Title: Accelerating Research on ME/CFS

Goal: Present high-quality science studies of ME/CFS to better understand the state of the science and help drive the field forward by identifying gaps and opportunities. Presentations should emphasize newer work or in some cases critical previous work that fits with current models of ME/CFS. Audience is expected to be scientists, clinicians, patients and other ME/CFS stakeholders. Conference will be webcast and publicly available.

#MECFSatNIH19

Day 1: April 4, 2019
Masur Auditorium, NIH Clinical Center

9-9:20 AM Welcome/Introductions – Walter Koroshetz (NINDS), Anthony Fauci (NIAID), Vicky Whittemore (NINDS), Joseph Breen (NIAID)

9:20-10:00 AM Setting the stage – ME/CFS 101- Lucinda Bateman

Metabolomics/Metabolism of ME/CFS
Joe Breen (NIAID) - moderator

10-10:30 AM “Metabolic features of chronic fatigue syndrome” Robert Naviaux (UCSD)

10:30-11 AM BREAK

11-11:30 AM “Informatics tools for investigating metabolic dysregulation in ME/CFS” Oliver Fiehn (UC Davis)

11:30-12 NOON "The Biochemistry to Support the Evidence of Neuroinflammatory Involvement in ME/CFS” Jonas Bergquist (Uppsala Univ)

12:00-1:00 PM LUNCH

Immunology of ME/CFS
Nancy Klimas (NOVA SE) – moderator

1-1:30 PM "Cytokine networks and HLA genetic susceptibility associated with ME/CFS and disease severity" Jose Montoya (Stanford University)

1:30-2 PM “Potentially important T cell activity in CFS/ME” Mark Davis (Stanford University)

2-2:30 PM “Disturbance of the immune system during ME/CFS” Derya Unutmaz (Jackson Labs)
2:30-3PM “Cellular Metabolism of Immune Cells” Maureen Hanson (Cornell University)

3:00-3:30 PM BREAK

Provocation Studies
Andrew Breeden (NINDS) - moderator

3:30-4 PM “Accelerating to Clinical Trials – Modeling to Predict Intervention”
Nancy Klimas (NOVA SE)

4:00-4:30 PM “Pathophysiology and treatment of exertional intolerance in ME/CFS: insights from cardiopulmonary exercise testing” David Systrom (BWH/Harvard)

4:30-5 PM “Exertion intolerance: What is the evidence telling us?”
Betsy Keller (Ithaca)

5-5:30 PM “’Role of circulating microRNAs in ME/CFS pathogenesis: From molecular stratification to therapeutic targets” Alain Moreau (U. de Montreal)

Group Discussion Q&A
5:30-6PM - Terri Wilder (#MEAction) - moderator

6:00-7PM – Poster Session – posters from Workshop for Young Early Career ME/CFS Investigators – FAES Terrace, NIH Clinical Center

end of day one

Day 2: April 5, 2019
Masur Auditorium, NIH Clinical Center

8:30-9:30 AM Clinician Panel Discussion
Tony Komaroff- moderator – 10 min per presentation; highlighting one area of ME/CFS treatment/practice that would complement others (minimal overlap), introduced by Sadie Whitaker (Solve ME/CFS)

Lucinda Bateman – Orthostatic intolerance
Susan Levine – Mast cell activation syndrome and incidence; quick overview of biology, diagnosis, and treatment
Jose Montoya – Is there a role for anti-herpes therapy in ME/CFS?
Daniel Peterson – Precision medicine and artificial intelligence in the diagnosis and treatment of ME/CFS
Peter Rowe – Neurodynamic dysfunction
9:30-10AM Q and A session with Clinician Panel – Open mic questions

10-10:10 AM Welcome and Remarks - Francis Collins (NIH Director), introduced by Walter Koroshetz (NINDS Director)

NINDS/NIH Intramural study update
Vicky Whittemore – introduction

10:15-10:45 AM “NIH ME/CFS Intramural Study Update” Brian Walitt (NINR)

10:45-11:15 AM BREAK

Microbiome/Virome
Sadie Whitaker (Solve ME/CFS) - moderator

11:15-11:45 AM “Center for Solutions for ME/CFS: 18 months in...” Ian Lipkin (Columbia)

11:45-12:15 NOON "From metagenomes to therapeutics: decoding the interactome"
    Julia Oh (Jackson Labs)

12:15-1:00 PM LUNCH

1-1:30 PM “Pathogenic alterations of mitochondrial dynamics: A working model for ME/CFS” Bhupesh Prusty (Wuerzburg)

New Technology for ME/CFS Research
Joe Breen (NIAID) - introduction

1:30-2 PM The Molecular Basis of ME/CFS - Ron Davis (Stanford Genome Center)

Imaging of the CNS and ME/CFS
Fred Friedberg (Stony Brook) - moderator

2:00-2:30 PM “Neuroinflammation in ME/CFS” Jarred Younger (UAB)

2:30-3:00 PM “Optimizing techniques for neuroimaging brainstem in ME/CFS during post-exertional malaise and neuroinflammation” Mike VanElzakker (Harvard)

3:00-3:30 PM BREAK

Orthostatic/Autonomic Disorders
David Systrom (BWH/Harvard) - moderator

3:30-4:00 PM “Orthostatic Intolerance in ME/CFS: Gains and Gaps” Peter Rowe (JHU)

4:00-4:30 PM “Small Fiber Neuropathy; A Common Contributor” Anne Oaklander (MGH)


5:15 – 6:15 PM – Next Steps for ME/CFS Research (30 min) and Open Question/Answer with Panel (30 min)

Panel: Joe Breen (NIAID), Vicky Whittemore (NINDS), Maureen Hanson (Cornell), Sadie Whitaker (SMCI), Jose Montoya (Stanford)