

INTRODUCTION

This newsletter provides updates and information about myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) research news, ME/CFS Collaborative Research Network (MECFSnet) news, and new and ongoing activities at the NIH related to ME/CFS.

Do you have suggestions for our newsletter? Please send them to info@mecfsnet.org.

2022 MECFSnet PUBLICATIONS

MECFSnet is pleased to spotlight a recent publication that offers the first metabolomic evidence of peroxisomal dysfunction in ME/CFS. Peroxisomes play an important role in metabolism, or processes that provide the body with energy for essential body functions. These findings suggest a series of related metabolic changes that may contribute to ME/CFS and offer potential biomarkers for this disabling and complex illness. These findings were published in the *International Journal of Molecular Sciences*.

[Metabolomic Evidence for Peroxisomal Dysfunction in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#)

Network researchers have published five papers this year and several papers are underway. Each publication is the result of hard work, innovation, and commitment to improve the diagnosis and treatment of ME/CFS.

Here is a complete list of network papers that were published in 2022:

- **[Metabolomic Evidence for Peroxisomal Dysfunction in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#)**
Che X, Brydges CR, Yu Y, Price A, Joshi S, Roy A, Lee B, Barupal DK, Cheng A, Palmer DM, Levine S, Peterson DL, Vernon SD, Bateman L, Hornig M, Montoya JG, Komaroff AL, Fiehn O, Lipkin WI
- **[Plasma metabolomics reveals disrupted response and recovery following maximal exercise in myalgic encephalomyelitis/chronic fatigue syndrome](#)**
Germain A, Giloteaux L, Moore GE, Levine SM, Chia JK, Keller BA, Stevens J, Franconi CJ, Mao X, Shungu DC, Grimson A, Hanson MR
- **[Survey of Anti-Pathogen Antibody Levels in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#)**
O'Neal AJ, Glass KA, Emig CJ, Vitug AA, Henry SJ, Shungu DC, Mao X, Levine SM, Hanson MR
- **[The Facilitation of Clinical and Therapeutic Discoveries in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Related Diseases: Protocol for the You + ME Registry Research Platform](#)**
Ramiller A, Mudie K, Seibert E, Whittaker S
- **[Orthostatic Challenge Causes Distinctive Symptomatic, Hemodynamic and Cognitive Responses in Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#)**
Vernon SD, Funk S, Bateman L, Stoddard GJ, Hammer S, Sullivan K, Bell J, Abbaszadeh S, Lipkin WI, Komaroff AL

NETWORK NEWS

MECFSnet Launches New Social Media Profiles

[MECFSnet](#) is excited to announce the two new ways to get updates on ME/CFS research news, NIH news, and our community outreach and engagement activities. Please take a moment to visit our pages and click “Like” or “Follow.”

Join us on [Twitter!](#)

Join us on [Facebook!](#)

MECFSnet Webinar Series

MECFSnet was created to synergize ME/CFS research efforts. The MECFSnet Webinar Series provides updates about ongoing research and tools that have been developed during the first 4 years of the network.

Each webinar features a 30-minute presentation from each research center and a 30-minute Q&A session. Questions were thoughtfully developed by patients with ME/CFS who are members of the network’s Community Advisory Committee (CAC).

[Watch the full video series](#) or save to watch at your convenience.

Fifth Annual All Centers Research Consortium Meeting: Collaborative Research Update

The MECFSnet convened its fifth annual meeting on June 13-14 on the NIH campus in Bethesda, MD. The hybrid meeting was attended by members from each research center—Columbia’s Center for Solutions for ME/CFS, Cornell’s ME/CFS Collaborative Research Center, the Interdisciplinary Canadian Collaborative ME Research Network, the Jackson Laboratory’s ME/CFS Collaborative Research Center, and RTI International’s Data Management and Coordination Center. NINDS director Dr. Walter Koroshetz provided opening remarks, and CAC members, including individuals with ME/CFS, convened a roundtable discussion.

Participants heard research updates from more than 30 speakers on topics such as metabolomics, immune profiling, data integration, and Long COVID. The meeting exemplified the vision of the research network—to encourage collaborative research in partnership with individuals and advocacy groups to better understand and treat ME/CFS.

RESEARCH NEWS

Research Tool Update: mapMECFS

mapMECFS (www.mapmecfs.org) is designed to ease common data-sharing hurdles, allowing ME/CFS researchers to browse, share, compare, and download ME/CFS-related datasets from within one data repository. Created by the NIH-funded MECFS Network, mapMECFS is a growing repository of ME/CFS data on a secure, flexible data-sharing platform with enhanced search capabilities available to all [registered](#) researchers.

mapMECFS hosts > **15 biological datasets from MECFS Network Principal Investigators** encompassing a range of data types including the microbiome, metabolomics, immune signatures, proteomics, and more. In total, the site contains > **40 datasets**, > **250 result files** with analytic results from > **260,000 analytes**, and > **90 registered participants** from around the globe.

Our most recently released dataset is from the Cornell ME/CFS Collaborative Research Center titled *Survey of Anti-Pathogen Antibody Levels in ME/CFS*. This includes the data and analytic results from 122 pathogen antigens in a study of 59 ME/CFS and 44 healthy control participants ([O’Neal et al. 2022](#)).

For more information about the site, please see the [mapMECFS manuscript](#) in the *Journal of Translational Medicine*. Stay tuned to future ME/CFS Network Newsletters for more updates from mapMECFS.

COMMUNITY NEWS

We are pleased to announce that the NIH ME/CFS Research Network Community Outreach and Engagement initiative is now being coordinated by the DMCC at RTI.

The cornerstone of this effort is the CAC, which was established to bridge the gap between researchers and the ME/CFS community with the goal of accelerating the pace of ME/CFS research. The CAC is a group of individuals from various professional backgrounds, all of whom have lived experience of the disease including people living with ME/CFS, caregivers, advocates, and representatives from the research centers, #MEAction, Solve ME/CFS Initiative, the Bateman Horne Center, and the U.S. ME/CFS Clinician Coalition.

The CAC, established in 2020, supported the network by developing [Guidelines for the Design of Clinical Studies in ME/CFS](#) and [Priorities for ME/CFS Research](#). The CAC also led the [MECFSnet Webinar Series](#) by developing researcher questions and interviewing teams from each research center. The CAC is currently working to translate and promote findings from recent network publications.

Please stay tuned for more communication updates from the CAC as we work to promote network research and better understand the implications of these findings.

NIH IN THE NEWS

NIH Program Director Vicky Whittemore, PhD, joined with other ME/CFS experts to explore how Long Covid might shed light on ME/CFS in a recent [Freakonomics, MD podcast](#). The 33-minute episode covers a number of important topics, including the history and stigma of ME/CFS and how NIH is funding collaborative research to understand the disease and develop better diagnosis and treatment.

To prepare for the future of ME/CFS research, NINDS will lead a strategic planning effort to develop an ME/CFS Research Roadmap to outline research that will lead to a better understanding of the cause(s) of ME/CFS and improvements in diagnosis and treatment. Using previous input as a starting point, ME/CFS stakeholders, including people affected by the disease, advocates, and researchers and clinicians will work together to develop the ME/CFS Research Roadmap. More information will be distributed soon!

RESOURCE SPOTLIGHT

Tools for Researchers:

- [mapMECFS](#) - 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](#) - searchMECFS is an interactive search tool for navigating biospecimens available for research purposes from studies of ME/CFS.