

Dear ME/CFS community members,

The National Institutes of Health (NIH) is seeking self-nominations of persons living with ME/CFS, individuals with a family history of ME/CFS, caregivers/care partners for persons with ME/CFS, or ME/CFS patient advocates to serve on the newly formed **ME/CFS Research Roadmap Working Group** of the National Advisory Neurological Disorders and Stroke (NANDS) Council.

This Working Group will meet regularly in 2023 to discuss and develop a Research Roadmap for ME/CFS, identifying research priorities that will lead to interventional clinical trials for ME/CFS. The Working Group will include ME/CFS basic and clinical experts from the research community, leaders of ME/CFS 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 identify as ME/CFS patient advocates. Members of the Trans-NIH ME/CFS Working Group will coordinate the activities of the ME/CFS Research Roadmap Working Group together with staff from the National Institute of Neurological Disorders and Stroke (NINDS) Office of Science Policy and Planning and the NINDS Office of Neuroscience Communications and Engagement.

Self-nominations from individuals from historically under-represented groups are encouraged. See eligibility requirements and application information below.

Qualifications of Eligibility

- Experience with ME/CFS, e.g., as a person with living with ME/CFS, person with a family history of ME/CFS; a family member or a caregiver/care partner of a person with ME/CFS; or a patient advocate
- Have some knowledge of current research on ME/CFS
- Available and able to participate in up to eight 60-minute videoconference or phone meetings over the next 10-12 months
- Have a reasonable command of the English language
- Able to clearly and succinctly articulate your views through oral and written communications (use of proxy permitted)
- Have a reasonable level of comfort with email and in navigating the internet (downloading and uploading files, filling forms etc.), with assistance, if needed.
- Over the age of 18
- Willing to have your name publicly posted on the roster for the ME/CFS Research Roadmap Working Group

Details of Role

Self-nominees invited to serve on the Working Group will be full-voting members and will be expected to follow all guidelines put forward for the group. During Working Group meetings, all members will be expected to participate in discussions and share their opinions and perspectives. Self-nominees should be comfortable expressing their individual views on a panel that includes clinician scientists, researchers, and subject matter experts.

Selection Process

NIH staff will review the self-nominations and make selections based on nominees' connection to ME/CFS research, stated interest and ability to participate in the Working Group's efforts, and to ensure a diversity of backgrounds and perspectives. NINDS staff may contact short-listed nominees in

December 2022 by email, phone, or videoconference for final selection before an invitation is sent to participate on the Working Group. Self-nominees who are not selected for this Working Group will have the option to indicate if they wish to be contacted for future possible engagement opportunities.

To Apply

Complete this form: [{LINK}](#)

AND

Email a resume (in Microsoft Word format) to MECFSResearchRoadmap@ninds.nih.gov with the email subject line: Self-Nomination for ME/CFS RRWG - [YOUR FULL NAME]

The application deadline is December X, 2022 by XX:XX PM ET.

Please send any questions to MECFSResearchRoadmap@ninds.nih.gov.