

Transcript for the 11th CDC Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Stakeholder Engagement and Communication (SEC) Conference Call

May 10, 2018

3:00 pm CT

Dr. Dana Brimmer

Our guest presentation today is entitled “ME/CFS, The Invisible Disease and its Educational Implications for Young People,” by Dr. Faith Newton. Before Dr. Newton begins, we're going to hear from Dr. Elizabeth Unger, the Chief of the Chronic Viral Diseases Branch at CDC. She will provide updates about CDC's ME/CFS Program. After Dr. Unger and our guest speaker finish, we will answer questions submitted via email. I will first read the questions aloud and then our speakers will answer each one.

Before we start, I need to read a disclaimer. These calls are open to the public. Please exercise discretion when sharing sensitive content and material as confidentiality during these calls or items submitted via email cannot be guaranteed. Today's call is being recorded by CDC and transcripts will be made available at a later date on CDC's website.

The views of non-CDC presenters expressed during this conference call are their own and do not necessarily represent the views of the US Department of Health and Human Services or the Centers for Disease Control and Prevention. I would now like to ask Dr. Unger start the call. Welcome Dr. Unger.

Dr. Elizabeth Unger

Thank you very much, Dana. And welcome to everybody on the call. Just to emphasize a little more about what Dana told you, I want to remind you that the reason that we set these calls up was to have a regular forum where we could communicate with the ME/CFS community about CDC's activity.

But most importantly to have a forum where experts external to CDC could share information on their work related to ME CFS. The process we use is that we identify a topic for each call. And sometimes this is based on suggestions that we receive in the mailbox, so please do send them in.

We then invite speakers based on their expertise and availability. The participating speakers prepare their talks independently and present their own views. And therefore they do not represent CDC's official position.

Most importantly, we really thank our speakers because they've all volunteered their time and we really appreciate their participation. Because the main goal of our call is to allow our guest presenters to share their information with the community, we've not set up our call lines to allow individual participants to ask their own questions.

And we do apologize that we can only answer a few questions each time. We do try to keep the phrasing as much as the questions were submitted, but sometimes -- in order to get as many questions in as possible -- they may be shortened. And I apologize if this is not always phrased the way you had hoped.

So now I'm going to shift to give you an update on some of CDC's activities. And I'd like to start with our surveillance initiatives through state health departments. It would be really great to know how many cases of ME/CFS there are in the US. That is to say, we would like to know the prevalence of ME/CFS.

And one way that we could get this information on a regular basis is to rely on the participants to self-report information about their diagnosis. This is an efficient method that's useful in following trends. And if we could add these questions to surveys that are already in place, it would further reduce the cost.

CDC's Behavioral Risk Factor Surveillance System—known as BRFSS—was established in 1985 with 15 states participating. It's expanded since that time and now includes all 50 states. Adding questions about ME/CFS into BRFSS would allow information about ME/CFS to be gathered at a state level basis. In addition, the health, activity, dietary, and other behavioral information already collected in the survey could be studied in relationship to this illness.

The state health departments that collaborate with CDC in this activity though determine which questions appear on the survey and you can imagine this is a very competitive process. Core questions are used in all states. And then, there are optional sets of questions called modules that states can choose to use. And finally, states can decide to simply add questions, and these are called State Added Questions.

When our program first asked states to include ME/CFS questions, the module unfortunately did not receive enough votes to be included as an option module. However, five states—Alabama, Connecticut, Kansas, Nebraska, and North Carolina—added these ME/CFS questions to their 2014 BRFSS survey. Three states—Alabama, Kansas, and North Carolina—continued to include these questions in the 2016 survey.

The ME/CFS questions are, “Have you ever been told by a doctor or other health professional that you had Chronic Fatigue Syndrome, CFS, or Myalgic Encephalomyelitis, ME?” And if the response is yes, the second question is, “Do you still have Chronic Fatigue Syndrome, CFS, or Myalgic Encephalomyelitis, ME?”

We are very grateful to the states who added these questions. The ability to find out about the number of patients—persons with ME/CFS—on a state-by-state basis really brings home the message about the burden of

this illness in each state. We will present preliminary results of the BRFSS findings at the 2018 Council of State and Territorial Epidemiologists Conference that's occurring in June in Florida.

This past April we once again presented our proposal for ME/CFS questions at the BRFSS Training Workshop. Many of you had reached out to your state health departments to emphasize the importance of including ME/CFS in BRFSS. We thank each of you. And in particular Dr. Lily Chu and ME Action for their coordination of the call to action “Urge Your State Health Departments” to Track ME.

With your outreach, many state representatives had been already made aware of the need for these questions prior to the BRFSS conference. And so we are really excited to share the great news that the ME/CFS questions have been approved as a new optional module for the 2019 BRFSS Survey. We will continue to update you on the progress in future SEC calls.

I'm now going to shift gears to talk about our round table stakeholder engagement. In 2016, we began a process for broad stakeholder input into how to best use the CDC website to communicate the 2015 Institute of Medicine recommendations on diagnosing ME/CFS.

One of the strengths of the round table meeting was that it provided an opportunity for direct communication between stakeholders with different points of view. We involved medical professional groups to make it more likely that they would share ME/CFS information with their members. And because of the success we continued the process for another year. This time the focus is on determining the kinds of ME/CFS educational materials and formats that are most useful to health care providers.

The round table will also provide advice on how to reach more clinicians with this information and how to increase the number of health care providers who adopt the Institute of Medicine's approach to the clinical diagnosis of ME CFS. We have begun teleconference calls for this process and are in the next steps of planning the face-to-face round table meeting.

I would like to provide some additional information about CDC's website. The sections for the general public were posted last summer. We use comments and suggestions gathered at the round table meeting to update and revise this section of the website for health care providers, which is our next section that we're updating. In addition, we had external ME/CFS experts and other health care professionals review the draft as we move forward. We are now at the final stage of the clearance process and expect it will be available this summer.

We've also initiated a “Voice of the Patient” section to our web page. This features stories of patients living with ME/CFS. We are hopeful that this new feature will increase awareness and understanding of the profound impact that ME/CFS has on individuals and their families. We want to give our heartfelt thanks to the first two patients who took the time to tell us their stories. We will continue to add the stories of more patients to the site.

Shifting again, I would like to update you on our continuing medical education course development with WebMD Medscape. Medscape's preparing a continuing education course using a videotaped moderated panel discussion about how to diagnose ME/CFS using the recommendations of the 2015 Institute of Medicine report. The ME/CFS Spotlight—as the feature will be called—will be hosted on the Medscape website with CME credit available for one year. Medscape has a nation-wide distribution to health care professionals and so it's an ideal platform to reach health care providers. In addition, Medscape will be providing some evaluation criteria of this educational information. The panel members for this new CME course include Drs. Lucinda Bateman, Nancy Klimas, Jose Montoya, and Natalie Azar. The taping is scheduled for August and we anticipate that the new course will be available in late November 2018.

We continue to be involved in other partnerships. CDC has been actively collaborating with the ME/CFS Advisory Committee—the CFSAC—CFSAC working groups, and other Health and Human Services agencies. The cooperative spirit is very encouraging. And I'd like to mention just a few examples.

As recommended by CFSAC, CDC is working with the Department of Education and the Center for Parent Information and Resources to develop a page on the Center's website that provides basic information about ME/CFS and then links to additional information. This section is being finalized and should be available within a week.

The ME/CFS Common Data Elements Project was a joint initiative with CDC and the National Institute of Neurologic Disorders and Stroke—NINDS—at the National Institutes of Health and was facilitated by Emmes Corporation. The ME/CFS CDE project involved almost 60 members of the international ME/CFS community organized across 11 different work groups. The first recommendation for ME/CFS Common Data Elements to standardize data collection in studies of ME/CFS was posted and updated last April on the NINDS website. These will continue to be reviewed and updated as new information is available.

CDC's preparing to participate in the Food and Drug Administration's (FDA) qualification process for ME/CFS Outcome Measures. We've had calls with representatives from FDA's Drug Development Tool Qualification Program and the American Institutes for Research, focusing on how data from our ongoing multi-site clinical assessment of ME/CFS study could be used to identify fatigue measures for ME/CFS. The goal is to define clinical outcome assessments that will determine whether a drug has provided benefit. The FDA recognizes this as a critical need for ME/CFS clinical trials.

Finally, just a brief note that May 12, 2018, marks the 26th ME/CFS and Fibromyalgia International Awareness Day. We feel like this webinar is the kick off for us for that recognition. CDC will be using the CDC Features home page to publicize ME/CFS Awareness Day. The feature includes a link to our new Voice of the Patient section.

This concludes CDC's update. I'd like to thank you for your attention and participation. At this point I would like to turn the call over to Dr. Dana Brimmer, so that she can introduce our speaker.

Dr. Dana Brimmer

Thank you Dr. Unger. I'd now like to introduce our speaker. Dr. Faith Newton is a Professor of Education at Delaware State University in Dover, Delaware, where she also serves as Coordinator of Middle Level Education. She has served on the HHS Chronic Fatigue Syndrome Advisory Committee where she chaired the Pediatric Education Working Group. Dr. Newton, welcome.

Dr. Faith Newton

Thank you. I'm just waiting for the slides to come up. Okay, a little bit of background. What I'm going to do today is talk about the Invisible Disease, as it is known, and its educational implications for young people, so for our children that are in schools.

So the first slide, actually, it's slide two for those of you that are watching. My background is as an educator and a parent. I have twins. My son Michael initially got sick when he was in third grade with a mono-like virus. And then again in fourth grade and he never recovered.

My daughter Alexis never got the disease. Michael was initially diagnosed by our family physician and then by Dr. David Bell, the world-renowned adolescent pediatrician in ME/CFS. He never went back to school full-time until college, where both he and Alexis just graduated last weekend.

Background for me is I've been a Principal, Assistant Superintendent, and now have been in higher ed the past eight years as a Professor of Education. And my specialty is Middle Level Education, Classroom Management, and, for the last eight to ten years, also Special Education. I've done—since Michael has been sick with ME/CFS—accommodations and modifications for students with ME/CFS.

What is ME/CFS? For this presentation, we have a lot of nurses listening and a lot of parents. So I'm trying to gear it towards those folks in the audience, so that we can do a little bit more proactive work in our schools. I call it the Invisible Disease. We have no known cause. Treatment is for symptoms only, but no cure.

Myalgic Encephalomyelitis, Chronic Fatigue Syndrome—or ME/CFS—is a disabling chronic disease characterized by the symptoms of insufficient energy to sustain the activities of normal living. Current estimates are that Americans suffering from this disease range from 1 to 2.5 million, with many of them being children.

What is ME/CFS, the Invisible Disease, from the parent perspective? Your child gets sick with a mono-like virus. They may get the flu. Or perhaps they don't feel good one day and they don't get out of bed the next day. Or they could be at a soccer meet and they get so tired they just go to bed and they never get up.

Or one mother's daughter told me that she would go to swim meets. And after the swim meet, she just never got out of bed. So what do you do? You spend months trying to figure out what is wrong with your child, your son or your daughter. You take them to the doctor. Physicians often have no idea what's wrong. Many physicians have never heard of ME/CFS. Others still erroneously believe it's a psychosomatic or a mental health condition. Next slide.

[Inaudible], if nothing else, [inaudible] the parents out there, if you hear nothing else from this presentation, the course of the illness and the prognosis.

In a follow up study of nearly 700 young people, the average duration of the illness of those who reported as having “recovered” was four to five years. With a range of 1 to 15 years. So by five years, 60% report recovery. By 12 years, 88% reported recovery. So approximately 15% don't recover. Of those who reported recovery, about one third admitted to modifying their activities to remain feeling well. My son started to feel well around—I shouldn't say feel “well”—feel better around year seven to eight.

Feedback from young people—and this is extremely important—indicates that an important determinant of their functioning as adults was the effort made to enable them to remain engaged in education. So what did we do when they got sick either in elementary, middle, or high school? How did we keep them involved in school? It's very, very important.

So what is ME/CFS? Now the next number of slides, all of this information has been taken from this primer, ME/CFS Primer for Clinical Practitioners, 2014 revision. I was one of the contributing authors on Chapter Nine, the educational chapter.

So point number one. ME/CFS is characterized by an overwhelming fatigue with a substantial loss of physical and mental stamina. Cardinal features are post-exertional malaise (PEM), flu-like exhaustion, and a worsening of symptoms following minimal physical or mental activities.

And that's extremely important. How we define minimal physical or mental activities can simply be standing up and walking down the steps. Or sitting up. Or reading a book. It's, for each child, it's very different depending on whether it's a mild case of ME/CFS or a severe case.

These post-exertional symptoms can persist for hours, days, or weeks and are not relieved by rest or sleep. Probably the most frustrating thing for parents is that the symptoms and levels of fatigue change unpredictably from day to day or week to week.

I'm on slide seven. PEM—post-exertional malaise—is characterized by the loss of physical or mental stamina, substantially reducing the ability for our children to take part in personal, educational, or social activities. They also are subject to sleep dysfunction, non-refreshing disturbed sleep. There's a lack of cognitive focus, brain

fog. They can't sleep, they can't think sleep, excuse me, they can't think clearly. They have chronic joint and muscle pains and aches. Some may have headaches of new onset or severity.

Some children have swollen glands, recurrent sore throat or flu-like symptoms, as well as new sensitivities to food and or medications. Some children have neurological cognitive manifestations, including confusion, impaired concentration, short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval. And perceptual and sensory disturbances.

This is all pretty connotated. And what I'm going to do is, after I go through the symptoms, is I'm going to give you some examples of how this applies in the classroom. And then, how we teach children differently who have ME/CFS.

Autonomic manifestations. Orthostatic intolerance. Changing from literally standing or a sitting position results in our children becoming light headed and or passing out. Neurally mediated hypotension or postural orthostatic tachycardia syndrome.

Neuro-endocrine manifestations include difficulty regulating body temperature. Developing new allergies or changes in status of old ones. Some children have gastrointestinal symptoms such as irritable bowel-like symptoms. The onset of apparent food allergies. Eating former favorite foods causing severe abdominal pain, blood in the stool. Some children have sweating episodes. Recurrent feelings of fever symptoms and cold extremities. Some have intolerance of extremes of heat and cold. Slide ten.

So how do we manage this disease in children? Its successful management is based on determining the optimum balance of rest and activity to help prevent that post-exertional malaise from worsening. And that's very, very difficult. How do you balance that rest and that activity?

Orthostatic intolerance—OI—is treated by medications. Keeping our children well hydrated. Increase intake of salt. And teaching patience in those around them to be observant of the symptoms. Some medications work for some children. Some don't work for others. You literally have to try it out child by child. Medications that are helpful to treat pain, insomnia, OI, and other symptoms. Next slide, which is 11.

So what does that minimal physical or mental exertion look like for our students? So how do we describe brain fog? You have difficulty thinking, concentrating, forming thoughts. Your students may have known the answer to a simple question yesterday, but they have no idea what the answer is today. They may have known yesterday that three times five is fifteen, but today they can't even begin to even remember what that is. It might take them three minutes to come up with the answer. That's brain fog.

They try to push through symptoms to complete work or attend school, and this is detrimental to our children. Pushing through makes things worse for them. They get sicker. Schools are inclined to push kids, but our kids

need to manage their energy and manage their effort. Schools can have a tremendous impact in either validating the child's experience with the disease or trivializing it. And it's very, very difficult.

Attending school. While some of our young patients can attend school on a full- or a part-time basis, many others are wheelchair-dependent, house bound, or bed-bound. So how sick is the child? One minute the child can be sitting in class, the next minute the child can be in bed and won't be able to get out of bed or out of the house for weeks or months. I can remember in Michael's sophomore year, it was January. He had got - been going to school in September, October, November couple hours a week for three or four months. About the second week of January, he went to school on a Tuesday. Wednesday he didn't get back out of bed. Every day he would get up and wonder, was he going to school. Three months later, every single day. We had no idea. And that's how it goes with parents of children who have ME/CFS. You have no idea if your child is going to be able to get up and get out of bed the next day or the next day. You simply don't know. It's very unpredictable, it's really frustrating.

So what do you do with a child who has ME/CFS in your school? The first thing you need to know is that this disease does not look the same from child to child, teen to teen, young adult to young adult. You can have two students in your school and they can have very different manifestations of the disease. What may work for one child may not work for another child.

That means every case has to be individually assessed. You cannot assume, like I said, that what works for one will work for the next one. Because it just isn't going to happen. Slide 14.

So the spectrum of severity. Mildly affected young people might be able to attend full-time or part-time, but they might have to limit sports and after-school activities. But they will have frequent school absences, usually 15 days or more. ME/CFS has been found to be the most common cause of long-term school absences in the school.

For those of you that are not familiar with the disease, I would recommend that you watch Jennifer Brea's Sundance award-winning documentary on ME/CFS. It's her personal journey from being a patient to an advocate to storyteller. She's 28-years-old and she was working on her PhD at Harvard. And she was months away from marrying the love of her life when a mysterious fever left her bedridden. I did put the trailer on my slide. And you can watch it. I would not recommend that you let your child watch it unless you've seen it first, but it is an excellent commentary on what the disease is like for children and adults. Next slide, 16.

So parents and schools. If you're the parent of a child suffering from ME/CFS, dealing with the school can rival—even replace—securing medical treatment as the most stressful element of having a child suffering from this chronic illness. Parents will spend more time dealing with teachers and other school officials than they will be dealing with physicians.

And here's what parents are afraid of. Will our child get better? Will that child receive an education that allows them to be employed? That allows them to live on their own? What will happen with our children? Slide 17.

Sometimes school becomes a nightmare. In the morning, are you going to school today? You're a month behind. Communicating with the school. You hear from the teachers "She's not paying attention in class" or the teacher's not answering my emails.

Then you get "extreme stressors," as we call them. I've seen cases of officials coming to the house to force that child to go to school. Or a threatening letter, "Your child has been tardy 20 times and they've missed 31 days of school." Or parents being turned over to social services for neglect. Or a child being drug-tested because they thought the child was on drugs. They didn't believe the child had ME/CFS. Or now the child is being classified as having an emotional or a psychological disorder. Instead, the child has ME/CFS. Next slide, slide 18.

So now what I wanted to do was I wanted to take the next couple slides and I want to tell you what you teachers may see in the classroom, so that you understand their perspective. And then after that I am going to give you ways in which we can give you accommodations, so that it makes it easier for our children to learn at school.

All right, so what do we see in schools? What do the teachers see? So our families become so familiar with the symptoms of ME/CFS that they don't always realize that the teachers see things differently because don't forget, this is an "invisible" illness.

The teacher just sees the child sitting there in the classroom. They only see the child during the school day and that child shares the focus with dozens of other children in the classroom. So the teachers interpret what they see through the lens of the classroom, their experience. Most of them don't even know what ME/CFS is and they look at those attributes of what they see with the child as disinterest, maybe immaturity, ADHD, other problems.

So I labeled these slides Seeing and Not Understanding. So post-exertional malaise and fatigue. The teacher sees child becoming lethargic, falls asleep in class. Teacher thinks child obviously needs an earlier bedtime.

Teacher may see child who misses a large number of classes. Looks fine to me. Teacher thinks this child needs more motivation. Somebody needs to make sure this child gets up in the morning. Next slide.

Pain. Teacher sees child's looking uncomfortable, complains about non-specific pain. School nurse can't find anything. Teacher may think hypochondriac, psychological disorder, maybe it's symptoms of abuse.

Remember the teacher doesn't know anything about ME/CFS.

Teacher sees neuro-endocrine manifestations. Child complains about being too hot, too cold to function in the classroom. Classroom is comfortable for me. Teacher thinks these children are trying to get away - are trying to avoid working. My classroom's fine. They just want to get out of class. Okay, they just want to go to the nurse. It's a maturity issue. Next slide, 22.

Neuro-cognitive manifestations. Teacher sees distractibility, confusion. Hey, they turned around, they're paying attention to the student behind me. Teacher thinks child is immature. Why can't they learn to concentrate? Teacher sees I just gave them the directions. They can't follow the readings or answer comprehension questions. Teacher thinks this child's just not motivated, looks like it's ADHD to me.

Neuro-cognitive manifestations. Teacher sees why can't they finish the test and the assignment on time? They spent ten minutes working on this assignment, okay, and they haven't done question one. The parent needs to get involved in the homework. Teachers sees repeated dyslexic and or dyscalculia errors. Dyscalculia is simple mathematical errors for those of you. Let's say can't do two - they don't remember how to do simple multiplication problems like three times five or two plus three, but they can do really complex problems. So the child isn't ready or smart enough for advanced classes is what the teacher is thinking. So how do we meet the needs of students suffering from ME/CFS? Most educators do not have a strong understanding of ME/CFS. They probably haven't even heard about it.

In schools we have autism, ADHD, dyslexia, whatever we're dealing with, and many school districts have what we have called a menu of programs and options for our special needs populations, whether they're on a 504 plan or the Individuals with Disabilities Act, IDEA. So there are different options that we use to make accommodations and modifications for our students. Next slide, 25.

But how do we improve education for our students who have ME/CFS? So the first thing we have to do is we have to recognize the reality of the disease. Students can't push through or self-monitor the disease because if they do, they get sicker, okay? Second point there. Concentration issues result from neuro-cognitive symptoms, not immaturity, so that has to be recognized. Irregular attendance, again, is from ME/CFS, okay? Even part-day schedules can tax a student's energy, leading to a crash. Some students cannot go to school at all. How do we improve performance? Specific strategies. They have to be built for the individual student. We are going to emphasize mastery over completion. So in homework and in testing, we want them to learn the material. We we're not concerned about the number of problems. We grade students on work produced, not on what they don't complete. Third part. Year-round schooling supported by home-bound instruction is essential. I do not know of a single student with ME/CFS who has not had home-bound instruction year-round and was graduated from high school or middle school. You have to have that tutoring support. There also has to be long-term plans to include a specified route to graduation.

So back to mastery over completion. So those skills have to be specified. You have to focus your tasks and assignments on meeting critical skills. Look at the third bullet for my parents out there. Repetitive homework is not essential. All we're looking for is sufficient practice. We demonstrate mastery of a skill. We eliminate assignments that are not directly related to this critical skill. Next slide, 28.

Home-bound instruction. So for our students with severe or moderate ME/CFS, we have tutors who visit the home and allow students to get some work done when it's not possible for them to attend school. You may have home-bound instruction year-round for some of your classes. Michael was home-bound instruction for English and math throughout his entire high school - or English and social studies throughout his entire high school career.

Tutors can administer tests in chunks over several sections, so that students do not lose valuable instructional time. They may provide focused homework support and projects, and they can work with the student during the best hours. They can be available on weekends and over the summer. In many cases, tutors will become the primary instructor for at least some of the classes if not all. Next slide, 29.

The problem when we deal with rehearsal and repetition for our students with ME/CFS is that they don't know where to start an essay or a project and they can't see that they're finished. This is very typical. Use the same strategies consistently. We teach one pre-writing strategy rather than introducing several. We provide checklists. We break tasks into essential components, thereby providing a route to completion of the assignment. We build additional time to complete some tasks into the assignments. We shorten assignments. We reduce other assignments. So I'm being very, very specific here for nurses and teachers that are listening and parents that are listening.

So how do we improve executive functioning in the classroom? So students with ME/CFS, part of the disease is that they are disorganized and distracted. Well, how do we get them focused? Okay, again. This is not a behavior problem. This is disease-related. A quieter location with less noise to complete work. Checklists to be completed, structure the tasks sequentially. We complete the vocabulary. When that gets completed, we move to the next task. We don't do three different things in the class period. Check on the student at regular intervals, helping redirect them back to the task if necessary. The tutor can do that. Reduce or limit multitasking. Next slide, 31.

Processing speed. Perhaps the most difficult thing for our children, teachers, and parents. Students with ME/CFS simply don't have the ability to work quickly. The strategy here is to provide chunking and to provide pre-formatted notes to allow students to concentrate on listening. If the student is at home and the school district and the school has the capability, they can Skype into the classroom. Is there ability to provide that assistive technology, that tablet, that laptop to record lectures or to Skype into that classroom and keep track of the timing?

Are there microphones and earphones to reduce auditory distractions? Can the teacher give prior notice when asking questions to allow extra time to generate and format answers? Can we break tasks and assignments into smaller chunks, so that they can be completed in sequence and to provide natural stopping places to rest?

Nurses in our schools. What can our nurses do? Our nurses are the medical professionals who can understand and explain ME/CFS to other educators. They can help teachers locate resources. They can validate children's suffering from ME/CFS and provide a safe, secure place to rest. Our children need place to rest. They can help manage medications taken at school. They can communicate with clinicians and with physicians during the assessment process. They can be an active advocate for the child that is suffering from a real disease (in team meetings). Next slide, 33.

Parents, how do you partner successfully with the school? First thing you need to remember, the school knows nothing about this illness. We need to provide concrete information on the illness and the potential accommodations, giving staff time to digest the material before instructional plans are made. We have to communicate frequently and positively with teachers and staff. Educate rather than confront. This is a job for a good parent advocate who can translate between the clinic and the classroom. We're going to start saying, Dr. Unger mentioned, that we are (parts of staff) working with the CDC and the Office of Education on having a linking page with the parent information centers.

So on this slide you'll see parent information centers and find your center and some help that you can get for working with parent advocates. But take what the school is willing to give you and build on those small successes. Also, make your child into a person with that teacher, that staff member. Next slide, 34.

There are also laws that govern special needs students. So students with mild to moderate cases of ME/CFS could possibly qualify for a 504 plan and that provides what are called accommodations to their educational environment.

Students with moderate to severe ME/CFS could qualify for an individual education plan—what we call an IEP—that will provide those accommodations and modifications to their educational environment. And I'm going to explain that in a minute. Students on an IEP have until they are 21 to get their high school diploma. Next slide, 35.

Okay. Difference between accommodations and modifications. The terms are not interchangeable. So accommodations change the learning environment to allow students to meet the same standard or requirement as their peers. So alternative activities in a PE class. Extended time for tests or on assignments.

Now most students who have ME/CFS need modification, all right? They cannot take Physical Education. The modifications are changes that are made in the learning environment that changes the standard or the requirements that a student must meet. So for example, eliminating PE as a graduation requirement. Reducing the number or length of tests and or assignments.

Next slide, 36. So your child may qualify for an IEP or a 504 plan. If they qualify for an IEP, they would probably fall under the category "Other Health Impaired". If they qualify for a 504, they come under the Americans with Disabilities Act, which allows for accommodation.

So an IEP under "Other Health Impaired" allows for modifications. Five or four plans allow for accommodations, but let me go to that third bullet on slide 36. IEPs require a full assessment and a federally compliant process, but provide more options and protections for your son or daughter. Students with moderate to severe ME/CFS may qualify for IEPs and they have until 21 to get their high school diploma. All right, so the next slide is slide 37. Actually, let me go back to slide 36.

If you have a child that is severely ill, a team would be put in place and you would get documentation from your physician, and the team at the school would meet to determine whether or not they were qualified for an IEP. 504 plans are the same thing. You would approach the school and see whether or not they qualified under the Americans with Disabilities Act for accommodations.

Next slide, 37. The bright side, student success. With appropriate accommodations and modifications, even students with moderate to severe ME/CFS can succeed in school. Many young people suffering from this disease not only graduate from high school, but go on to successful college careers. The best begins when we manage disease as the obstacle, not the child suffering from it.

The last slides: 38, 39, 40, and 41 are fact sheets that I have used. I have fact sheets that I've been doing since 2012. These latest fact sheets are the 2018 fact sheets and they are aligned with the primer.

Some of the resources that I've used for this PowerPoint are, you look at the end, are: Dr. Rowe, Dr. Underhill, Dr. Friedman, Dr. Gerwitz, Dr. Menril-Schwartz. ME/CFS Diagnosis and Management in Young People, a Primer. That was the basis of my PowerPoint. And the fact sheets have also been aligned to that, I asked Dr. Friedman to do the alignment. Questions, Dr. Brimmer?

[Dr. Dana Brimmer](#)

Thank you so much, Dr. Newton. We'll now move on to the questions. The first question. What question do you get asked the most from parents of children with ME/CFS?

[Dr. Faith Newton](#)

The question I get asked most is, Is my child going to get better? And are they going to get through school? Probably. A lot of parents don't know - they don't know that there's a course of the illness. They don't know that this illness has a range of 1 to 15 years. They don't know that most children will start to recover somewhere around years four and five—with Michael it was year seven—and that by twelve years around 85 to 88% will report recovery. They have no idea. And that information needs to get out into the public.

The second question I get asked a lot is what has happened to my child? They were smart, they knew all this, you know, they were doing really well in school. Now look at them. And I say to the parent, it's because of the disease. They are still smart, they're just thinking slower. It's the cognitive issues. It doesn't mean your child is

stupid, that's not what's going on here. They just need extra time. They need material taught differently. They need materials taught in order. We just need to make modifications and accommodations for them and we can get them through the material from middle and high school. And that if we teach our students differently, they can master the material and they can be successful in school. And if we provide those supports, they can do well and graduate and make their way in the world. And I think that's what needs to happen and we need to give our parents that hope and let them understand that that is possible and that it can happen.

Dr. Dana Brimmer

Thank you. A second question for Dr. Newton. Recently, the Department of Education has made many changes to their rules and guidance to educational institutions. For instance, on March 5 of this year the Department of Education Office of Civil Rights updated their rules. The rules now contain a provision that allows investigators to disregard cases they consider burdensome to the Office. Burdensome was not defined. Given the extensive disbelief around this disease and the grave possibility that OCR may now deem a family's civil rights complaint too burdensome and not investigate, how can parents ensure their children get the education they are entitled to? And I should just clarify to say that how can parents with children with ME/CFS get the education that their children are entitled to?

Dr. Faith Newton

I consulted with Carmen Sanchez on this and—she's one of the staff members—and in individual cases parents should know that there are procedural safeguards under IDEA. And what I would encourage parents to do is to go to their individual parent center and that was one of the links in the slide. Those parent centers are very parent-friendly and geared toward the particulars of each state. So each state has their own parent center. In that parent center site, it will tell you about how to make an administrative complaint to your state and the issues that affect children under IDEA. There's also - it's on the National Center Cadre—C-A-D-R-E—that does an excellent job of explaining their safeguards. And I'll give you the link for that one because it's not that difficult. It's W-W-W dot Cadre Works—C-A-D-R-E-W-O-R-K-S—dot org. But when you are at a school, you can ask for the procedural safeguards under IDEA. But again, I would go to the parent information centers of your state and get your answer there. Unfortunately, I'm not a lawyer and I don't work for the Office of Civil Rights, so that's a very interesting question. But I think if you work through the parent information centers you can—it'll be interesting to see if you can—you should be able to get answers there about what to do.

Dr. Dana Brimmer

Thank you. I'm now going to switch gears and I have a question for Dr. Beth Unger and then we will try to get back to Dr. Newton again. Dr. Unger, last year the CDC issued an RFP—a Request for Proposal—for an independent organization to do the clinical assessment of 300 pediatric patients as part of the multi-site study.

My questions are how many proposals were received by the CDC for this contract? How many pediatric patients have been identified as a result? And how many pediatric patients total are now enrolled in the study?

Dr. Elizabeth Unger

Okay, thank you. We only had one organization respond to the RFPs. The contract was awarded to Eagle Scientific at the end of September 2017. The work so far has been for the contractor to identify clinics and clinicians who are able to participate and we just now received IRB approval to extend the protocols for both pediatric patients, as well as the ill comparison group into additional clinics. So we have not enrolled any patients or participants as a result of these new contracts yet.

Each of the clinical sites - again, we're relying on the participant clinicians to adjudicate and determine the diagnosis of patients. We were hoping that Dr. Rowe would be able to participate in this contract, but unfortunately he was not able to do this. However, he is interested in the success of our project overall and indicated his willingness to serve as a consultant to Eagle Scientific if needed. Currently, we have 25 patients in our, 25 pediatric ME/CFS patients, in our protocol, enrolled in our protocol that have complete data. And that is really the reason why we added on this additional RFP, in order to increase the number of pediatric patients. The main problem is that the seven clinical sites that participated in the original contracts really were adult clinics and they just didn't see the pediatric and adolescent population to be able to enroll them.

Dr. Dana Brimmer

Okay, thank you. We are nearing the end of our call and I do have one final question for Dr. Newton. Dr. Newton, how and when will you ensure that the distinction between impaired function and post-exertional malaise, PEM, is appropriately and promptly addressed and all errors and misquotes are corrected?

Dr. Faith Newton

I asked Dr. Ken Friedman to give me some help with this question when I've done fact sheets since 2012. The latest version is the one that's the 2018 one is aligned with the primer. Both statements—and I'm going to quote him—both statements are correct and the statements are not in conflict with each other. The difference between the two statements is the aspect of (unintelligible) to be emphasized. PEM appears to be a symptom of ME/CFS. At this junction, we must exercise caution in our statements concerning PEM because one, PEM, at this point in time as it's currently defined, is not unique to ME/CFS, and two, studies are still underway to demonstrate that PEM is a universal feature of all ME/CFS patients. The first statement emphasizes the fact that PEM appears to be a symptom found in the majority if not all ME/CFS patients. Thus a disproportionate fatigue at time of activity may still be classified as a fatigue derived from other maladies. Individuals with anemia, for example, exhibited a disproportionate amount of fatigue for a given amount of exercise, but that

would not qualify as PEM. For PEM to be present, the fatigue, which is linked to the exercise, occurs after the expected arrival time.

Thus for an ME/CFS patient, a two-mile walk may induce tiredness after the walk. But the day or perhaps two days after the walk the patient could not get out of bed. Where the questioner sees contradictions between the two statements, I see complementation.

Both statements are correct, but taken together the concept of PEM is defined with greater precision. So I appreciate the comment. And I also want to make sure that people are careful that they use the latest version of the fact sheet. Thank you Dana.

[Dr. Dana Brimmer](#)

Thank you so much, Dr. Newton. And this brings us to a close for our call today. Many thanks again to Dr. Newton for taking the time to be with us today and to all of our call participants for your time and interest. We look forward to having you join us again on our next call. And you may submit questions or ideas for future topics and speakers at the MECFSSSEC@CDC.gov email address. Again, thank you to everybody today.

[Dr. Faith Newton](#)

And thank you for having me. And I would like to thank Dr. Friedman and Ms. Sanchez and all of the writers of the primer for their support.

[Coordinator](#)

This concludes today's call.