Thank you. And I'd like to welcome you all to the 18th Stakeholder Engagement and Communication (SEC) call, CDC's forum for regular communication with the ME/CFS community. I will present updates on some of CDC's ME/CFS activities and then Dr. Hector Bonilla will share his presentation. We would like to extend a warm welcome to Dr. Bonilla and thank him for taking the time to share his experience working with ME/CFS patients.

If you have suggestions for speakers or topics for future meetings, please email us at mecfssec@cdc.gov. This is also the address to use if you would like to be added to email notifications about upcoming calls.

Now moving on to updates. The CDC ME/CFS program recently held the third Roundtable meeting in mid-October focused on encouraging partnerships and collaboration, titled "Working Better Together." While prior Roundtables were held in-person, this one was held virtually due to COVID restrictions. Our contractor, McKing, was able to use the Zoom platform for plenary sessions and created breakout sessions to allow small group discussions. They also created an informal networking session to give participants a chance to get to know each other a bit. We appreciated everyone's flexibility in adapting to the new format, and hope that future sessions will once again allow us to meet in person. In preparation for the roundtable meeting McKing held small group phone calls with members of the ME/CFS community to get their feedback on partnership experience and their ideas for discussion. Based on this feedback the meeting focused on three topics: Healthcare Workforce Education, Surveillance and Expanding the Science, and Awareness and Stigma. Over the course of two afternoons, roundtable participants heard presentations from patient organizations, healthcare providers, professional organizations, and federal and state agencies. On the first day, Division Deputy Director Jennifer McQuiston welcomed meeting attendees and I gave a presentation providing an overview of work being done by the CDC ME/CFS program. Tim McCleod, Senior Policy Analyst, and

Donovan Newton, Associate Director for Policy presented information to help meeting participants understand ways in which CDC can have successful partnerships while adhering to policy rules and guidelines.

Presentations on successful partnerships from other areas of CDC rounded out day one. Judith Griffith of HIV Prevention, Wendy Ruben from Birth Defects and Developmental Disabilities, and Michele Walsh from Population Health, all provided insights into how successful partnerships have worked for their CDC programs.

The second day of the Roundtable consisted of virtual breakout groups divided by the three topic areas. McKing asked attendees to rank their preference of topics and then they were split into groups. As a "floater" I was able to pop into each of the breakout groups and I found the ideas and suggestions interesting and helpful to envisioning future partnership activities. The meeting concluded with a summary of ideas from each breakout group and potential projects. Information about this Roundtable meeting including the agenda, participants, and presentations have been posted to our website. We expect the summary report to be finalized and posted at the beginning of next year.

As we have discussed before, the overlap between ME/CFS and post-COVID conditions, referred to as Long COVID by many of those affected, creates an opportunity to better understand both conditions and to increase awareness among healthcare providers. We are supporting two studies that will follow people who had COVID-19, including those who have long-term symptoms and those who fully recovered, to better understand the illness. The first study, COVID: Understanding the Post-viral Phase (COVID-UPP), will enroll participants three to six months following their initial COVID diagnosis. It will follow patients who continue to have fatigue and other symptoms and a comparison group who have fully recovered, using online surveys to gather information about their health for

three years to describe the course of illness over time. A subset of participants will be invited for in-depth clinical and laboratory testing that will allow comparisons to ME/CFS.

Another study, "Research on COVID-19 Long-Term Effects and Risk Factors（COVID-RELIEF)," will use electronic health records to investigate conditions and characteristics that increase the chance that a person will have a severe COVID infection or an infection that leads to long-term illness. A subset of patients will be invited to participate in a biomarker study that includes an interview and laboratory testing.   We expect the results will help identify risk factors for persistent illness and may identify approaches for early intervention to improve recovery.

CDC supports a modeling project that will estimate the number of people in the United States with post COVID-19 conditions, and an implementation research project with a federally qualified health center to build the capacity of primary care physicians to care for patients with post-COVID conditions, ME/CFS and other post-infectious syndromes.

In previous calls, we've mentioned our new 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. Most patients with ME/CFS are diagnosed after experiencing symptoms for many years, so identifying individuals much closer to the time of illness onset is a key priority. The first phase of this project is almost finished and involves a retrospective look at Kaiser medical records to develop an algorithm to identify patients with prolonged fatigue who are most likely to be diagnosed with ME/CFS.   In phase 2 the algorithm will be used to enroll a prospective cohort of patients. We will sample adults in 4 study groups: 1) Patients diagnosed with ME/CFS; 2) Patients identified by algorithm as high risk for ME/CFS; 3) Patients identified as moderate or low risk for ME/CFS; and 4) Patients with prior COVID-19. Data will be collected through a self-administered electronic survey at baseline and then at 1 year and will be

compared among the groups.   Following up on people at elevated risk of ME/CFS will allow us to describe the onset and early course of illness for ME/CFS. Including people with a history of COVID will allow investigation of the occurrence of ME/CFS after COVID, and comparison of long-term COVID symptoms with ME/CFS symptoms in people who do not have a history of COVID. The protocol for Phase 2 is under review by Kaiser's Institutional Review Board. We expect to start in early 2022!

We have also continued to expand our healthcare provider educational offerings. Currently three continuing education courses are available through Medscape and a new Spotlight course has completed filming via Zoom platform. The expert faculty included the moderator Dr. Benjamin Natelson, from Icahn School of Medicine at Mount Sinai, and panelists Dr. Donna Felsenstein, from Harvard Medical School; Dr. Mitchell Miglis, from Stanford University; and Dr. Dale Strasser, from Emory University. The course title is "A Fresh Look at ME/CFS: Diagnosis and Management of a Multisystem Illness." We anticipate having this course launched in early 2022.

For educating medical students, we continue to expand our work from the Standard Patient (or SP) learning and training program which has been published in the Journal of Translation Behavioral Medicine and MedEd Portal. The SP project is a vital tool for educating medical students and residents on ME/CFS. We have produced 6 videos and published one of them in MedEd Portal. Currently, we are working with Dr. Howard Selinger of Quinnipiac University to evaluate a pediatric ME/CFS module. This module consists of a video and slide presentation. Medical students at Quinnipiac University will view this module session and complete pre- and post-session testing to assess learning. When the testing is complete, we plan to publish the findings and disseminate the education module.

Also related to pediatric ME/CFS, the Phase 2 contract for school-based active surveillance has been awarded to the National Association of School Nurses. The kick-off meeting was held late this summer. Phase 2 will build upon prior work and expand our reach to include more schools in at least 10

states. Data will be collected on ME/CFS, post-COVID conditions, chronic absenteeism, and student health. Through this partnership project, we will also educate school nurses who could raise awareness of the illness and provide guidance on how to identify students with ME/CFS symptoms. Nurses can help students manage the illness and be successful in school.

Since the Multi-site Clinical Assessment of ME/CFS (MCAM) study was closed out in 2020, we have been working on five manuscripts for publication. Two of them are currently in review by journals: the first paper focused on the work Dr. Dane Cook presented in our May SEC Call, the response to exercise. The second paper assesses orthostatic intolerance using a tool called the NASA lean test. In later stages of the MCAM, all sites began using the 10-Minute NASA Lean Test, a clinical tool shared with the group by Dr. Benjamin Natelson. He has been using this clinical tool for decades; one benefit of the tool is that it collects a measurement called end Tidal CO_2 which allows for identifying reduced carbon dioxide levels in the blood. Other papers in progress include one for cognition testing presented at the recent IACFS/ME meeting, one describing the differences among patients with ME/CFS in MCAM clinical sites, and one describing the association of Natural Killer cell function with other measures of ME/CFS illness. We continue to work on a paper reporting on the use of PROMIS measures of sleep and pain to describe the experiences of people living with ME/CFS. We expect to have at least three of these manuscripts published next year.

We also continue to add new content to our website. There are ongoing efforts to provide more Spanish translations to our existing content. In August we posted our Patient and Healthcare Provider toolkits for both ME/CFS and Post COVID-19 Conditions in Spanish.

The Voice of the Patient segment featured on our website continues to grow with first-hand accounts of the disease from people living with ME/CFS. Our most recent post is from the perspective of a mother and son both living with ME/CFS. Over the past three years, The Voice of the Patient segment

has garnered nearly 300,000 webpage views. We are working on a new post which should be on the website by the end of the year.

Finally, I would like to update you on the report of the systematic review of evidence related to the management of ME/CFS. As you likely remember, we undertook the systematic review as the first step in what we hoped would lead to the development of comprehensive ME/CFS treatment guidelines. We are committed to advancing the research and supporting the ME/CFS community however we can and recognize that improving clinical care remains a critical issue. However, after assessing the systematic review, we've decided that there is not enough evidence to move forward with treatment recommendations at this time. In the interest of transparency, we will be posting the final report, comments and responses on our ME/CFS website. We will not be publishing the systematic review in a peer reviewed journal. I want to note that, with the posting of the systematic review, we are not endorsing specific studies. But we do want the information to be available should others in the ME/CFS field undertake a review of the literature in the future. We continue to provide other resources that clinicians can refer to, such as a link to the ME/CFS Clinician Coalition website and the IACFS Primer. We will also be adding a link to the United Kingdom NICE guidelines (National Institute for Health and Care Excellence) published the end of October 2021.

Now I would like to introduce our guest speaker. Dr. Hector Bonilla is a Clinical Associate Professor of Infectious Diseases with Stanford University Medical Center. Dr. Bonilla received his medical degree from the Universidad del Valle School of Medicine in Cali, Colombia. After completing his residency at Sinai Hospital of Detroit, he moved to the University of Michigan where he completed a fellowship in infectious diseases. He spent much of his early career in Clinical Management of HIV/AIDS and Hepatitis C at Louisiana State University. In 2018 he received the Ramsay Award from Solve ME/CFS Initiative for his work on a genetics project encompassing ME/CFS and the herpes virus.

Welcome, Dr. Bonilla.