

Emory Study of Learning and Movement

What is the Emory Study of Learning and Movement?

The Emory Study of Learning and Movement, or ESLM, is a study of the gene called *FMR1* and its effect on learning and movement problems in older men. Carriers of one form of this gene (called “premutation”) are at increased risk for a late-onset neurodegenerative disorder, fragile X-associated tremor/ataxia syndrome (FXTAS). We are recruiting men with or without symptoms of FXTAS, to participate in this study. You do not have to be a carrier of fragile X mutation to be eligible for this study.

How do I participate?

In order to participate, you will be asked to sign a consent form and provide a cheek brush sample. A cheek brush is a gentle, sterile brush which you rub on the inside of the cheeks in your mouth. You may collect the sample yourself and mail it back to us. A small portion of participants will be asked to be in the follow-up study of learning and movement. By donating a cheek brush you are not obligated to participate in the follow-up study. Some people will be asked to donate a blood sample so that we may learn more about this gene.

Where will the study take place?

The collection of the cheek brush sample can take place at your home. We will mail you a collection kit with a postage-paid return envelope. The follow-up portion of the study involves tests of learning and movement, and a neurological evaluation. This part may take place at Emory University or, if it is more convenient, at your home.

How is this study funded?

We are funded by the National Institutes of Health (NIH). Projects funded by the NIH must follow strict guidelines regarding participant confidentiality and informed consent.

Will I be informed of my genetic test result from this study?

Yes. If you want to know your genetic result, we will tell you. Some men we test may have a premutation form of the gene that puts them at risk for having a grandchild with fragile X syndrome. Also, men with the premutation form of the gene may be at risk for a movement disorder (tremor/ataxia syndrome). These findings may cause emotional discomfort. We can reduce possible discomfort by offering resources and counseling. If you so request, we will NOT inform you of your test result.

What are the benefits of participating in this study?

Eligible participants will receive a neurological exam, including a brain MRI, and a summary of the findings from the neurologist to share with your physician. We cannot promise that our study will be of direct benefit to you, but by taking part, you will help us understand how the *FMR1* gene influences learning and movement problems.

If you would like to participate in our research or if you would like additional information, please contact Lisa Shubeck, Senior Research Coordinator, at (404) 778-8478 or lshubec@emory.edu.