

MYOTONIC DYSTROPHY CLINICAL RESEARCH NETWORK



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Active DMCRN Natural History Studies

Establishing Biomarkers and Clinical Endpoints in Myotonic Dystrophy Type 1 (END-DM1)

This is an observational study following DM1 patients at 3-4 visits over 24 months.

Inclusion Criteria:

- 18-70 years old at time of enrollment
- Clinical diagnosis of DM1 or positive genetic test

Exclusion Criteria:

- Symptomatic renal or liver disease, uncontrolled diabetes or thyroid disorder, or active malignancy other than skin cancer
- Current alcohol or substance abuse
- Concurrent enrollment in clinical trial from DM1 or participation in the past 6 months of enrollment
- Pregnancy at any time point of participation
- Concurrent medical condition that would compromise participation or safety

*Non-ambulatory participants are not excluded, but limited to 15% of total enrollment

Assessing Pediatric Endpoints in DM1 (ASPIRE-DM1)

This is an observational study following CDM/ChDM patients at 4 visits over 18 months.

Inclusion Criteria:

- Neonate to 4 yrs, 11 mos at time of enrollment
- Diagnosis of CDM or ChDM, both symptomatic and genetically confirmed

Exclusion Criteria:

- Any other illness that would compromise participation or safety
- Significant trauma within 1 month of enrollment
- Internal metal or devices
- History of bleeding disorder or platelet count <50,000
- History of reaction to local anesthetic

DMCRN Sites

Contact Jennifer or Ruby for which sites are actively recruiting for END-DM1 and ASPIRE-DM1 studies.

NORTH AMERICA

HOUSTON METHODIST RESEARCH INSTITUTE

THE OHIO STATE UNIVERSITY

STANFORD UNIVERSITY

UNIVERSITE DE SHERBROOKE – QUEBEC

UNIVERSITY OF CALIFORNIA, LOS ANGELES

UNIVERSITY OF CALIFORNIA, SAN DIEGO

UNIVERSITY OF COLORADO, DENVER

UNIVERSITY OF FLORIDA

UNIVERSITY OF IOWA

UNIVERSITY OF KANSAS

UNIVERSITY OF ROCHESTER

UT SOUTHWESTERN

VIRGINIA COMMONWEALTH UNIVERSITY

EUROPE

CENTRO CLINICO NEMO

INSTITUT DE MYOLOGIE – PARIS

FRIEDRICH-BAUR INSTITUT - LMU MUNICH

RADBOUD UNIVERSITY – NL

ST. GEORGE'S, UNIVERSITY OF LONDON

UNIVERSITY COLLEGE LONDON

NEW ZEALAND

UNIVERSITY OF AUCKLAND