

Hello,

The Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) investigative team at NIH would like to extend you an invitation. As you know, persons with ME/CFS frequently experience adverse symptoms after exertion, an experience called 'post-exertional malaise'. We are currently looking for volunteers with ME/CFS to participate in a focus group that will discuss the experience of post-exertional malaise.

A focus group is a type of research in which a group of people is asked about their perceptions, opinions, and experiences. For this study, questions about post-exertional malaise will be asked to all the members of the group, who are then free to discuss their answers with each other. The information collected as part of this focus group will be used to develop an interview tool for assessing post-exertional malaise. This tool will be used in an NIH study of post-infectious ME/CFS (see <http://mecfs.ctss.nih.gov/> for details). The focus group will take place over the telephone and will last one to two hours. The focus group will consist of about five participants. The identity of all participants will be kept confidential. We will use first names only. Participants are not required to use their actual names if they prefer not to. The telephone call will be recorded and transcribed.

To participate, you need to have been diagnosed with ME/CFS, have experienced post-exertional malaise, and be willing to provide the investigative team basic information about yourself. Participants in the focus group will not be eligible to participate in the NIH study of post-infectious ME/CFS. If you wish to seek to participate in the post-infectious ME/CFS study, you should NOT participate in the focus group. There is no compensation for participating in the focus group.

If you are interested in participating or have any additional questions about the focus group, please call (301) 496-1788. You also may contact Ms. Barbara Stussman, the NIH investigator who will conduct the focus groups at the email address below:

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