



University of Colorado **Anschutz Medical Campus**

# PARTICIPATING IN RESEARCH



# TYPES OF RESEARCH STUDIES

## OBSERVATIONAL

- Observational studies collect information from participants over a period of time without intervention
- Used to help researchers, clinicians, and industry partners better understand FSHD to improve care and hasten therapeutic development

## INTERVENTIONAL

- Interventional trials test the safety and efficacy of a potential treatment
- Used to help researchers and industry partners evaluate potential therapies for FSHD

# VISITS AND ASSESSMENTS

## VISITS

- Observational studies typically involve less visits
- Interventional trials require more frequent visits to monitor safety and supply the study medication
- The length of a visit varies depending on the type and number of assessments required

*Common assessments one can expect at a study visit for FSHD:*

- Vital Signs
- Electrocardiogram (or ECG)
- Physical and Neurological Exam completed by an Investigator
- Manual Muscle Testing and Reachable Workspace completed by a clinical evaluator
- Blood draw
- Questionnaires

*Less common assessments that can lead to longer visits:*

- MRI
- PK Sampling

# QUESTIONS TO CONSIDER

- What is required of me during the trial?
- What is the time commitment?
- How will this affect my day-to-day life?
- Does this trial offer travel arrangement or reimbursement for onsite visits, or will I have to cover that myself?
- What are the potential risks?
- What are the potential benefits?
- How will your care during the trial be managed?
- What are my alternatives to participating?

# WHERE TO FIND STUDIES

## LOCALLY

- Neuromuscular Research page within the Department of Neurology at CUAnschutz.edu (QR code below)



## NATIONALLY

- ClinicalTrials.gov
- FSHDSociety.org

Both have key information about eligibility, study design, and participating locations





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**THANK YOU**