

Thank you, Christine, for that introduction. Welcome all of you to the 20th SEC call!

I would like to begin with a celebration and recognition of the hours and years of work of many ME/CFS patient organizations and advocates that led to the update of the ICD-10-CM codes on October 1, 2022, to include a specific code for myalgic encephalomyelitis/chronic fatigue syndrome. Code G93.32 applies to “myalgic encephalomyelitis/chronic fatigue syndrome,” “chronic fatigue syndrome,” and “myalgic encephalomyelitis.” The update also directs coders to add the code U09.9 for post-COVID conditions, when appropriate, thus making it clearer when ME/CFS occurs following SARS-CoV-2 infection.

This enables clear documentation of ME/CFS in medical records. The new release also modifies the description of tabular listing code G93.3 to encompass both viral and non-viral causes. Even though there is a new code, it can't be used if providers don't know how to accurately diagnose. To make sure they can, we continue to focus our efforts on educational activities.

Now, I'll turn to updates on some of these educational activities. As of October 2022, we have partnered with Medscape to produce six online courses and one print supplement on ME/CFS. Through the online courses, we have reached over 110,000 learners, 45,170 test takers, and issued about 36,285 certificates. The spotlight online course titled, “A Fresh Look at ME/CFS: Diagnosis and Management of a Multi-symptom Illness,” and our webpage content is being promoted by WebMD, the National Association of School Nurses (NASN), and the Association of American Medical Colleges (AAMC) through their member listservs and networks. To promote the course to a wider audience, we worked with the Medscape team to publish a print supplement titled, “Update on the Clinical Evaluation and Care of Patients with

ME/CFS” in the July 2022 issue of Medscape’s partner journals: Family Practice News, Rheumatology News, and Internal Medicine News. We will renew the accreditation for the spotlight course for another year in December and have just issued a contract to Medscape for new spotlight course expected to launch January 2024.

As we shared during the last call, we partnered with WebMD to assess knowledge, attitudes, and beliefs about ME/CFS among the general public. The results were featured in an [new article and accompanying video](#) posted on the WebMD website in May 2022. [The video](#) includes interviews with a former nurse who is living with ME/CFS and with Dr. Valerie Montgomery-Rice, the Dean of the Morehouse School of Medicine, and highlight the challenges of getting care for ME/CFS, especially for women of color. The article and video webpage on WebMD-dot-com has attracted over 12,000 unique visitors. A shorter video was also posted on Medscape.org. The links to the article and videos can be found on CDC’s ME/CFS website. WebMD has been promoting the article and video through their Facebook ad, and those posts have a click-through rate of more than 10 percent. This far exceeds WebMD’s social media benchmarks of 2 percent click-through rates, which shows us there is public interest in learning more about ME/CFS. This work was also presented at the 2022 conference of the International Association for CFS and ME (IACFS/ME).

We continue to partner with the National Association of School Nurses (also called NASN) to not only collect information about ME/CFS in schoolchildren but also to educate school nurses about ME/CFS. The training curricula include three courses, a toolkit, and a manual to educate school nurses on the symptoms of ME/CFS and how to identify and refer students for diagnosis. To date, there have been about 22,000 school health professionals to

complete the training. As part of NASN's ME/CFS module, our Medical Officer Dr. Nanda Issa also recorded a webinar highlighting the similarities between ME/CFS and post-COVID conditions. School nurses anticipated the need to track and identify post-infectious symptoms in students as they returned to school after the summer break. They believe that the school-based active surveillance process for absenteeism and ME/CFS will be instrumental to track symptoms among students.

An overview of the School-Based Active Surveillance project can be found on our website under section called "CDC's ME/CFS Program". In brief, the first phase was completed in September 2021. We shared some preliminary work at the 2022 IACFS/ME conference and the manuscript was recently accepted for publication in the Journal of School Nursing. The title of the paper is "Chronic Absenteeism and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Nurse-Led Approach to Establish the School-Based Active Surveillance Process." The second phase of this project expands the work to more sites across 24 states over the next two years!

We continue to add to our publications based on findings from our multi-site clinical assessment of ME/CFS, or MCAM, study, which was closed in 2020. In previous calls, we mentioned two manuscripts in review by journals. The first, titled "Assessing Sleep and Pain among Adults with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Psychometric Evaluation of the PROMIS® Sleep and Pain Short Forms" has been published in the journal Quality of Life Research. The second manuscript, titled "Natural Killer Cytotoxicity in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Multi-site Clinical Assessment of ME/CFS (MCAM) Sub-study," is still in review. Other manuscripts in progress include one

describing cognitive dysfunction in people with ME/CFS, one describing the burden of multiple medical conditions in people with ME/CFS and one describing the differences among individuals with ME/CFS in different MCAM clinical sites. We expect to have at least three more of these manuscripts published next year.

Next, we'll turn to a discussion about our work and plans regarding Post-COVID Conditions, often called Long COVID. As you know, the similarities between ME/CFS and Long COVID offer a unique opportunity to study and gain a better understanding of chronic conditions that began after infection. We are leveraging interest and study of Long COVID to raise awareness of ME/CFS and related conditions among members of the healthcare community. Through our work on post-COVID conditions, we have successfully recruited several new experts to our branch. I'd now like to introduce one of our new members, Dr. Jennifer Cope. Dr. Cope is board certified in infectious diseases and a 2011 graduate of CDC's Epidemic Intelligence Service program. In 2013, she completed CDC's Preventive Medicine Residency and earned a Master of Public Health degree. She is a captain in the US Public Health Service and joined our branch after spending more than a decade working at CDC on waterborne diseases. She began working on post-COVID conditions in December 2020 as part of CDC's COVID-19 emergency response and will continue that work now with our branch.

Dr. Cope will finish our CDC updates and introduce our guest speaker, Dr. David System.

Thank you for the introduction, Dr. Unger. I am very pleased to have the opportunity to talk with you today. Since joining the branch in March, I have become thoroughly involved in the work examining the link between ME/CFS and Long COVID.

Last month, I was interviewed by Medscape about what providers should know about both ME/CFS and Long COVID, how to diagnose and manage these conditions, and ongoing areas of research. In the article, I provided an update to clinical audiences on the new-ICD-10 code we mentioned earlier that will aid in the diagnosis of ME/CFS. The article is available on the Medscape website, titled “ME/CFS and Long COVID: Q&A With the CDC's Dr. Jennifer Cope.”

Last September, we posted our 9th story in the Voice of the Patient web series, offering the first-hand account of a nurse who was diagnosed with ME/CFS following COVID illness. Over the past four years, these Voice of the Patient stories have had hundreds of thousands of views. They are also promoted through channels like the NASN’s Weekly Digest and one of CDC’s Twitter accounts.

In early Fall, our Branch entered into a cooperative agreement with the CDC Foundation to bring together patient advocacy groups and community-based organizations working to raise awareness and help people with Long COVID, ME/CFS and similar infection-related long-term illnesses. The Infection-Initiated Chronic Conditions Understanding and Engagement (or ICUE) Project aims to develop collaborations, tools, and strategies to address the concerns and challenges of people living with Long COVID, ME/CFS and similar conditions. The kickoff

meeting with patient advocacy groups and community-based organizations will be held in mid-December 2022.

Our work to empower primary care providers to manage the health of patients with complex post-infectious illness like Long COVID and ME/CFS continues through the Long COVID and Fatiguing Illness Recovery Program (or LC&FIRP). This program is a collaboration with the Family Health Centers of San Diego, the ECHO Institute at the University of New Mexico, the University of Washington Post-COVID Rehabilitation and Recovery Clinic, and the Western Regional Public Health Training Centers at the University of Colorado. The monthly ECHO webinar series from this program offers didactic presentations by subject matter experts in Long COVID, on topics such as the History of ME/CFS and Disability and Post-COVID Conditions. The webinar series includes an expert panel with patients who have lived with these conditions and caregivers of those who have ME/CFS or Long COVID. This year, we have held 11 monthly webinar sessions averaging over 400 attendees per session. The next monthly webinar will be on December 8. We encourage patients with ME/CFS or Long COVID to participate. Information on upcoming webinars can be found online by searching LC-ampersand-FIRP and the ECHO Project (spelled E-C-H-O).

Additional information on CDC's studies of post-COVID conditions can be found on CDC's post-COVID conditions webpages.

If you have suggestions for speakers or ideas for other topics for the upcoming SEC calls, please e-mail us at mecfssec@cdc.gov. This address can also be used if you'd like to be added to our e-mail notifications about upcoming calls.

Now, I would like to introduce our guest speaker, Dr. David Systrom. Dr. Systrom is a member of the pulmonary and critical care staff at Brigham and Women's Hospital and an Assistant Professor of Medicine at Harvard Medical School. In early 2022, Dr. Systrom became co-director of the newly named Ronald G. Tompkins Harvard ME/CFS Collaboration at the Harvard Affiliated Hospitals. He received his medical degree from the Geisel School of Medicine at Dartmouth, completed his residency in internal medicine at the Emory University School of Medicine, and a fellowship in internal medicine at Massachusetts General Hospital. Dr. Systrom is the principal investigator of an ongoing \$8 million study of limb skeletal muscle mitochondrial dysfunction in ME/CFS and just completed the first randomized clinical trial of pyridostigmine for treatment of ME/CFS.

His presentation today is titled, "Neurovascular Dysregulation Underlies Exercise Intolerance in ME/CFS." Welcome, Dr. Systrom.