

CDC's 23rd ME/CFS Stakeholder Engagement and Communication (SEC) Call

May 6, 2024, 3 p.m. ET

Dr. Beth Unger: Thank you, Christine, for that introduction. And welcome everyone to the 23rd SEC call. As we approach ME/CFS International Awareness Day on May 12th, I would like to begin by recognizing the millions of people battling ME/CFS, as well as their loved ones, caregivers, patient organizations, and advocates.

To begin CDC's recognition of this year's ME/CFS Awareness week, our ME/CFS program will once again participate in a CDC Light Up event. During these events, CDC illuminates its visitor center - one of its most prominent buildings - to bring attention and awareness to the impact of a disease or other public health issue. In this case, we are lighting up the building blue in honor of all people with ME/CFS - both diagnosed and undiagnosed. Tonight, we will be joined by members of the Georgia chapter of MEAction and their caregivers at the CDC campus for the light up. The blue lights will be on each night through May 12. The sign at CDC's main entrance on Clifton Road will also announce CDC's recognition of ME/CFS Awareness. We have additional activities planned. Each day, we will post a new social media message on X and, on May 12, CDC Facebook will post a message in honor of ME/CFS Awareness Day. The ME/CFS program posts a CDC ME/CFS Awareness Day webpage every year in support of Awareness week, and it was just posted. It can be found at www.cdc.gov/me-cfs. On this webpage, visitors can read about ME/CFS Awareness Day activities.

We would like to share that MEAction Georgia will be presenting the first Wilhelmina Jenkins ME/CFS Service Award to journalist Ryan Prior and Emory University physician Tiffany Walker at

a panel discussion and award ceremony being held May 8. The award honors Georgians who have made a significant difference in the lives of people with ME/CFS. I look forward to attending this event and honoring the recipients. Finally, we are excited to recognize Jaime Seltzer, Scientific Director for MEAction. She was just honored by Time Magazine as one of the Time 100 health award winners. Jaime is being recognized as one of the most influential people in health in 2024 for her work with ME/CFS and infection associated chronic illness.

Congratulations Jaime from all of us! We appreciate your work and dedication to the field!

Now, I'll turn to sharing updates on our program's work since the last SEC call. I'd like to start our updates by highlighting a recent publication from the Multi-site Clinical Assessment of ME/CFS study. The study was published in the Journal of Clinical Medicine and is titled, "Heterogeneity in Measures of Illness among Patients with ME/CFS Is Not Explained by Clinical Practice." It addresses whether the clinical characteristics of patients with ME/CFS differed by the clinical setting and medical specialty background of healthcare providers. Seven specialty clinics led by healthcare providers who are experienced in diagnosing and caring for patients with ME/CFS recruited participants. Standardized questionnaires were used to evaluate ME/CFS symptoms. We found the symptom profiles of patients did not differ between clinics. However, patients in each clinic showed a large range in the frequency and severity of all symptoms. The conclusion is that patients with ME/CFS differ due to the large number of symptoms and range of severity. The patient differences indicate that subgrouping on standardized measures of illness characteristics could bring more consistency to findings across studies.

Our program is continuing outreach and education activities for healthcare professionals and the general public. One of these projects was the posting of two videos from our collaboration

with WebMD. During, the past year, these videos reached more than 28,000 members of the public and 300 physicians. The videos highlight how knowledge, attitudes, and beliefs about ME/CFS can affect patients and healthcare providers. The videos can still be viewed at Medscape and WebMD. Based on what we learned from this project, some questions were adapted and included in CDC's rapid survey for evaluating the public's knowledge of and attitudes toward Long COVID. Data from the first round of that survey were released in February and provided some meaningful insights. For instance, we found that 32% of adults have never heard of Long COVID, and among those who had heard about Long COVID, 82% at least somewhat agree that Long COVID is a real illness.

As noted in prior calls, our branch is funding the program called Infection-Associated Chronic Conditions Understanding and Engagement (abbreviated to ICUE), which is a partnership between the CDC Foundation and patient and community-based partner organizations. A short public report based on the first year of the ICUE project work was published in February. This report summarizes opportunities for collaboration among the participating organizations, including promoting comprehensive research, enhancing patient and caregiver quality of life, advancing public awareness of infection-associated chronic conditions, identifying health care needs and gaps, and supporting clinician education. Additional information about the ICUE project, along with the report, can be accessed on the CDC Foundation web page. (And I should mention that when we post the transcript of this call, we will also include hyperlinks to this and other resources to make it easy for you to find them if you want to).

We continue to partner with the National Association of School Nurses (or NASN as it's abbreviated), not only to collect information about ME/CFS in school children, but also to train

school nurses to recognize ME/CFS symptoms and help children with possible ME/CFS and their families find appropriate medical resources. There are currently 30 schools across 9 states participating in Phase 2 of the School-Based Active Surveillance project. During the 2021 to 2023 school years, a total of 139,440 students at these 30 schools had chronic absenteeism. Preliminary school-level data showed that among absences due to health concerns, 3.24% were due to symptoms that can be found in ME/CFS. Also, in collaboration with NASN we have submitted questions about ME/CFS for the National Examination for School Nurses Certification. The National Board of Certification for School Nurses Examination Committee will consider whether to add these questions to the exam given to all school nurses before they receive their certification. We are also continuing our work on the Long COVID and Fatiguing Illness Recovery Program, or LC&FIRP, 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 University of Colorado School of Medicine. As you may remember, this project is aimed at empowering primary care providers to manage the health of patients with complex post-infectious illness like Long COVID and ME/CFS. On March 14, 2024, the LC&FIRP team hosted a webinar on “Patient Resources and Support.” The speaker was patient advocate Alison Sbrana, who was a member of the board of Body Politic before the group disbanded. Webinars are available on-line through the ECHO institute’s online software platform, which is called iECHO platform.

In the last SEC Call, Christine Pearson from our division’s communications group described CDC’s Clean Slate project to update and streamline the CDC’s website. Our program continues to work closely with CDC communicators on this project and the relaunched cdc.gov website is

expected to go live on May 15. We think the public will find the new website easier to use – especially on mobile devices.

In April, I had the pleasure of participating in the first International Conference on Clinical and Scientific Advances in ME/CFS and Long COVID, which was held in Portugal. The conference was organized by ME/CFS and Long COVID lived experience experts to address the critical need to educate healthcare providers about these conditions. Many well-known researchers and clinical experts presented in person or virtually via the internet. I presented on CDC’s public health approach to these conditions and there was interest in leveraging CDC’s educational materials for use in Portugal and Brazil. The organizing committee is continuing its strategic campaign to raise awareness and improve clinical care in Portuguese- speaking countries.

I am excited to announce that, on September 18, Emory University School of Nursing will be hosting a panel with CDC and MEAction Georgia. The panel event is called “ME/CFS – Voice of the Patient” and will feature volunteer ME/CFS lived-experience experts who will be telling their stories. The event will take place at Emory’s School of Nursing, located at 1520 Clifton Road.

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 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. 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 would like to introduce our guest speakers. Our first speaker will be Dr. Brian T. Walitt. Dr. Walitt has been collaborating with the National Institutes of Neurological disorders and

Stroke (NINDS) as a clinician with National Institutes of Nursing Research (NINR) since the launch of the National Institutes of Health (NIH) Director's Initiative study of ME/CFS in 2016. He officially joined the NINDS Clinical Neurosciences Program as a staff clinician in 2021. Dr. Walitt earned his M.D. degree from the State University of New York Health Science Center at Syracuse and a master's degree in public health at George Washington University. His research protocols focus on deep phenotyping people whose symptoms develop after exposures, such as infection. Currently, he is working with patients with ME/CFS, Gulf War Illness, and Post-Acute Sequelae of SARS-CoV-2 infection.

Our second speaker will be Dr. Avi Nath. Dr. Nath is the Clinical Director and Senior Investigator with National Institutes of Neurological disorders and Stroke (NINDS). Dr. Nath earned his M.D. degree from Christian Medical College in India in 1981. He joined NIH in 2011 as the clinical director of NINDS, the director of the Translational Neuroscience Center and chief of the Section of Infections of the Nervous System. His research focuses on understanding how retroviral infections affect the brain and on developing methods to diagnose and treat these illnesses. He applied his expertise in the interaction of infections with the nervous system to understanding ME/CFS and other post-acute infection syndromes. Today's presentation will focus on "Deep Phenotyping of Post-Infection Syndromes and the Way Forward". Welcome Drs. Walitt and Nath.