

\_\_\_\_\_, 2014

To those of you with knowledge of ME, CFS and ME/CFS:

**DePaul University's Center for Community Research is currently recruiting respondents for a study on myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) mortality. We are looking to recruit surviving family members, friends, and/or caregivers of individuals who had been diagnosed with ME or CFS and are now deceased.**

A number of patient organizations are now using the term Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS ) to describe the disease, while others know the disease as Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME). We would like your responses, regardless of what you call this disease.

Our intention is to document the experience of these deceased individuals, and the experience of their family and friends, to improve our knowledge of ME and CFS and to help those individuals who are currently suffering from the illness. We understand that more than one person may occasionally report on the same individual who has passed away, and that is completely fine. There has been almost no research done on ME and CFS mortality in the U.S. or internationally since it is not generally recognized that people die as a direct result of having ME or CFS.

**Participation in this study is voluntary.** We understand that this is a sensitive topic and it may be emotionally difficult for some individuals to participate. However, we believe the information we will obtain in this study has the potential to change the perception of this disease from “just being tired” or at worst not too serious to the reality of its life-altering disability for those who suffer from it.

**The medical community and relevant government agencies need to be informed of the frequency and circumstances of deaths resulting from having ME and CFS. The purpose of this study is to document the severity and consequences of ME and CFS.**

The study will have two phases: phase 1 will involve a confidential online study. At the end of phase 1, participants can choose to identify themselves and volunteer for phase 2 which will consist of an in-person or phone interview.

We would greatly appreciate your forwarding this email, along with the attached flyer, to your contacts with interests in or connections to ME and CFS so we can reach the largest audience possible. DePaul University has published many studies of ME and CFS and is a well-respected source of information about the disease.

**If you meet the criteria for the study (knew someone well who was diagnosed with ME or CFS and is now deceased, and you are at least 18 years old), please use this link to access the study:**  
**<https://redcap.is.depaul.edu/surveys/?s=DHxuYxScEn>**.

You can also contact the study by telephone at 773-325-1164 or by email at **[DePaulMECFSResearch@gmail.com](mailto:DePaulMECFSResearch@gmail.com)** with any questions you may have or to receive a copy of the questionnaire by postal mail. Thank you for your time, consideration, and help. Although there is no financial incentive for this study, your participation can serve to help those still struggling with ME and CFS.

Sincerely,

Abby Brown, M.A.  
Principal Investigator, ME and CFS Mortality Study  
DePaul University  
Center for Community Research  
990 West Fullerton Avenue, Suite 3100  
Chicago, IL 60614  
773-325-1164; [depaulmecfsresearch@gmail.com](mailto:depaulmecfsresearch@gmail.com)