For some U.S. veterans and 9/11 first responders, the long-term impact of service takes the form of debilitating and chronic headache disorders. But the health care these men and women rightly deserve is often out of reach.

To explore this challenge, The Headache & Migraine Policy Forum in partnership with the Alliance for Headache Disorders Advocacy hosted “Chronic Headache Disorders & Toxic Exposure,” a national virtual policy panel discussion. The event focused on the long-term impact of airborne hazards and burn pit exposure on 9/11 first responders and veterans. The forum coincided with the 14th annual Headache on the Hill advocacy day.

In his opening remarks, U.S. Representative Mark Takano (D-CA), chairman of the House Committee on Veterans’ Affairs, said the country has a responsibility to help veterans living with headache and migraine disorders.

“"If America is willing to send our service members into harm’s way to defend our democracy," he said, “then she must be willing to take care of all those who went into battle.”

Rep. Takano is committed to improving access to care not only for veterans with headache and migraine, but for any American struggling with these disorders. As he told audience members, “For me, this issue is personal. I experience migraines from time to time and know how debilitating they can be.” Rep. Takano has pledged to move forward comprehensive legislation to ensure all veterans exposed to toxic substances during their service—including those with headache and migraine disorders—can access the care and benefits they’ve earned.

“"For me, this issue is personal.”

U.S. Rep. Mark Takano
As a national advocate for 9/11 first responders and veterans exposed to military burn pits, former host of The Daily Show Jon Stewart urged policymakers to do what's necessary for service personnel with toxic exposure.

Over the years Stewart has been vocal on this issue. In 2010, he devoted an episode of his late-night show to increasing public awareness for a bill aimed at providing health benefits for federal responders. And in 2019 Stewart headed once again to Capitol Hill, where he pleaded with members of Congress to help protect the men and women who protect America.

This year, he returned with the same level of passion. “This is an eminently solvable problem,” Stewart said of health care for veterans and first responders exposed to burn pits. Stewart referenced the newly introduced presumption bill. If passed, the bill will provide benefits to the service members who have been deployed and have illnesses due to burn pits and toxic exposure. Stewart said, “The urgency is now. People will continue to die and suffer needlessly if we don’t get this done.”

Stewart emphasized that the VA should be an advocate for veterans’ health care, not an obstacle. He concluded with a call to action for the audience. “All that I ask of you is, when the time comes, and we need to activate you,” he said, “you place pressure on our congressional members about this issue.”

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Jon Stewart
Joe McKay
New York Fire Department 9/11 First Responder and Cluster Headache Patient Advocate

Joe McKay, a retired New York City firefighter, started having cluster headache attacks after responding to the devastation at the Twin Towers on September 11, 2001. When he experienced his first cluster headache, McKay recalled, he thought he was dying. “I would literally bang my head against the wall to distract myself from the pain,” he said.

McKay now channels his pain toward increasing education and awareness about cluster headache. Explaining to the panel that cluster headache is one of the most painful conditions known to man, he added, “Cluster headache is also known as suicide headache. I learned you’re 20 times more likely to end your life [if you have] this condition.”

McKay stressed that service members need the help of policymakers. He referenced the fact that Medicare will not cover high-flow oxygen, a proven treatment to quell cluster attack symptoms. McKay said Medicare advised patients to instead, “just go to the emergency room for oxygen.”

“That needs to change,” McKay insisted.

John Feal
9/11 First Responder, Army Veteran and Activist

John Feal touched on the stigma and misconceptions that surround headache and migraine disorders. Comparing headache to other commonly stigmatized disorders, Feal said, “It’s the new post-traumatic. Years ago, no one would want to talk about PTSD; now it’s the same.”

Feal also emphasized the need for policies that recognize service by allowing timely and appropriate health care. “We always say, ‘Thank you for your service,’” Feal said. “But it should be, ‘Thank you for your service. Thank you for your sacrifice. What can I do to help you ease the pain you’ve suffered?’”

Feal reiterated that the country has a responsibility to do better for veterans and first responders facing chronic headache disorders. “If we can’t do that, that one little thing,” Feal reflected, “we fail not only as a country but as human beings.”
Jason Sico, MD
National Clinical Lead, VA Headache Disorders Centers of Excellence

Jason Sico, MD, followed up on fellow panelists’ concerns by sharing real-life data on what veterans experience coming home. “Exposure can lead to problems even years later. More than 26% of veterans exposed to burn pits will get severe headaches,” Dr. Sico reported. He also noted that:

- 14% of veterans being treated by the VA have at least one headache disorder
- Half of veterans with a headache disorder have at least one other mental health condition
- Almost two-thirds of veterans with a headache disorder have at least one other non-headache painful condition
- More than 27,000 veterans have cluster headache.

Dr. Sico urged headache and migraine patients to seek medical attention if they need it. “If you need help and you’re not getting it, ask someone else,” he said. “There are a lot of therapies out there.”

Paula Dumas
Migraine Patient Advocate and President, World Health Education Foundation

The debilitating impact of headache and migraine disorders is twofold, explained moderator Paula Dumas. “The disability is not just a physical disability,” she noted, “but a financial disability people experience as well.” Dumas noted that, in some cases, people are forced to quit or switch jobs because they cannot work efficiently with their condition.

“I interviewed a woman police officer who couldn’t function on the job because she couldn’t access her medication,” Dumas recalled. “She had to retire to a desk job.”

Dumas also pointed out that migraine disease, historically thought of as a “woman’s disease,” is nearly as prevalent among veterans as among women. “Approximately one in five veterans have migraine disease, but no one is talking about it,” she said.
Migraine is the second leading cause of disability in the U.S., said Robert Shapiro, MD, PhD, noting that 350,000 service men and women were exposed to a traumatic brain injury. “After their exposure, over half of them reported having chronic migraine. These individuals really are experiencing a disabling condition.”

Dr. Shapiro emphasized the need for more education about headache and migraine disorders for health care professionals specifically. “Every primary caregiver knows how to treat asthma. They should be able to treat these conditions, too,” he said.

Dr. Shapiro also noted the importance of accurate data and patient-centered care. “It’s one thing to provide good care, it’s another thing to provide the best care we can because we understand these diseases better,” he said. “And we cannot do that without research.”

He closed the event by underscoring that everyone can be an advocate, but that lawmakers have the power to change policies that can improve the quality of life for headache and migraine patients. “We are urging every member of Congress to be a champion of this issue,” he said.

“Every primary caregiver knows how to treat asthma. They should be able to treat these conditions, too.”

Robert E. Shapiro, MD, PhD
Policy Recommendations

In light of the data and insights shared during the policy panel discussion, advocates call for:

A comprehensive approach to burn pit legislation.
- Veterans and 9/11 first responders have endured enough suffering. It’s time for Congress to step in and help the hundreds of thousands of Americans in pain.

Expanding VHA Headache Disorders Centers of Excellence.
- The centers provide direct care for veterans, education and training for doctors caring for veterans, and research to improve veteran health care.

Equitable access for specialized headache care to all veterans who need it.
- An estimated 408,000 veterans sought specialized headache care within the VHA system in 2020, but only half of these veterans live in regions with access.

Increased participation in VA airborne hazards and open burn pit registry.
- A registry was established in 2014 to collect data on the potential health effects of airborne hazard exposures. The goal is to provide substantial data that will help veterans access the treatment they need.

To learn more about topics discussed at the event and The Headache & Migraine Policy Forum’s policy priorities and advocacy initiatives, visit www.headachemigraineforum.org.