Fall 2021—20th Anniversary Issue
18 Years. 70,000 Enrollees. Over 140 Research Papers.

The Registry has published over 140 research papers on short- and long-term 9/11 health outcomes, unmet health care needs, quality of life and functioning. The scope of the research includes existing and potentially emerging 9/11-related health conditions, many of which fall under the conditions covered by the World Trade Center (WTC) Health Program. Registry research findings have helped inform federal policymaking, including the work of the James Zadroga 9/11 Health and Compensation Act.

The Registry continues its mission of researching the long-term physical and mental health effects of 9/11. To view the infographic in high resolution, visit www1.nyc.gov/ assets/911health/images/newsletter/wtchr-infographic.pdf.

**The Art of Remembrance**

**Major League Baseball** – Turner Sports is producing a documentary titled “More Than Just a Game: Baseball Remembers 9/11,” about baseball’s role in New York and America’s 9/11 recovery.

**Spike Lee** – Together with HBO, Spike Lee has produced a documentary titled “NYC Epicenters 9/11 -> 2021½,” which looks at New Yorkers’ lives from 2001 to 2021.

**CDC Museum**

To commemorate the 20th anniversary of 9/11, the Centers for Disease Control and Prevention’s (CDC) David J. Sencer CDC Museum is creating a unique installation on WTC disaster exposures and related health conditions. The exhibition will also look at related work since 2001 by groups like the Registry and WTC Health Program. To learn more, visit cdc.gov/museum/index.htm.
Health Concerns After 9/11
Shortly after 9/11, the NYC Department of Health and Mental Hygiene (NYC Health Department) recognized the need for a registry to track health impacts among people who were exposed to the WTC disaster. Providers, scientists, and community and labor stakeholders also expressed concerns about the health impacts of 9/11. A scientific advisory committee was created.

Registry Is Established
The NYC Health Department received federal funding from the Federal Emergency Management Administration and CDC’s Agency for Toxic Substances and Disease Registry (ATSDR) to establish the Registry in collaboration with the ATSDR. Labor and community advisory committees were formed over time.

Wave 1 Enrollment Survey
More than 71,000 rescue and recovery workers, area workers and residents, and passersby who enrolled in the Registry were interviewed about their physical and mental health symptoms and conditions as well as their exposure to and experiences regarding 9/11.

Wave 2 Survey
In addition to follow-up health questions about the Wave 1 Survey, the Wave 2 Survey had other questions on dust cloud exposure and potential hearing loss after 9/11.

Combined Survey Findings
Combined findings from the Wave 1 and Wave 2 surveys were reported in an article published by the Journal of the American Medical Association. Notably, 25% of enrollees had both 9/11-related asthma and PTSD.

Wave 3 Survey
The Registry collected updated information on enrollees’ physical and mental health, including functioning and disability, unmet health care, and, for the first time, depression.

Wave 4 Survey
The Registry collected updated information on enrollees’ physical and mental health for 14 years after 9/11. Enrollees who had asthma after 9/11 were asked to complete an additional Asthma Survey.

Wave 5 Survey
Building upon data from four previous Wave surveys, the Registry added new topics to the Wave 5 Survey, including sleep quality, Alzheimer’s disease, oral health, menstrual history and vaping.

First Registry Research
Findings from the Registry’s publication “Surveillance for World Trade Center Disaster Health Effects Among Survivors of Collapsed and Damaged Buildings,” such as an association between exposure to 9/11 and hearing loss, stroke and psychological distress, were validated in later Registry studies.

Wave 1 Survey Findings
The Registry released more findings from its 2003 and 2004 enrollment interviews. Notably, 67% of adult enrollees reported new or worsening respiratory symptoms and 16% likely had post-traumatic stress disorder (PTSD).

Hurricane Sandy Survey Findings
Adult enrollees who had 9/11-related PTSD and experienced traumatic events related to Hurricane Sandy in 2012 were significantly more likely to have had Hurricane Sandy-related PTSD five to 12 months later than enrollees who did not have 9/11-related PTSD.

Adolescent and Young Adult Mental Health Findings
The Registry assessed trauma-related behavioral issues in adolescents and their mental health outcomes later as adults. Enrollees with abnormal scores on the Strengths and Difficulties Questionnaire as adolescents were more likely to smoke, have PTSD, and have two or more self-reported, health care provider-diagnosed mental health conditions as adults.

COVID-19 Survey
The COVID-19 Survey assessed the effects of the COVID-19 public health emergency on enrollees with questions on COVID-19-related symptoms and hospitalizations, access to health care, mental health, quality of life, and employment and financial difficulties, among other topics.
**Enrollee Stories**

**Marya Columbia: Her Music Was a Glimmer of Light as She Played for the Workers at Ground Zero**

After 9/11, Marya Columbia played in a group of musicians for the rescue and recovery workers who came to St. Paul’s Chapel for a break from their physically and emotionally draining daily work at ground zero.

Marya volunteered for months, and her time at ground zero greatly contributed to her lung cancer diagnosis in May 2019. The Registry worked alongside Marya and her husband Ron to have her admitted into the WTC Health Program as the first musician to receive benefits through the program. When asked, Marya said she joined the Registry out of principle so other musicians could access benefits too. Sadly, Marya Columbia passed away from lung cancer on October 23, 2019.

**Registry Stories**

**Dr. Marijo Russell O’Grady: Remembering Her Professional Dedication and Inspiring Personality**

With great sadness we note the 2020 passing of Dr. Marijo Russell O’Grady, who served for many years as chair of the Registry’s Community Advisory Board (CAB). We fondly remember her dedication, focus, availability and calmness in the wake of 9/11. Her ability and desire to communicate helped immensely in guiding the CAB through trying times.

While chair of the CAB, Dr. O’Grady also served as associate vice president and dean for students at Pace University’s Manhattan campus, coauthored the book “Crisis, Compassion, and Resiliency in Student Affairs,” and received awards for her extensive public and community service.

She leaves behind the loves of her life, her husband Mark D. O’Grady and their son James Russell O’Grady. The Registry expresses condolences to Dr. O’Grady’s family and is thankful for all of her inspiring work.

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**20 Years Later**

Listen to enrollees talk about their relationship with the Registry and their lives 20 years after 9/11. View their testimonials, including Marya’s, at [www1.nyc.gov/site/911health/enrollees/testimonial-videos.page](http://www1.nyc.gov/site/911health/enrollees/testimonial-videos.page).

**20th Anniversary Virtual Town Hall with the NYC Health Department and Registry**

In September, view a special NYC Health Department town hall online about the 20th anniversary and the Registry’s work since 2003. Visit [nyc.gov/911health](http://nyc.gov/911health) or email wtchr@health.nyc.gov for more information.
“We were and still are committed to responding whenever the need arises. When asked if I knew then what I know now of the dangers and the health issues, would it have changed what I did? My response was and remains, ‘In a heartbeat, we go where we are needed. As a retired police officer, we never ran away from the danger; we went head-on to meet and deal with the situation.’

I am proud to have had the opportunity to serve on 9/11 and the aftermath. I am proud of all those who served with us. I am especially proud as a chaplain to have been allowed the opportunity to bring some comfort, and I hope healing to … [the] brave police and fire personnel who climbed those stairs to rescue those people from certain death. They gave their lives to save others; they are the real heroes. May God bless them and reward them with eternal life in heaven. They served their time in hell on 9/11.”

— Anonymous

“Dear WTCHR,

As a Pearl and Catherine Slip resident, I want to thank you so very much for being there, caring and never giving up on your health watch over all these years.

A friend recently posted an image of the World Trade Center ‘skeletal ghost’ taken on 9/11. She is a photojournalist and was documenting the site. The image caught me off guard and brought me back to when I saw that with my own eyes on that day. On seeing that photo, I broke down and began to cry. It was odd, but assume it was an outlet of years of buried hurt — a wound of love.

My apartment was coated with dust, and I did continue to live downtown after 9/11. Luckily, my physical health appears to be OK. However, I do have a series of unsettling images that are seared into my memory. Your presence and your work are a godsend. It is wonderful to know you are still there on this 20th anniversary.”

— A Pearl Street resident

The Continued Health Impacts of 9/11

According to a 2019 study, systemic autoimmune diseases are an emerging health concern among people who were exposed to the dust cloud created after the WTC disaster.

The Registry’s health materials are one of its most popular sources of information. They describe symptoms and treatments for some of the 52 conditions, including melanoma and sinusitis, covered by the WTC Health Program. To read the systemic autoimmune diseases handout and others, visit nyc.gov/911health and search for health materials.

Need Care?
If you are an enrollee and think you may have a 9/11-related health condition, email the Registry's Treatment Referral Program at trp@health.nyc.gov. A staff member will respond to help see if you are eligible.

Resources
The federal WTC Health Program provides monitoring and treatment, including medications for physical and mental health conditions related to 9/11. Services are offered at no cost to you, no matter where you live now. You can apply online at cdc.gov/wtc or call 888-982-4748 to have an application mailed to you.

Get Vaccinated Against COVID-19
It has never been easier to get a COVID-19 vaccination in NYC. People age 12 and older can get vaccinated. Many vaccination sites do not require appointments. It is important that people with chronic conditions get vaccinated. Visit nyc.gov/vaccinefinder to find a city vaccination site near you. Outside NYC, visit vaccines.gov.

To find this e-newsletter in Simplified Chinese, Spanish and Traditional Chinese, visit nyc.gov/911health and click on the Research tab, then choose Publications from the top menu, and select e-Newsletter from the drop-down. To contact the Registry, email wtchr@health.nyc.gov.