

# NIH ME/CFS NEWSLETTER

VOLUME 1: ISSUE 1 MARCH 11, 2022

## UPCOMING EVENTS

**March 28, 2022**

3:00 – 4:00 PM EST

NIH ME/CFS Telebriefing, Guest Speaker Dr. Benjamin Natelson from Ican School of Medicine at Mount Sinai.

<https://nih.zoomgov.com/j/1605311243>

**May 17-19, 2022**

11<sup>th</sup> International ME Colloquium, Invest in ME, London, UK

<https://www.investinme.org/cindex.shtml>

**May 20, 2022**

15<sup>th</sup> Invest in ME Research International ME Conference, London, UK

<https://www.investinme.org/cindex.shtml>

**July 27-30, 2022**

IACFS Conference – in-person in Stony Brook, NY

<https://www.iacfsme.org/2022-conference-main-page/>

## INTRODUCTION

This newsletter provides updates and information about new and ongoing activities at NIH related to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). We welcome suggestions for information and updates that you would like to see in this newsletter. Please send your suggestions to: [NIHMECFSEInformationList@mail.nih.gov](mailto:NIHMECFSEInformationList@mail.nih.gov).

## PUBLICATION OF NEW FUNDING ANNOUNCEMENTS

The NIH announces the publication of two funding opportunity announcements to support research at up to three ME/CFS Collaborative Research Centers and one Data Management Coordinating Center (DMCC). These funding opportunity announcements will provide 5 years of support for the Centers and DMCC. The Requests for Applications (RFAs) can be found here:

RFA-NS-22-019 Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Collaborative Research Centers (CRCs) (U54, Basic Experimental Studies Involving Humans Allowed)

<https://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-019.html>

RFA-NS-22-020 Data Management and Coordinating Center (DMCC) for the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Collaborative Research Centers (CRC) (U24)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-NS-22-020.html>

Ongoing funding opportunity announcements for ME/CFS:

PAR-20-165 Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) (R01 Clinical Trials Not Allowed)

<https://grants.nih.gov/grants/guide/pa-files/PAR-20-165.html>

PAR-20-168 Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) (R21 Clinical Trials Not Allowed)

<https://grants.nih.gov/grants/guide/pa-files/PAR-20-168.html>

## MECFSEnet Webinar Series

NIH, together with the Community Advisory Committee (CAC) for the ME/CFS Research Network, recently launched a webinar series to provide information and updates on the ongoing research in the ME/CFS Collaborative Research Centers (CRC) and the Data Management Coordinating Center (DMCC). Each webinar features a presentation by the Principal Investigator of the Center or DMCC followed by a question and answer session with members of the CAC.

The first video in the NIH MECFS webinar series features the DMCC at RTI. Drs. Linda Brown and Matthew Schu, DMCC Principal Investigators, describe the work that RTI has been doing to support research efforts at the ME/CFS Collaborative Research Centers. Watch the video here: [https://www.youtube.com/watch?v=-VtVMjnz\\_o](https://www.youtube.com/watch?v=-VtVMjnz_o)

The second video in the webinar series features the Columbia University Center for Solutions for ME/CFS. Dr. Ian Lipkin and his research team discuss their latest findings. Watch the video here: <https://youtu.be/Y71Y91GyoxQ>

The third video in the webinar series features the Cornell University, Center for Energizing NeuroImmune Disease. Dr. Maureen Hanson and her colleagues discuss their latest findings. Watch the video here: <https://youtu.be/AomPPtzZHgc>

## QUESTION CORNER

### **How does NIH receive funding, and how do we decide to fund research?**

Each year, Congress provides funding to NIH and to all of the federal agencies through the federal appropriation bills. Congress sets the budget provided to each of the federal agencies through this bill. NIH receives an overall budget that includes individual budgets for each of the Institutes, Centers and Offices that make up the National Institutes of Health.

Within the NIH Institutes, there are two divisions:

1. Intramural research – these are the researchers who are actually NIH staff and do their research in NIH laboratories in Bethesda, MD or at the other NIH sites. These individual investigators receive funding for their research through the budget for this on-site research.
2. Extramural research – these are the researchers who are not NIH staff but who are employed by academic institutions, foundations, small businesses, and other entities outside of NIH. These investigators are funded through grant mechanisms and are required to submit grant applications that undergo peer review at NIH – this is called investigator-initiated research. Their applications are scored in the peer review panels, called study sections, and then ranked based on those scores. Each NIH Institute has their own funding priorities, policies and strategies for funding these investigator-initiated grant applications. The investigators whose grants were not funded have the opportunity to revise and resubmit their grant applications taking into account the comments on the strengths and weaknesses of their applications provided to them in the written summary statement of the review of their application. In addition, the Program Directors from each of the Institutes, Centers and Offices are available to discuss the review with the investigator and offer advice about how to improve their application for the next grant submission. No grant is ever rejected by NIH. Every grant is reviewed and receives comments from the reviewers that the investigators can use to improve their grant application for the next submission.

### **Does NIH award grants based on disease burden?**

The funds used to support disease oriented research comes out of the budgets for each of the NIH Institutes. These grants compete with grants in all the other areas of research and diseases that are supported in each of the Institutes. NIH does not have a specific budget for any disease research, unless specifically appropriated by Congress (for example, there are specific Congressional appropriations for research on autism spectrum disorder and Alzheimer's Disease).

## RECENT PUBLICATIONS SUPPORTED BY FUNDING FROM NIH

### **[The Enterovirus Theory of Disease Etiology in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Critical Review](#)**

Adam J O'Neal, Maureen R Hanson

### **[Redox imbalance links COVID-19 and myalgic encephalomyelitis /chronic fatigue syndrome](#)**

Bindu D. Paul, Marian D. Lemle, Anthony L. Komaroff, Solomon H. Snyder

### [mapMECFS: a portal to enhance data discovery across biological disciplines and collaborative sites](#)

Ravi Mathur\*, Megan U Carnes\*, Alexander Harding, Amy Moore, Ian Thomas, Alex Giarrocco, Michael Long, Marcia Underwood, Christopher Townsend, Roman Ruiz-Esparza, Quinn Barnette, Linda Morris Brown, Matthew Schu

### [Differential Effects of Exercise on fMRI of the Midbrain Ascending Arousal Network Nuclei in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(ME/CFS\) and Gulf War Illness \(GWI\) in a Model of Postexertional Malaise \(PEM\)](#)

James N. Baraniuk, Alison Amar, Haris Pepermitwala, Stuart D. Washington

### [Exercise modifies glutamate and other metabolic biomarkers in cerebrospinal fluid from Gulf War Illness and Myalgic encephalomyelitis /Chronic Fatigue Syndrome](#)

James N. Baraniuk, Grant Kern, Vaishnavi Narayan, Amrita Cheema

### [The development of an instrument to assess post-exertional malaise in patients with myalgic encephalomyelitis and chronic fatigue syndrome](#)

Leonard A Jason, Carly S Holtzman, Madison Sunnquist, Joseph Cotler

### [COVID-19 Symptoms Over Time: Comparing Long-Haulers to ME/CFS](#)

Leonard A. Jason, Mohammed Islam, Karl Conroy, Joseph Cotler, Chelsea Torres, Mady Johnson, Brianna Mabie

### [Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome](#)

Anthony L Komaroff, W Ian Lipkin

## **INFORMATION AND RESOURCES**

NIH ME/CFS website: <https://www.nih.gov/mecfs>

ME/CFS Research Network website: <https://mecfs.rti.org/>

### **Tools for Researchers:**

mapMECFS: <https://www.mapmecfs.org/>

mapMECFS is an interactive data portal providing access to research results across many biological disciplines from studies that are focused on advancing our understanding of ME/CFS.

searchMECFS: <https://searchmecfs.org/>

searchMECFS is an interactive search tool for navigating biospecimens available for research purposes from studies of ME/CFS.

ME/CFS Common Data Elements:

<https://www.commondataelements.ninds.nih.gov/Myalgic%20Encephalomyelitis/Chronic%20Fatigue%20Syndrome>

## **NEWSLETTER EDITORS**

Crystal Lantz, PhD, NINDS/NIH

Barbara McMakin, MS, NINDS/NIH

Vicky Whittemore, PhD, NINDS/NIH

