

2019 ME/CFS Clinician Summit Post-Summit Announcement

On March 15-16, leading ME/CFS expert clinicians from across the United States gathered in Salt Lake City for the second annual ME/CFS Expert Clinician Summit. The goal of this summit was to grow the collaborative network of disease experts, identify ways to expand their ranks and improve the clinical care of patients with ME/CFS, and accelerate the ME/CFS research agenda, with a particular focus on drug trials and subtyping strategies.

"The ME/CFS Clinicians Summit is a historic opportunity to distill decades of knowledge into consensus documents that will help millions of patients, providers, and researchers to further understand ME/CFS and, finally, be able to see the disease in its entirety," said Dr. Jose Montoya, one of the Summit attendees.

ME/CFS affects an estimated 1 to 2.5 million Americans and yet an estimated 85-90% remain undiagnosed. Even once they are diagnosed, patients struggle to get appropriate clinical care and are sometimes harmed by treatment recommendations because their doctors don't understand the disease or its clinical management.

To address this gap in understanding, the summit attendees focused on driving consensus across the group on clinical practices so these could be mainstreamed across the broader medical community. They agreed to implement a website as one vehicle to share this information. Publishing expert consensus on laboratory tests and procedures useful in diagnosis and management as well as guidance of use of medications in peer-reviewed medical journals used by healthcare providers is also planned.

Compounding the lack of accurate clinical management guidelines, there are less than two dozen ME/CFS expert clinicians in the entire country and the majority of them are nearing retirement age. This negatively impacts both the ability of patients to access clinical care and also our ability to ramp up research. To address this clinical crisis, the summit attendees discussed ways to advance education of all clinicians but especially ways to grow the ranks of clinicians who specialize in ME/CFS by providing tele-mentoring to those clinicians, starting with those who have already begun to develop expertise in the disease.

Further complicating the clinical management of ME/CFS is the lack of FDA approved drugs for this disease. And yet, ME/CFS expert clinicians are successfully using drugs to help improve the quality of life of people with ME/CFS. The ME/CFS Clinician Coalition agreed that the time is ripe for clinical drug trials and agreed to the following statement:

The field of ME/CFS needs evidence-based treatments. The combined clinical experience of ME/CFS clinicians supports efficacy of several treatments that have potential and warrant testing. Appropriate funding

mechanisms are warranted. In addition, funding should support a clinical trials consortium. The ME/CFS Clinician Coalition agrees that our first priority is a trial of LDN (low dose naltrexone).

As a first step, the ME/CFS Clinician Coalition agreed that a first priority is a trial of LDN.

The physicians in this strategic group include:

- Dr. Lucinda Bateman - Internal Medicine, Salt Lake City, Utah
- Dr. Alison Bested - Hematological Pathologist, Miami, Florida
- Dr. John Chia - Torrance, California.
- Dr. Theresa Dowell - Family Nurse Practitioner, Flagstaff, Arizona
- Dr. Susan Levine - Infectious Disease, New York, New York
- Dr. Anthony Komaroff – Internal Medicine, Boston, Massachusetts
- Dr. David Kaufman - Internal Medicine, Mountain View, California
- Dr. Nancy Klimas - Immunologist, Miami, Florida
- Dr. Charles Lapp - Charlotte, North Carolina
- Dr. Jose Montoya - Infectious Diseases, Stanford University California
- Dr. Ben Natelson - Neurologist, New York
- Dr. Morris Papernik - Internal Medicine, Hartford, Connecticut
- Dr. Dan Peterson - Internal Medicine, Incline Village, Nevada
- Dr. Richard Podell - Internal Medicine, Summit, New Jersey
- Dr. Irma Rey – Environmental Medicine, Miami, Florida
- Dr. Andy Selinger – Family Medicine, Hamden Connecticut

This collaborative effort is being led by Dr. Lucinda Bateman of the Bateman Horne Center and Mary Dimmock, parent of a son with ME/CFS. After decades without clinical guidance, Cindy and Mary proposed an opportunity for the leading ME/CFS physicians to collect their clinical experience and intuition about ME/CFS. This work has expanded into a strategic effort to bridge the gap between science and medical practice and improve the clinical outcomes for patients everywhere.

If you are a US clinician and are interested in additional information, please use [this form](#) to provide your contact information.