National Institutes of Health

NIH ME/CFS Newsletter

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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).

Developing an ME/CFS Research Roadmap

In September 2022, at the National Institute of Neurological Disorders and Stroke (NINDS) Advisory Council meeting, Walter Koroshetz, M.D., Director of NINDS, announced that a working group of Council will initiate a strategic planning effort to develop a Research Roadmap for ME/CFS, which will identify research priorities to move the field toward translational studies and clinical trials. We anticipate that the roadmap will be presented at the NINDS Advisory Council meeting on February 14-15, 2024.

The working group will include basic and clinical experts from the research community, leaders of non-profit advocacy and research organizations, and people who are living with ME/CFS, have a family history of ME/CFS, are caregivers/care partners of people living with ME/CFS, or are ME/CFS patient advocates.

Interested in participating on the working group? Learn about eligibility and how to apply here. The deadline is February 9, 2023!

Service to NIH is Important for the ME/CFS Community

The NIH depends on the community of researchers, health care providers, and the public to provide service through volunteering on grant review panels (study sections), advisory panels, working groups, scientific advisory boards, to provide feedback, and for many other activities. Your participation is critical to bring the research and clinical expertise about the disease and the voice of the community to the table. For NIH-funded investigators, your service is noted in your NIH profile and is taken into consideration for some awards and other honors.

Ways for investigators to participate:

- Serve as an NIH grant reviewer
- Serve as a reviewer of grant applications or as a scientific content expert on working groups for the NIH RECOVER Initiative

Ways for individuals with ME/CFS, advocates, and caregivers/care partners to participate:

- Serve on the ME/CFS Research Roadmap Working Group (apply now!)

Investigators, individuals with ME/CFS, advocates, and caregivers/care partners can serve on NIH Advisory Councils (NINDS, NIAID) and provide feedback to Requests for Information (RFIs) or other requests that seek input from the community. Stay informed about opportunities related to ME/CFS by joining our listserv. **Questions about participation? Contact the Trans-NIH ME/CFS Working Group.**

PREVIOUS EVENTS

- **NIH ME/CFS Advocacy Call | August 26, 2022** (video, transcript, presentation) Dr. Lily Chu, Vice President of IACFS/ME, discussed highlights from the IACFS/ME Conference that took place in July 2022, which was supported by an NIH R13 Scientific Meeting Grant.
- **2022 IACFS/ME Conference | July 27-30, 2022** (read the conference summaries to learn more)

ME/CFSnet Newsletter

MECFSnet
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Research Network

The ME/CFSnet Newsletter is live on the website with information and news about ongoing research at the NIH-funded ME/CFS Collaborative Research Centers and Data Management Coordinating Center. Read the latest newsletter (PDF, 164KB).

QUESTION CORNER

How will research coming out of the NIH RECOVER Initiative advance knowledge about ME/CFS and benefit the ME/CFS community?

Long COVID provides an unprecedented opportunity to improve our understanding of recovery from viral infections and will provide important insights that can be applied to ME/CFS. The ability to closely study such large numbers of people as they recover from the same pathogen at the same time is a natural experiment that we have never been able to do before.

Will ME/CFS researchers be involved in RECOVER?

Investigators and clinicians with research expertise and clinical experience with post-infection syndromes, including ME/CFS and POTS, are contributing their expertise and knowledge to the RECOVER Initiative, participating in oversight committees and working groups that determine what assessments and tests are incorporated into the protocols, and helping design ancillary protocols to complement studies in this area. Please see a list of individuals here (PDF, 195KB).

PUBLICATIONS SUPPORTED BY FUNDING FROM NIH

- **Altered Fatty Acid Oxidation in Lymphocyte Populations of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome** (*Int J Mol Sci*, Jan 2023)
  Jessica Maya, Sabrina M Leddy, C Gunnar Gottschalk, Daniel L Peterson, Maureen R Hanson
- **A new clinical challenge: supporting patients coping with the long-term effects of COVID-19** (*Fatigue: Biomedicine, Health & Behavior*, Oct 2022)
  Neal C. Goldberg, Sabrina Poirier, Allison Kanas, Lisa McCorkell, Carrie Anna McGinn, Yochai Re'em, Kathi Kuehnel, Nina Muirhead, Tahlia Ruschioni, Susan Taylor-Brown, Leonard A. Jason
- **Metabolomic Evidence for Peroxisomal Dysfunction in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome** (*Int J Mol Sci*, July 2022)
  Xiaoyu Che, Christopher R Brydges, Yuanzhi Yu, Adam Price, Shreyas Joshi, Ayan Roy, Bohyun Lee, Dinesh K

Barupal, Aaron Cheng, Dana March Palmer, Susan Levine, Daniel L Peterson, Suzanne D Vernon, Lucinda Bateman, Mady Hornig, Jose G Montoya, Anthony L Komaroff, Oliver Fiehn, W Ian Lipkin

- **Activity measurement in pediatric chronic fatigue syndrome** (*Chronic Illness*, June 2022)
  Bernardo Loiacono, Madison Sunnquist, Laura Nicholson, Leonard A Jason
- **Survey of Anti-Pathogen Antibody Levels in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome** (*Proteomes*, June 2022)
  Adam J O'Neal, Katherine A Glass, Christopher J Emig, Adela A Vitug, Steven J Henry, Dikoma C Shungu, Xiangling Mao, Susan M Levine, Maureen R Hanson
- **Plasma metabolomics reveals disrupted response and recovery following maximal exercise in myalgic encephalomyelitis/chronic fatigue syndrome** (*JCI insight*, May 2022)
  Arnaud Germain, Ludovic Giloteaux, Geoffrey E Moore, Susan M Levine, John K Chia, Betsy A Keller, Jared Stevens, Carl J Franconi, Xiangling Mao, Dikoma C Shungu, Andrew Grimson, Maureen R Hanson
- **Evaluating case diagnostic criteria for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): toward an empirical case definition** (*Disability and Rehabilitation*, March 2022)
  Karl E Conroy, Mohammed F Islam, Leonard A Jason

RESOURCES

Resources for Researchers

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.
- **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.

Resources for the ME/CFS Community

The Community Advisory Committee for the ME/CFS Research Network developed a webinar series to provide updates about ongoing research and tools that have been developed during the first four years of the research network. Each webinar features a 30-minute presentation about each research center followed by a Q&A session. Watch the full video series here.

Do you have suggestions for our newsletter? Contact us!

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