

# MTM1 CARRIER SURVEY

## GOAL/OBJECT OF STUDY

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The Beggs Lab invites *MTM1* carriers to complete a questionnaire examining the features and possible symptoms present in women who are carriers for genetic changes, or mutations, in the *MTM1* gene. When a male has inherited this genetic change, he is affected with X-linked myotubular myopathy. We hope to learn more about what symptoms, if any, a female carrier may have to be better able to characterize the impact of *MTM1* mutations on the body.

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## STEPS FOR PARTICIPATION

Women who choose to complete this questionnaire will be asked to answer questions about their past medical history and current health status during a telephone interview. This call will take between 30 to 45 minutes and can be scheduled at your convenience. We will send the questionnaire to you in advance if you would like to review the questions prior to our scheduled phone call.

## GET INVOLVED

If you **are enrolled in the Beggs Lab** and would like to complete this questionnaire for *MTM1* carriers, please contact Lindsay Swanson, the genetic counselor for the Beggs Lab, to arrange a time for the telephone interview.

If you **are not previously enrolled in the Beggs Lab** and would like to participate in this questionnaire, please contact Lindsay to discuss how to get involved as a participant in the Beggs Lab.

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If you have any questions about our research or myotubular myopathy in general, please contact:

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