

## **CDC's 22nd ME/CFS Stakeholder Engagement and Communication (SEC) Call**

**December 18, 2023, 3:00 p.m. ET**

**Christine Pearson:** Before we get to Dr. Unger's remarks, I'd like to share a short update on a CDC-wide initiative to improve the agency's website. As part of this project, CDC communicators and scientists are currently hard at work reviewing, updating, reorganizing pages on cdc-dot-gov. The goal is to create a more readable, user-friendly cdc.gov that meets our audiences' needs.

Now, a little about why our director's office created this initiative: First of all, CDC's entire website is huge (over 200,000 pages!) and hard to navigate. Some pages are duplicative or outdated. Our research shows web users can't find information they need, and they struggle to find the information they are looking for. With a fresh start, CDC can focus on improved communication for all of our audiences – whether the general public, partners, healthcare providers or state health departments.

We know CDC's MC/CFS site serves a need for the community and is imperative to help raise awareness about ME/CFS and the disruption it causes in the lives of people affected by it. We are dedicated to making sure the ME/CFS information is available for you, for healthcare providers and for people who may be diagnosed in the future. Rest assured, nearly all of the ME/CFS current content will continue to be available on the CDC website.

Some changes you can anticipate include:

- A more mobile-friendly layout
- Easier navigation
- Pages that are easier to read. You may notice shorter sentences, shorter paragraphs, more plain language, and less jargon.
  - Pages for healthcare providers will continue to use higher reading level language.
- Information from meetings held more than two years ago, and older Voice of the Patient features will be archived. This information will continue to be publicly available on an archive called CDC Stacks and a new archive website ([archive.cdc.gov](https://archive.cdc.gov)). This is a separate environment from CDC.gov where you can find all historically important information archived.

We will be re-designing the website through the end of March 2024, when CDC will be launching the new [cdc.gov](https://www.cdc.gov). We are excited about the new site. If you have questions on Clean Slate, you may ask them during the Q&A section of this call or by sending an email to our ME/CFS mailbox at [me-cfs-s-e-c@cdc.gov](mailto:me-cfs-s-e-c@cdc.gov).

Now we'll turn to over to Dr. Unger to start the program.

**Elizabeth Unger:** Thank you, Christine, for the important information about CDC's Clean Slate program to improve our online information. We look forward to continuing to work with you and other CDC communicators on this initiative.

Welcome everyone to the 22nd SEC call. To allow time for our speakers and the question and answer period, I will keep my remarks short, but I would like to share brief updates on some of our ME/CFS program activities.

We entered into a cooperative agreement with the CDC Foundation in December 2022 to launch an effort called the Infection-Initiated Chronic Conditions Understanding and Engagement Project, or ICUE for short. The project brings together patient partner groups and community-based organizations who are actively working to help people with ME/CFS, Long COVID, and other infection-associated chronic illnesses and to raise awareness of these conditions. The ICUE Project Team is made up of members of the CDC Foundation, the Long COVID Alliance, and Commonality, Inc. The project leaders include members of Solve ME, Dysautonomia International, the COVID-19 Longhailer Advocacy Project and the Patient-Led Research Collaborative.

In 2023, the ICUE project brought together more than 60 key partner organizations to identify and prioritize the community's needs and shared goals. The CDC Foundation worked with the Long COVID

Alliance and Commonality, Inc. to organize and host an ICUE Project national webinar titled “Opportunities for Action: Infection-Associated Chronic Conditions” on October 24, 2023. The webinar featured an overview of the priorities and goals identified during meetings with participating organizations this year and was attended by 375 attendees.

Prompted by the increased recognition of unexplained post-acute infection syndrome resulting from Long COVID, CDC launched a new web page in October titled, “Chronic Symptoms Following Infections.” This webpage gives an overview of the possible causes of chronic symptoms following acute infection and how they affect people. It briefly addresses talking with your healthcare provider about your symptoms and also touches on the disease agents that have been linked to chronic symptoms. There are many similarities in the post-acute infection symptoms and those experienced by people with ME/CFS. CDC’s experience with ME/CFS guided development of this new web page. CDC believes that by looking for similarities and differences between ME/CFS and chronic symptom syndromes that develop following a variety of known and unknown acute infections, we will be able to learn more about how often and why they occur, as well as how to diagnose and treat them.

CDC continues to partner with our collaborators on a variety of ME/CFS and Long COVID projects. We started with sharing our findings from various studies and projects our ME/CFS program supports. At the 2023 International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis conference, CDC and its partners collectively presented 5 abstracts and conducted 2 workshops. Two abstracts contained data from the multi-site clinical assessment of ME/CFS, or MCAM, to look at how often patients had co-morbidities, such as dysautonomia and Chronic Overlapping Pain Conditions (COPCs) like fibromyalgia, irritable bowel syndrome or chronic lower back pain, and how these co-morbid conditions affected patients. We found the NASA Lean Test and COMPASS-31 questionnaire were useful tools to identify orthostatic intolerance and other dysautonomia. These co-morbid conditions were

often present and were associated with worse symptoms and function in patients with ME/CFS. In addition, we shared early findings from several of our Long COVID projects, including an oral presentation titled “Addressing ME/CFS-like Symptoms in Long COVID patients” and another presentation titled, “ME/CFS-like illness among patients at three U.S. post-COVID clinics,” which discussed the overlap in clinical presentation between ME/CFS and post-COVID conditions.

For surveillance activities, we continue to partner with CDC’s National Center for Health Statistics to track ME/CFS and Long COVID through National Health Interview Survey. The September issue of NCHS’s Data Brief survey provided nationally representative prevalence estimates of Long COVID in adults and children. Using 2022 data from the National Health Interview Survey, we estimated that 6.9% of adults ever had Long COVID and 3.4% had Long COVID at the time of the interview. The prevalence rates were lower in children: 1.3% of children ever had Long COVID, and 0.5% of children had Long COVID at the time of interview. We also used 2021-2022 National Health Interview Survey data to track ME/CFS. The data brief report was just released in the December issue of NCHS Data Brief. Based on self-reported diagnosis by a healthcare provider, we estimate that 1.3% of adults had ME/CFS In 2021–2022. We will continue to use this survey to track ME/CFS in 2023 and 2024.

Now, I’ll turn to an update on our program’s educational activities. The newest online course introduced during the last SEC call launched on September 6, 2023. It is titled “ME/CFS Diagnosis and Management in the Age of COVID: Expert Insights” and will be available for continuing education credits for three years. The ME/CFS experts who participated include Drs. Anthony Komaroff and David Systrom from Harvard Medical School, and Dr. Lucinda Bateman from the Bateman Horne Center, an ME/CFS specialty clinic in Salt Lake City, Utah. The course is being promoted by WebMD, the National Association of School Nurses, and other partners through their member listservs and networks. CME certificate opportunities are available for one year. Through the seven online Medscape courses, we reached more than 120,000 learners, had 49,000 test takers, and issued about 40,000 certificates.

For a final update, I am tasked with making the bittersweet announcement that Dr. Jennifer Cope from CDC's Chronic Viral Diseases Branch has accepted a new position and promotion within CDC. We wish her well in her new role and thank her for time and service to CDC's ME/CFS program.

Now I would like to introduce Dr. Vicky Whittemore. Dr. Whittemore received a Bachelor of Science in zoology from Iowa State University and a Ph.D. in anatomy from the University of Minnesota Medical School. She did post-doctoral training at the University of California, Irvine, and at the Karolinska Institute. She was on the faculty of the University of Miami School of Medicine until 1994, when she began her work with non-profit organizations including the Tuberous Sclerosis Alliance, Genetic Alliance, Citizens United for Research in Epilepsy (CURE), and the National Coalition for Health Professional Education in Genetics. Dr. Whittemore joined the staff of the National Institute of Neurological Disorders and Stroke at the National Institutes of Health in August 2011. In this role at NIH, she oversees a grant portfolio focused on the underlying mechanisms of the epilepsies, including the genetic causes of the epilepsies, animal models, translational and clinical epilepsy studies, and Sudden Unexplained Death in Epilepsy, as well as grants on ME/CFS. She is well known as a leader in the Trans-NIH Working group as well as in the ME/CFS Research Roadmap project. Thank you so much, Vicky, for joining us today and for your leadership in bringing new researchers to the ME/CFS field.