

## SEC Call December 4, 2024

Dr. Elizabeth Unger: Thank you very much, Christine, for that introduction, and welcome everybody to the CDC's 24<sup>th</sup> SEC call. I would like to start the call by letting you know of a couple staff changes within the Chronic Viral Diseases Branch. First, we were sad to say farewell to Dr. Jeanne Bertolli who retired from CDC on November 30<sup>th</sup>. We are grateful for her strategic planning and dedication to the ME/CFS program and our branch. At the same time, I would like to welcome Joanna Regan, as our new medical officer and team lead working on ME/CFS. Joanna is trained as a pediatrician and also has a master's in public health. She came to work at CDC in 2009 in the Rickettsial Zoonoses Branch as a medical officer. Her past work at CDC has included investigations on an outbreak of Rocky Mountain spotted fever, and on Ebola and Middle East Respiratory Syndrome. She has worked with health departments and traveled to more than 20 countries for CDC. We are excited to have Joanna as part of CDC's ME/CFS program.

Our program is continuing outreach and education activities for healthcare professionals and the general public. As mentioned in our last SEC call, during planning for International ME/CFS Awareness activities with MEAction Georgia, we arranged for an educational session with nursing students in conjunction with the Emory School of Nursing. We planned this in recognition of the important role nurses play in the care of people with ME/CFS. This session occurred on September 18<sup>th</sup> in the Emory School of Nursing building. The event was titled "ME/CFS Voice of the Patient: A Panel Presentation with #MEAction Georgia." The session included a brief overview of ME/CFS diagnosis and epidemiology followed by presentations from a patient with ME/CFS and two family members of people with ME/CFS who shared their personal experience in living with this illness. Each panelist used photos and stories that showed how living with ME/CFS has impacted their daily lives as well as those of their family and friends. It is recognized that patient stories are so much more meaningful and understandable to students than the impersonal clinical description of illness provided in textbooks. We are grateful to members of #MEAction Georgia for their support and the panelists' willingness to

spend their time and energy to provide this memorable education experience for students. We also appreciate the Emory University School of Nursing for hosting this event.

Over the past year, we have been working with the NIH-funded ME/CFS Data Coordinating Center at Research Triangle Institute to make the baseline data and biospecimens from the adult cohort of the Multi-site Clinical Assessment of ME/CFS study (which is abbreviated as MCAM) available to the research community to test their ideas about ME/CFS without the need to collect additional materials. This should allow studies to be completed more rapidly and with less cost. We are thrilled to announce that an extensive collection of more than 70 datasets and biospecimens from MCAM are now accessible through the websites mapMECFS and searchMECFS, respectively. Applications for data use and biospecimens are approved through data use agreements.

In addition to making MCAM data available more broadly through the websites I just mentioned, our group also continues to publish information from the MCAM study. Since our last call in May, we published “Chronic Overlapping Pain Conditions in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Sample from the Multi-Site Clinical Assessment of ME/CFS (MCAM) Study,” and “Cognitive Assessment in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Cognitive Sub-study of the Multi-Site Clinical Assessment of ME/CFS (MCAM).” Briefly, we report in these two publications that more than 75% of people with ME/CFS had at least one of the following chronic overlapping pain conditions: chronic low back pain, chronic migraines or headaches, fibromyalgia, interstitial cystitis or irritable bowel syndrome, or temporomandibular disorder. The people with ME/CFS who had these pain conditions had significantly poorer quality of life compare with those who did not. In the cognitive study, we found processing speed was significantly lower for people with ME/CFS when compared to healthy controls. We also found that the challenges associated with a clinic visit that includes cognitive testing worsened processing speed to the same extent as exercise testing.

Now, I'd like to shift to telling you a little about other projects our ME/CFS group is working on. We have moved into the third yearly contract with the National Association of School Nurses, or

NASN, as it's abbreviated. As a reminder or for those who may not be familiar with this project, CDC and NASN work together to collect information about ME/CFS among school children with chronic absences. To do this, NASN trained school nurses to recognize ME/CFS symptoms and help children and their families find appropriate medical resources to evaluate whether the children might have ME/CFS. Through the partnership with NASN, we have reached more than 40,000 school nurses with educational material designed to increase awareness and understanding of ME/CFS. Of these, 11,000 school nurses completed the educational activity, Nursing Continuing Professional Development (NCPD) courses on ME/CFS, during the past year. Additionally, we have tracked absences for over 15,000 students, identifying that approximately 3% were due to ME/CFS-related symptoms. In October, we began the next phase and aim to expand our data collection efforts across eight more states. This step will allow us to contribute even more significantly to the body of knowledge regarding ME/CFS among school-aged populations and hopefully guide the development of school accommodation interventions to help students experiencing health-related academic challenges.

In October, we wrapped up our partnership project, “Infection-Associated Chronic Conditions—Understanding and Engagement,” also known as ICUE. The last webinar of the ICUE project, “Uniting Voices, Amplifying Impact” was held on Friday, October 11, and attracted 144 participants. CVDB funded the CDC Foundation to implement the ICUE project in December 2022 and aimed to bring together patient advocacy groups and community-based organizations focused on raising awareness and helping people living with infection-associated chronic conditions to identify common objectives and opportunities to collaborate. The CDC Foundation’s lead partner organizations, Solve M.E., the COVID-19 Longhailer Advocacy Project, and the Patient-Led Research Collaborative hosted the final webinar, with logistical assistance from the group Commonality, Incorporated. At the webinar, speakers discussed the findings from the project, and about how interested organizations and individuals can contribute to and benefit from working together to increase awareness of infection-associated chronic conditions, support patients, and inform research.

During previous SEC calls, we've mentioned our collaboration with the Emerging Infections Program in California and Kaiser Permanente Northern California. This is the STOP ME/CFS project, standing for Surveillance To Optimize Protocols for early identification and subgrouping of ME/CFS. Recently, the STOP ME/CFS investigators have been exploring the relationship between COVID-19 and ME/CFS. They surveyed 9,825 patients in the Kaiser Permanente of Northern California health plan about their symptoms and their COVID-19 history, casting a wide net to find people who might have symptoms that fit the definition of ME/CFS but had not been diagnosed. In September, findings from this work were published in the PLOS ONE journal. Overall, the researchers estimated that 1.67%, or 45,892, of 2.7 million adult KPNC members of the Kaiser plan in Northern California had ME/CFS-like syndrome during the study period, which was July to October 2022. Of those, 14% developed the illness after COVID-19. The patients whose ME/CFS-like syndrome began after COVID-19 were more likely to be unvaccinated against COVID-19 and to have had COVID-19 before June 2021. We can't yet say how much COVID added to the overall incidence of ME/CFS. As part of the next stages of our study we expect to learn more about the interplay of these conditions.

We are also continuing our work to educate primary care providers about Long COVID, ME/CFS and other post-acute infection syndromes through the Long COVID and Fatiguing Illness Recovery Program. This project is a collaboration with one of the largest federally qualified health centers, the Family Health Centers of San Diego, along with the ECHO Institute at the University of New Mexico, and the Schools of Medicine at the University of Washington, and the University of Colorado. In this third year of the program, our collaborators have continued to host monthly webinars for continuing medical education credit. From the program's inception, the webinars have included presentations and discussion by both medical and lived experience experts (meaning either a patient or patient caregiver). In the past 6 months, webinars have covered recent research findings and other topics such as the diagnosis of post-exertional malaise and Long COVID Patient Navigation. Beginning November 7, the program expanded the opportunity to enroll in monthly case-consultation and mentoring through the ECHO online platform to primary care clinicians nationwide. On November 14, the program's 10th online short course for CME credit, called "Long COVID in Children and Adolescents," was posted.

Finally, in early November, we published a paper resulting from the COVID-RELIEF Project, our collaboration with the University of Washington, in BMC Infectious Diseases. The paper describes quality of life impairments and subjective cognitive decline associated with Long COVID two or more years after the patients' initial SARS-CoV-2 infection. Clinically significant cognitive complaints, fatigue, and pain were present even in those who reported they had recovered from Long COVID. These findings are important to document because of their implications for peoples' participation in work, education, and social activities.

Before I turn the call over to our guest speaker, I'd like to remind you that if you have suggestions for speakers or ideas for other topics for upcoming SEC calls, please email us at [mecfssec.gov](mailto:mecfssec.gov). This address can also be used if you'd like to be added to our email notifications about upcoming calls. And finally, just a note that the transcript of the entire SEC call will be posted on our website as soon as we can.

Now I'd like to introduce our guest speaker. Dr. Satish Raj is a Heart Rhythm Cardiologist. He completed his internal medicine and cardiology training at Queen's University, and then further trained in cardiac electrophysiology at the University of Calgary. He then spent 12 years working at the Vanderbilt Autonomic Dysfunction Center in Nashville, Tennessee. He is currently Professor of Cardiac Science at the Libin Cardiovascular Institute and the University of Calgary's Cumming School of Medicine and founder of the Calgary Autonomic Investigation & Management Clinic. His primary research interests relate to understanding and better treating postural tachycardia syndrome (POTS), vasovagal syncope, and orthostatic hypotension. He is conducting studies into the role of autoantibodies and inflammation in POTS and understanding the "brain fog" of POTS. He is also looking at repurposing drugs in novel ways to treat vasovagal syncope and orthostatic hypotension. Welcome, Dr. Raj.