

Self-Nomination for ME/CFS Research Roadmap Working Group

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The National Institutes of Health (NIH) is leading an effort to develop a Research Roadmap for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Towards this end, the National Institute of Neurological Disorders and Stroke (NINDS) has formed the **ME/CFS Research Roadmap Working Group of the National Advisory Neurological Disorders and Stroke (NANDS) Council**. This 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.

To identify members of the public who are living with ME/CFS, have a family history of ME/CFS, are caregivers/care partners or advocates for those living with ME/CFS to participate in the Working Group, NINDS is asking for interested individuals to self-nominate. Nominees should be comfortable expressing their individual view(s) on a panel that includes clinician scientists, researchers, and subject matter experts.

Please answer the questions below to nominate yourself as a potential participant in this Working Group. All information shared via this form is done entirely voluntarily. Please send any questions to MECFResearchRoadmap@ninds.nih.gov.

The deadline to submit responses is **December X, 2022 at X:XX ET**.

* Required

1. I am self-nominating to serve on the ME/CFS Research Roadmap Working Group of NANDS Council. *

Yes

No

2. Please share how you identify: *

- Person living with ME/CFS
- Person with a family history of ME/CFS
- Caregiver/care partner for person(s) living with ME/CFS
- Patient advocate
- None of the above

3. Please provide your first and last name. *

Enter your answer

4. Please provide your preferred email address to receive correspondence. *

Enter your answer

5. Please provide your preferred phone number for communications. *

Enter your answer

6. Please confirm you meet the following Qualifications of Eligibility (check all that apply): *

- 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

7. Please share the reason(s) for your interest in participating in this research roadmap development process. *

Enter your answer

8. Please indicate which ME/CFS advocacy groups, organizations, or foundations you are affiliated with, if any. *

Enter your answer

9. Please provide a **brief** description of any relevant experience; for example, experience with the disease, experience seeking out or participating in clinical research, or experience interacting with the broader ME/CFS community. Please be as specific as possible relating to involvement and/or interactions (ex. advisory, consultancy, participatory) with regard to ME/CFS research efforts. *

Enter your answer

10. Please send one resume (in Microsoft Word format) to MECFResearchRoadmap@ninds.nih.gov with the email subject line: Self-Nomination for ME/CFS RRWG – [YOUR FULL NAME]. *

I will email my resume ASAP

11. Please include any accommodation requests, including use of a communication proxy, here. *

Enter your answer

12. If I am not selected for this Working Group, I would be interested in future engagement opportunities. *

Yes, you can retain my data and connect with me regarding participation in future engagement opportunities

No, please do not retain my data and do not contact me about future engagement opportunities.

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