Schedule (DIS) in identification of major depressive disorder in WTC-exposed firefighters and found that the CES-D-m performed well in identifying those at elevated risk.

 $Synops is \ of \ Peer-Reviewed \ Literature-Human \ Health \ Effects \ related \ to \ the \ WTC \ Disaster$ 

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Page 17 of 17



## Study links post-9/11 work to autoimmune diseases

March 25, 2015

New York – People who performed prolonged work at the site of the 2001 World Trade Center terrorist attack may have an increased risk for developing autoimmune diseases such as rheumatoid arthritis and lupus, according to a study from Yeshiva University's Albert Einstein College of Medicine.

Researchers found that workers' risk to develop such diseases during the decade following 9/11 increased by 13 percent for every month that they spent at the site. Workers who spent 10 months at the cleanup site were more than 3 times as likely to develop the diseases as workers who stayed for one month.

Researchers said the most common autoimmune diagnoses included:

- Rheumatoid arthritis (37 percent)
- Spondyloarthritis (22 percent)
- Inflammatory myositis (14 percent)
- Systemic lupus ethythematosus (12 percent)
- Systemic scleroris (5 percent)
- Sjogren's syndrome (5 percent)

"We believe that this is the first study to demonstrate that prolonged WTC exposure is an important predictor of post-9/11 systemic autoimmune diseases," lead author Dr. Mayris Webber said in a press release. "It is our hope that increased awareness of this association can lead to earlier diagnosis and treatment."

The study was published online March 16 in the journal Arthritis & Rheumatology.



## • by Nancy Walsh Senior Staff Writer, MedPage Today

#### **Action Points**

- There is a strong association of new onset systemic autoimmune disease with prolonged work exposure at the World Trade Center disaster site after the 9/11 terrorist attack.
- The odds ratio for autoimmune diseases rose by 13% for each month individuals spent working at the site.

The list of ailments afflicting the World Trade Center first responders has grown to include systemic autoimmune diseases, a new study reported.

The conditional odds ratio for autoimmune diseases rose by 13% for each month individuals spent working at the site (OR 1.13, 95% CI 1.02-1.26), according to <u>Mayris P. Webber, DPH</u>, of the department of epidemiology and population health, Montefiore Medical Center in New York City, and colleagues.

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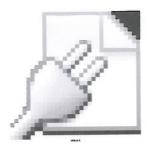
And for those who spent 10 months working at the site the risk tripled (OR 3.09, 95% CI 1.21-7.94), the researchers reported online in <u>Arthritis and Rheumatology</u>.

"The terrorist attacks on the World Trade Center (WTC) buildings and the subsequent building collapses and fires exposed rescue/recovery workers to aerosolized WTC dust, an amalgam of pulverized cement, glass fibers, silica, asbestos, lead, polycyclic aromatic hydrocarbons, polychlorinated biphenyls, and polychlorinated furans and dioxins," they noted.

The result has been the development of various respiratory and other diseases including asthma, gastroesophageal reflux, and <u>cancer</u> in up to 70% of the exposed New York City fire department (FDNY) members, but the entire range of potential health effects is not yet known and may take decades to fully manifest.

The <u>FDNY-WTC Health Program</u> has been following almost 16,000 firefighters and emergency medical system responders who worked at the site during the 10 months of cleanup that followed the attack.

Autoimmune diseases have been linked with multiple environmental exposures, including silica, hydrocarbons, and <u>particulates</u>.



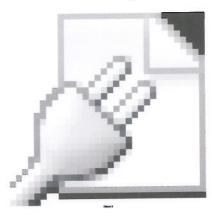
These autoimmune conditions include rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), dermatomyositis, vasculitis, and Sjogren's syndrome, and most often have been reported after many years of exposure and predominantly among women.

To examine the effects of either acute or chronic exposure on the incidence of these disorders among first responders, Webber and colleagues conducted a nested case-control study of enrollees in the FDNY-WTC Health Program who filled out routine health questionnaires every 12 to 18 months. Participants were asked about the potentially relevant factors of smoking and symptoms of post-traumatic stress disorder (PTSD), and whether they arrived at the site on the morning of Sept. 11, defined as acute exposure, or thereafter, considered chronic exposure.

Those who reported chronic exposure were asked how many months they worked at the site for at least 1 day.

For this analysis, the study population included 13,617 individuals, 59 of whom had medically confirmed autoimmune disease diagnosed by 2014.

A total of 37.3% had RA, 22% had spondyloarthritis, 13.6% had inflammatory myositis, 11.9% had SLE, and small numbers had scleroderma, Sjogren's syndrome, antiphospholipid syndrome, or granulomatosis with polyangiitis. The diseases were diagnosed from 2005 to 2010 in 61%.



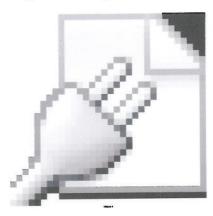
Each case was matched with four controls.

The vast majority of cases and controls were white males. Median age at the time of hire was 27, and median age at the time of diagnosis was 50. Exposure was considered high, with presence at the site during at least 2 months, in 73%.

Unlike chronic exposure, there was no significant association for acute exposure (OR 1.85, 95% CI 0.86-3.89). There also was no association with smoking (OR 1.16, 95% CI 0.62-2.20) or PTSD (OR 1.40, 95% CI 0.58-3.14).

In a sensitivity analysis intended to account for disease latency by removing the five cases that were diagnosed within the first 2 years after the attack, chronic exposure was associated with a 17% increase per month of exposure (OR 1.17, 95% CI 1.05-1.31), the researchers reported.

The finding of an increase in autoimmune disease among WTC responders was "unexpected and highlights the need for increased clinician awareness of the possibility of these and perhaps other autoimmune disorders in their WTC-exposed male patients."



"To the best of our knowledge, acute and chronic WTC exposures have been associated with respiratory conditions like asthma and PTSD, but not with the new onset of systemic autoimmune diseases other than sarcoidosis."

Current thinking holds that autoimmunity develops in a genetically susceptible host following a triggering event such as an infection or toxic exposure, "and then, through various immunologic-inflammatory-oxidative pathways, an autoimmune response occurs ultimately resulting in clinical symptoms and disease."

In addition, the triggering event actually may involve multiple events, at specific times, or in a specific sequence.

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The study was supported by the National Institute for Occupational Safety and Health.

Webber and co-authors disclosed no relevant relationships with industry.

 Reviewed by <u>Henry A. Solomon, MD, FACP, FACC</u> Clinical Associate Professor, Weill Cornell Medical College and Dorothy Caputo, MA, BSN, RN, Nurse Planner

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• by Nancy Walsh
Senior Staff Writer, MedPage Today

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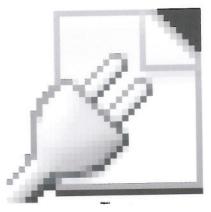
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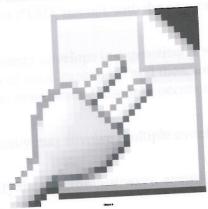
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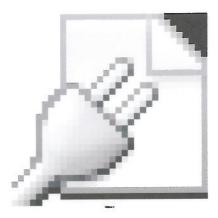
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last updated 03.19.2015

#### Primary Source

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## THE GUPTA GUIDE

Sanjay Gupta, MD, Editor

RHEUMATOLOGY 03.18.2015

0 COMMENTS \*

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by Nancy Walsh
Senior Staff Writer, MedPage
Today

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2 COMMENTS

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RHEUMATOLOGY 04.20.2015

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# Claims-Based Index for RA Severity Doesn't Match Disease Activity

— Healthcare insurance databases are prone to confounders.

by Pauline Anderson
Contributing Writer, MedPage Today

An algorithm that was developed to approximate rheumatoid arthritis (RA) severity using insurance claims-based variables is poorly correlated with a score for disease activity, a new external validation study has found.

The correlation between the claims-based index for rheumatoid arthritis severity (CIRAS) and the disease activity score in 28 joints calculated using C-reactive protein (DAS28-CRP) was poor (Pearson correlation coefficient=0.07; P=0.24), according to Rishi J. Desai, PhD, Division of Pharmacoepidemiology and Pharmacoeconomics, Department of Medicine, Brigham and Women's Hospital and Harvard Medical School, Boston, and colleagues.

The paper appeared in Arthritis Research and Therapy.

RA severity is a complex concept that depends on a combination of disease activity, physical function impairment, and physical damage to the joints. Studies using healthcare utilization databases are prone to residual confounding by disease severity.

To address this problem, another study developed an algorithm to create the CIRAS that uses variables from claims, and reported moderate correlations between medical records and claims-based indices.

In the absence of a standard clinical measure for RA severity, Desai and his research team used the DAS28-CRP to validate the claims-based severity measure. This activity measure often drives treatment selection, the authors noted.

The study included 315 RA patients who were enrolled in both the Brigham and Women's Hospital Rheumatoid Arthritis Sequential Study (BRASS) and Medicare, and had at least one valid DAS28-CRP measured after a year of continuous enrollment in Medicare.

Most of the subjects (81%) were female. Their mean age was 70 years and the median DAS28-CRP and CIRAS were 3.3 and 4.4 respectively

In addition to a low correlation between the CIRAS and DAS28-CRP, the study found the correlation between CIRAS and the multi-dimensional health

(Pearson correlation coefficient=0.08; P=0.17). MD-HAQ may be indicative of frailty and an important confounder, said the authors.

Adding more variables from both medical and pharmacy claims as predictors in a linear regression model didn't substantially improve the performance of the algorithm in predicting DAS28-CRP.

"These findings suggest that CIRAS may not accurately approximate disease activity or frailty in observational studies of RA treatments using insurance claims data," wrote the authors.

"Claims-based algorithms for clinical disease activity should be rigorously tested in distinct populations in order to establish their generalizability."

An important contribution of this study is that it highlights the importance of external validation of claims-based algorithms, said the authors.

There are several possible explanations for why CIRAS performed poorly in this study. The original study used RA records-based index of severity (RARBIS) and most clinical parameters measured through RARBIS, including arthritis flares and x-ray and lab results, aren't captured in claims or in CIRAS.

"Therefore, the poor performance of CIRAS against DA28-CPR may simply reflect the inability to account for important clinical parameters" wrote the authors

As well, they added, there were important differences between the original cohort and the one in this study, including differences in gender, healthcare utilization patterns, and disease activity.

Daniel H Solomon is supported by National Institutes of Health (NIH) grants, receives research grants from Amgen and Eli Lilly and Company,

serves in unpaid roles on studies sponsored by Pfizer, Novartis, Eli Lilly and Company, and Bristol-Myers Squibb and receives royalties from UpToDate.com. Seoyoung C, Kim is supported by an NIH grant, received research support from Pfizer and tuition support for the Pharmacoepidemiology Program at the Harvard School of Public Health partially funded by the Pharmaceutical Research and Manufacturers of America foundation.

Dr. Desai reports owning Biogen Idec stock due to spouse's employment.

Michael E Weinblatt has received consulting fees, speaking fees, and/or honoraria from MedImmune, Crescendo Bioscience, and Bristol-Myers Squibb (less than \$10,000 each) and has received research grant support from those companies.

Nancy Shadick has received research grant support from MedImmune, Crescendo Bioscience, Amgen, AbbVie and Genentech.

\_\_ LAST UPDATED 04.20.2015

**Primary Source** 

Arthritis Research and Therapy

Source Reference: Desai RJ, et al "An external validation study reporting poor correlation between the claims-based index for rheumatoid arthritis severity and the disease activity score" Arthritis Res Ther 2015; DOI: 10.1186/s13075-015-0599-0.

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