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Tuberous Sclerosis Complex Fact Sheet

The UCSF Memory and Aging Center has had an ongoing study of Frontotemporal Dementia (FTD) and related disorders including Alzheimer's disease (AD), since 2002. The name of the study is Frontotemporal Dementia: Genes, Images and Emotions. In the course of that study, we have evaluated participants who coincidentally have a diagnosis of Tuberous Sclerosis Complex (TSC). As we studied TSC, we have wondered whether some individuals with this condition offer clues into why some of us develop memory problems associated with aging and why others do not. We are asking you to participate in this study to better understand any links in the physiology of these diseases.

- 1) We are inviting you to participate in this study because you have been diagnosed with TSC.
- 2) The connection between TSC and FTD and AD is unknown; in order to better understand the physiology of both diseases, we are hoping to evaluate you through our protocol.
- 3) This is an exploratory approach to better understanding of the physiology of both diseases
- 4) As a participant you will be asked to:
 - a. Sign a consent form
 - b. Participate in cognitive assessments of memory and thinking
 - c. Complete an MRI of your brain
 - d. Complete a blood draw for genetic testing and research investigation of biomarkers
 - e. Interview with a genetic counselor
 - f. Meet with a neurologist who will ask you questions about your history, test your thinking, and assess your movement
 - g. Participate in additional studies of emotional and social cognition
 - h. Optionally be referred to and participate in additional research studies with our UCSF collaborators

To learn more about this project, please call Andrew Liu MD, MS at 415-502-7602 or email andrewj.liu@ucsf.edu

Thank you for your consideration of participation in this program,

Bruce L. Miller, MD

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