



2023

# The Headache & Migraine

POLICY FORUM

## Long COVID & Headache Disorders

A Policy Panel Discussion





# Introduction

Long COVID-19 poses a growing and complex challenge for the headache and migraine community.

For about one in five long-COVID patients, headache is among the symptoms that linger after acute COVID-19 infection subsides.

Some people experience the onset of migraine attacks for the first time. Others undergo a worsening of existing headache disorders. In both situations, the experience can be confusing, painful and debilitating. It can also worsen the stigma of their disease. Long-COVID headache may accompany other symptoms, such as fatigue, sleep disturbances, brain fog and loss of smell.

Continued training and research are necessary to better understand long-COVID headache.

To explore the issue, The Headache & Migraine Policy Forum hosted “Long COVID and Headache Disorders,” a national policy panel discussion held both virtually and in person at the U.S. Capitol Visitor Center in Washington, DC. The Headache & Migraine Policy Forum, led by Executive Director Lindsay Videnieks, has been a catalyst for policy change. The forum coincided with the 16th annual Headache on the Hill day, sponsored by the Alliance for Headache Disorders Advocacy.

# Featured Speaker U.S. Senator Ed Markey (D-Mass.)



U.S. Senator Ed Markey provided prerecorded keynote remarks for the event.

“While our nation is fighting to emerge from the ongoing COVID epidemic,” Sen. Markey said, “many Americans will continue to feel the lingering impact for weeks, months and even for years.”

He described long-COVID symptoms like headache as “debilitating” and “as diverse as they are complicated.” In addition to impacting the lives of individual Americans, Sen. Markey explained, long COVID has a “huge impact” on health care systems and the workforce.



***“We can’t sit idly by.”***  
**U.S. Sen. Ed Markey**

Sen. Markey advocated for an “all-hands-on-deck approach,” outlining the steps that he and his colleagues in the U.S. Congress have already undertaken. Congress has appropriated more than \$1

billion for research on long COVID, Sen. Markey noted, adding that congressional leaders “are already seeing those funds being put into action.”

Additional congressional efforts include:

**The CARE for Long COVID Act**, which would improve research by compiling patient data and educating both patients and medical providers about long COVID. The bill, which Sen. Markey co-sponsored with Senator Tim Kaine (D-Va.) and Senator Tammy Duckworth (D-Ill.), would also help patients access needed social services and legal services.

**The TREAT Long COVID Act**, which would provide to \$2 million to treat and expand long-COVID clinics and would help prevent patients from being denied necessary services

“We need to get these critical bills passed this Congress,” Sen. Markey emphasized. “Our recovery is incomplete without truly understanding and addressing long COVID.”

# Panel Discussion



## Carrie Dougherty, MD

*MedStar Georgetown University Hospital Headache Center*

Neurologist Carrie Dougherty, MD, moderated a panel discussion on the experience and treatment of long-COVID headache, as well as policy efforts to further research and treatment.

Dr. Dougherty described the “enduring, persistent and unexplained symptoms” that some patients experience after acute COVID. “It’s not well understood,” Dr. Dougherty said of long-COVID headache. To the patients in the audience she added, “Providers are learning with you.”

Though research on long-COVID headache is ongoing, health care providers can support patients with personalized treatment and a listening ear. “Patients appreciate being able to be heard,” Dr. Dougherty remarked, “even if there aren’t answers – just hope, and validation that someone’s working to find them.”



## Matthew Robbins, MD

*Weill Cornell Medical Center*

Neurologist Matthew Robbins, MD, defined long-COVID as a condition in which symptoms begin within three months of an acute COVID infection and last for at least two months. The definition is broad, Dr. Robbins acknowledged, “showing how poorly we understand the disorder.”

Neurological symptoms including headache are common. “There’s not a day where we don’t see someone in our practice where COVID influenced their migraine,” Dr. Robbins reflected.

People with long-COVID headache may feel the onset of symptoms that just get “stuck,” Dr. Robbins explained. “There’s not the traditional start and stop of a migraine attack. With these symptoms, there can be no end.”

Co-morbid conditions like chronic fatigue syndrome and fibromyalgia make matters worse for some patients. And these challenges can be more pronounced for patients have been dealt a difficult hand in life, Dr. Robbins explained, highlighting the impact of social determinants of health.

Meanwhile, clinicians face challenges of their own. “We don’t know if traditional methods and treatments will work with these headaches,” Dr. Robbins noted. He cited the need for more research funding and encouraged patients with long-COVID headache to go to their doctor armed with as much detail as possible about their experience. Audience members noted that it is important for patients not to treat their long-COVID symptoms as an afterthought or a casual conversation at the end of an existing doctor appointment. Instead, patients should try to make time for a separate appointment to address long COVID with their provider.



## Marnie Russ

### *Patient Advocate*

For migraine advocate and former Senate staffer Marnie Russ, headache attacks began early in life. As a teen she was diagnosed with migraine disease. In her 20s, as attacks became more frequent, Marnie’s diagnosis advanced to chronic migraine.

To treat the attacks, which often included nausea and vomiting along with headache pain, “people just threw stuff at me to see what would stick,” Marnie recalled. Even effective treatments “would stop working after a while,” Marnie explained.

After a bout with COVID-19, Marnie’s headache experience changed. The regular migraine attacks were replaced by “a low-grade headache at all times,” Marnie said. “Long COVID is different,” Marnie reflected, adding, “I don’t know how to handle it - the devil I knew seemed to be better than the one I didn’t.”

“I’m taking [over-the-counter] meds, not regular migraine meds,” Marnie explained. “I lose my words a lot more than I ever have with migraine. I always worry that that makes me lose my credibility.”

Marnie noted that, for years, she revealed her migraine struggles only with family and close friends. Now, she said, talking about it helps.



## Samantha Koehler, MPH

*Senior Health Policy Advisor  
Office of U.S. Senator Tim Kaine*

U.S. Sen. Tim Kaine (D-Va.) has been open about his long-COVID journey, explained Samantha Koehler, the senator's senior health policy advisor. One symptom has lingered for three years after the senator's acute COVID infection: persistent tingling.

It took a while to recognize the symptom as long COVID, Samantha explained. But the experience ultimately prompted Sen. Kaine to champion the cause of long-COVID patients across the country. Sen. Kaine sponsored the CARE for Long COVID Act in 2022 and reintroduced the bill in March 2023 alongside Senators Ed Markey (D-Mass.) and Tammy Duckworth (D-Ill.). The legislation, which attracted 8 Senate co-sponsors, would ensure that people with long COVID have access to necessary services.

Sen. Kaine also hosted a summit in his home state of Virginia for health care providers to share experiences and best practices for treating long-COVID patients.

Samantha noted that Congress passed a funding bill that included \$10 million for translational research to put findings into practice for patients as soon as possible. Samantha said the senator hopes to build on these and other steps, including ongoing efforts by the Biden administration.



## Julienne Verdi

*Executive Director  
Alliance for Headache Disorders Advocacy*

Julienne Verdi closed the event by urging attendees to advocate for policy change. "When we join together and put a human face to issues the headache disorders community faces," Julienne said, "we can and will help patients get the relief and care they need and deserve."

# Policy Recommendations

Building upon the panel discussion of long COVID and headache disorders, the Alliance for Headache Disorders Advocacy's Headache on the Hill advocates now ask policymakers to:

- Co-sponsor and pass the 2023 CARE for Long COVID Act and ensure that the legislation specifically prioritizes research on migraine and other headache disorders caused or exacerbated by long COVID.
- Develop a new House Headache Caucus to prioritize the policy needs of Americans living with migraine disease and other headache disorders.

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](http://www.headachemigraineforum.org).





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advances public policies and practices that  
promote accelerated innovation and improved  
treatments for persons living with headache  
disorders and migraine disease.



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