

NIH ME/CFS Newsletter

November 2023

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This newsletter provides updates and information about new and ongoing activities at the NIH related to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

ME/CFS Research Roadmap Update

In 2022, the [ME/CFS Research Roadmap Working Group](#) began developing a roadmap for ME/CFS, which will identify research priorities to move the field toward translational studies and clinical trials. Now, the working group is holding a public webinar series on different areas of ME/CFS research to assess current efforts and identify opportunities for research. Learn about how to join an upcoming webinar and contribute your ideas by visiting the [webinar series website](#). The final roadmap will be presented at the NANS Council meeting on May 15-16, 2024.

Upcoming webinars:

- Chronic Infections | Nov 30, 2023 at 11:00 AM EST
- Physiology | Dec 8, 2023 at 11:00 AM EST
- Less Studied Pathologies | Jan 5, 2024 at 11:00 AM EST



[Registration](#)

[Agendas](#)

Did you miss a prior webinar? Recordings and transcripts are **posted here!**

Registration is Open for NIH ME/CFS Events in December

We're excited to host a symposium and two-day conference in December! Both events will be held in person on the NIH campus in Bethesda, MD and virtually.

[Symposium for Promoting the Advancement of Research Knowledge in ME/CFS \(SPARK ME\) |](#)

December 11, 2023 The symposium will provide a forum for early career researchers to come together to network, learn about ongoing research on ME/CFS, and funding opportunities at NIH and the patient advocacy organizations. This event is only open to investigators doing research on ME/CFS who are undergraduates, graduate students, postdoctoral and clinical fellows, and early career investigators.

[Advancing ME/CFS Research: Identifying Targets for Intervention and Learning from Long COVID |](#)

December 12-13, 2023 Speakers will present the state of the science of ME/CFS research and identify targets for potential interventions that have arisen from the literature and clinical evidence from ME/CFS and Long COVID observations. This event is open to scientists, clinicians, patients, and other ME/CFS stakeholders.

PAST EVENTS

NIH ME/CFS Advocacy Call | May 1, 2023 ([video](#), [transcript](#), [presentation](#)) The webinar included a scientific presentation by Avik Roy, PhD, and Gunnar Gottschalk, PhD, investigators at Simmaron Research and the University of Wisconsin-Milwaukee.

NEWS

[Studies find that microbiome changes may be a signature for ME/CFS](#) | Press Release, Feb 8, 2023

Researchers have found differences in the gut microbiomes of people with ME/CFS compared to healthy controls. Findings from two studies, published in *Cell Host & Microbe*, add to growing evidence that connects disruptions in the gut microbiome, the complete collection of bacteria, viruses, and fungi that live in our gastrointestinal system, to ME/CFS. Read the [NIH Director's blog post!](#)

QUESTION CORNER

How can researchers, clinicians, non-profit advocacy and research organizations, individuals living with ME/CFS, and others in the ME/CFS community get involved in the research roadmap?

There will be multiple opportunities for input. You can attend the webinars, during which there will be opportunities for public comment and/or Q&A sessions. You can also use the crowdsourcing tool [IdeaScale](#) to contribute additional ideas and recommendations after each webinar. Details about IdeaScale are forthcoming. Subscribe to our listserv for updates [here](#). You can also provide comments at any time by sending an email to MECFResearchRoadmap@ninds.nih.gov.

Why do we want and need your insight and how will we use the information to develop a research roadmap?

Your feedback is important because it may help shape recommendations for research on ME/CFS. Comments from the broader ME/CFS community will help the NANS Council working group identify the most critical areas for inclusion in a research roadmap. The goal is to include priorities that are most appropriate and beneficial for those impacted by ME/CFS, while also moving the field closer to translational studies and clinical trials.

PUBLICATIONS SUPPORTED BY FUNDING FROM NIH

- [Myalgic encephalomyelitis/chronic fatigue syndrome and fibromyalgia are indistinguishable by their cerebrospinal fluid proteomes](#) (*Annals of Medicine*, Sept 2023)
Schutzer SE, Liu T, Tsai CF, Petyuk VA, Schepmoes AA, Wang YT, Weitz KK, Bergquist J, Smith RD, Natelson BH
- [Cytokine network analysis in a community-based pediatric sample of patients with myalgic encephalomyelitis/chronic fatigue syndrome](#) (*Chronic Illn*, Sept 2023)
Jason LA, Gaglio CL, Furst J, Islam M, Sorenson M, Conroy KE, Katz BZ
- [Bayesian Statistics Improves Biological Interpretability of Metabolomics Data from Human Cohorts](#) (*Metabolites*, Aug 2023) Brydges C, Che X, Lipkin WI, Fiehn O

- [Serum from Myalgic encephalomyelitis/chronic fatigue syndrome patients causes loss of coherence in cellular circadian rhythms](#) (*J Neuroimmunology*, Aug 2023)
Wei H, Adelsheim Z, Fischer R, McCarthy MJ
- [A multicenter virome analysis of blood, feces, and saliva in myalgic encephalomyelitis/chronic fatigue syndrome](#) (*J Med Virology*, Aug 2023)
Briese T, Tokarz R, Bateman L, Che X, Guo C, Jain K, Kapoor V, Levine S, Hornig M, Oleynik A, Quan PL, Wong WH, Williams BL, Vernon SD, Klimas NG, Peterson DL, Montoya JG, Ian Lipkin W
- [Surveying the Metabolic and Dysfunctional Profiles of T Cells and NK Cells in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#) (*Int J Mol Sci*, July 2023)
Maya J
- [Cognitive impairment in post-acute sequelae of COVID-19 and short duration myalgic encephalomyelitis patients is mediated by orthostatic hemodynamic changes](#) (*Front Neurosci*, June 2023)
Day H, Yellman B, Hammer S, Rond C, Bell J, Abbaszadeh S, Stoddard G, Unutmaz D, Bateman L, Vernon SD
- [Sex-Dependent Transcriptional Changes in Response to Stress in Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Pilot Project](#) (*Int J Mol Sci*, June 2023)
Gamer J, Van Booven DJ, Zarnowski O, Arango S, Elias M, Kurian A, Joseph A, Perez M, Collado F, Klimas N, Oltra E, Nathanson L

[Read More Publications](#)

RESOURCES

Learn about NIH funding for ME/CFS, research tools, and more by visiting the [NIH ME/CFS resources page](#).

- [mapMECFS](#): 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. mapMECFS is now listed as a domain-specific repository on the National Library of Medicine's [NIH-supported data sharing repository](#)!
- [searchMECFS](#): an interactive search tool for navigating biospecimens available for research purposes from studies of ME/CFS.
- [ME/CFS Common Data Elements \(CDEs\)](#): CDEs are data standards that can be used in clinical studies and clinical trials for ME/CFS.
- [ME/CFSnet](#): information about the ME/CFS Research Network (ME/CFSnet) supporting the ME/CFS Data Management Coordinating Center and the ME/CFS Collaborative Research Centers.

Do you have suggestions for our newsletter? [Contact us!](#)

Thanks to our newsletter editors Nina Lichtenberg, Ph.D., Barbara McMakin, M.S, and Vicky Whittemore, Ph.D. at the NIH/NINDS!

This newsletter is distributed as part of the NIH ME/CFS Information listserv.

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