

4/11/17

Dear Fabry Community,

Research Study Information

In the past 10 years, scientists have identified a link between Gaucher disease, a lysosomal storage disease, and Parkinson disease. There is evidence that Parkinson disease involves abnormalities in the lysosome, and may be associated with other lysosomal storage diseases as well. Though there are currently no strong evidence to associate Fabry disease with Parkinson disease, we are interested in examining if Fabry disease mutations may be linked to Parkinson's.

This survey is geared at estimating the prevalence of Parkinson's among individuals with Fabry disease and among their first-degree family members. Participation in the study requires only the completion of a questionnaire that asks about family history of Parkinson's. The questionnaire can be completed online, over the phone or in person, does not require any further participation or follow-up, does not ask for any personal identifying information, and can be completed in approximately 10-20 minutes.

You may access the survey here:

<http://bit.ly/2oRRpkG>

or at

https://cumc.co1.qualtrics.com/jfe/form/SV_6JQY7cfXYbmFNLD

If you have any questions about this survey project, please contact Dr. Amy Yang and the Lysosomal Storage Disease Program at Mount Sinai Medical Center at [212-241-0915](tel:212-241-0915).