



HEALTH WATCH

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Secretary Robert F. Kennedy Jr.
U.S. Department of Health & Human Services
Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201

August 8, 2025

Dear Secretary Kennedy,

9/11 Health Watch, Inc. was created by its stakeholder unions and others who fought diligently to get health care and compensation for those impacted by the toxins at Ground Zero. We are dedicated to ensuring that the programs implemented under the James Zadroga 9/11 Health and Compensation Act—the September 11th Victim Compensation Fund and the World Trade Center Health Program—provide care for injured and ill 9/11 responders and survivors as the law intended.

We have concerns about the continued program hiring freeze; the delays in the petition process to consider the extension of coverage for autoimmune, cardiac and cognitive issues; and the delays in issuances of program research grants, which were discussed in Senators Gillibrand and Schumer's letter of August 5, 2025.

But today I am writing specifically about the ongoing "Communications Pause" you have imposed on the Department of Health and Human Services, and the impact it has had on the World Trade Center Health Program and its members.

According to communications from your department, "*HHS has issued a pause on mass communications and public appearances that are not directly related to emergencies or critical to preserving health. This is a temporary pause to allow the new team to set up a process for review and prioritization.*"

It appears that this pause has been interpreted to shut down all communications between the 9/11 community and the World Trade Center Health Program. Given that it has now been six months since the new Administration took over, we want to know when this "Temporary Pause" will be lifted.

We don't understand why this "pause" is still in place, as we enter the seventh month after you've taken over as Secretary. What is its purpose as it applies to the care that injured and ill 9/11 responders receive?

We believe that the work of the World Trade Center Health Program is being adversely impacted by this continuing ban on communications, and that it is impacting the health of the over 140,000 responders and survivors who are in the program.

Before the new Administration took office and the communications ban was put in place, we had asked the WTC Health Program questions about the level of health surveillance that the program was conducting on program members and the incidence of several rare conditions. Because of this ongoing communications ban and the CDC's interpretation of its extent, we are being told that these issues cannot be discussed at this time.

While we acknowledge that the current "communications pause" does not prevent individual program members from talking to the program directly, it does prevent the 9/11 community and the program from discussing the details of the program's response to apparent increased incidence of these conditions. The normal functioning of the program, working in collaboration with concerned parties such as our organization and the unions representing police, fire, EMS, construction trades and other responders and survivors are prevented from discussing these conditions and the growing concerns that the 9/11 community has with their impact.

I am sure you would appreciate that 9/11 responders and survivors who have these conditions would want to know what the program is doing to study whether the prevalence of these conditions appear to be abnormally elevated, and what specific actions to determine this are being taken.

For example:

Immunoglobulin A nephropathy (IgAN). This condition is also known as Berger's disease, and is a progressive autoimmune kidney disease with a

possible incidence of 24 self-reported cases in the World Trade Center General Responder Cohort of over 55,000 participants. This incidence appears extremely high, given that the incidence reported in the literature for the U.S. is estimated to be around 1.4 per 100,000 person-years.

<https://pubmed.ncbi.nlm.nih.gov/39496243/>

Acquired Amegakaryocytic Thrombocytopenia (AAT). We understand that there have been some self-reported cases of AAT in the programs General Responder Cohort. While one case has been confirmed, the status of the other self-reported cases are unfortunately unknown. Given that this condition has only been reported 100 times in the literature across the world, the presence of one case is worrisome and the confirmation of more than one case would indicate an astonishingly high rate.

<https://www.ncbi.nlm.nih.gov/books/NBK568795/>

Angiomyolipoma of the Kidney. The overall incidence is about 5 cases per 1 million women. (Harknett EC, Chang WY, Byrnes S, Johnson J, Lazor R, Cohen MM, Gray B, Geiling S, Telford H, Tattersfield AE, Hubbard RB, Johnson SR. Use of variability in national and regional data to estimate the prevalence of lymphangiomyomatosis. QJM. 2011 Nov;104(11):971-9.) This condition typically affects women of childbearing age. This has an 80/20 split impacting women more than men. Given that the WTC Health Program responder cohort is mostly men, the self-reported 28 cases of this condition would appear to be unusually high.

<https://www.ncbi.nlm.nih.gov/books/NBK585104/>

Acoustic neuroma and vestibular schwannoma. For this condition the reported prevalence is 3 to 5 per 100,000 person-years. However, the incidence increases with age, reaching 21 per 100,000 person-years in those over 70. We understand the program's responder cohort has 90 self-reported cases. <https://www.ncbi.nlm.nih.gov/books/NBK562312/>

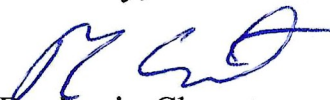
We want to be clear that these conditions might not, upon closer examination, prove to occur at increased frequency – but they do need to be reviewed. Given the current communications pause, it appears that the WTC Health Program cannot do this critical review at this time; and more importantly, that review cannot include the 9/11 community.

The issue of your continued communication ban needs to be immediately addressed so that the program can properly respond to answer these important

questions. If these conditions are shown to be elevated in frequency it may require alterations in clinical care and surveillance, and that should be done as soon as possible.

Thank you for your attention to this issue.

Sincerely,

A handwritten signature in blue ink, appearing to read 'B. Chevat', with a stylized flourish at the end.

Benjamin Chevat
Executive Director