To be filled out by parent/legal guardian of participant/subject:

Is there a family history of any of the following? Please indicate any first or second degree blood relatives (i.e., siblings, parents, cousins, grandparents) that have/had the following conditions:

Table 1 Family History

| Condition | Family History? | Family Side(see key 1) | Relationship of Family Member to Participant/ Subject(See Key 2 - Choose all that apply) |
| --- | --- | --- | --- |
| 1. Difficulty walking
 | [ ]  Yes [ ]  No | Data to be entered bData to be entered by site y site | Data Data to be entered by site to be entered by site |
| 1. Intellectual disability
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. Contractures
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. Muscle weakness
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |

Any history of consanguinity (parents distantly related to one another)? [ ]  Yes [ ]  No

Is there a family history of CMD to LGMD spectrum disorder? [ ]  Yes (fill out chart below)[ ]  No (end form)

Please indicate any first or second degree blood relatives (i.e., siblings, parents, cousins, grandparents) that have/had the following conditions:

Table 2 Family History of Consanguinity

| Condition | Family History? | Family Side(see key 1) | Relationship of Family Member to Participant/ Subject(See Key 2 - Choose all that apply) |
| --- | --- | --- | --- |
| 1. Collagen VI CMD
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. Dystroglycanopathy
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. Merosin deficient CMD
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. SEPN1 related myopathy (Rigid spine)
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. L-CMD
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. Alpha 7 integrin CMD
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. CMD, undiagnosed
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |
| 1. Other, specify:
 | [ ]  Yes [ ]  No | Data to be entered by site | Data to be entered by site |

Table 3 Family Member Keys

| Key 1 | Key 2 | Key 2 | Key 2 | Key 2 |
| --- | --- | --- | --- | --- |
| Maternal | Mother | Brother | Daughter | Aunt |
| Paternal | Father | Grandmother | Son | Cousin |
| Unknown | Sister | Grandfather | Uncle | Other, specify |

For each individual identified above in either table, please record thefollowing:

Table 4 Family Side/Relationship Table

| Family Side/Relationship (from above) | Alive/Deceased | Year of Birth | Age at First Symptoms | Age at Death |
| --- | --- | --- | --- | --- |
| Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site |
| Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site |
| Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site |
| Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site |

## General Instructions

Information on each disease is gathered for blood relatives based on self-report from the participant/subject or family member. The conditions listed are taken from the data collected for control samples in the NINDS Genetics Repository ([NINDS Human Genetics DNA and Cell Line Repository](http://ccr.coriell.org/Sections/Collections/NINDS/?SsId=10) ) and may need to be modified for a particular study.

## Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.

* Other Condition, specify – If a family member has a condition not listed, specify the condition under "Other".
* Family History? – If there is a history of this condition in the family, indicate yes.
* Family Side – Select the family side (i.e., maternal, paternal, unknown) of the individual with the condition. Choose only one.
* Relationship of Family Member to Participant/Subject – Select the relationship from the options of the family members listed in the “Name of Family Member with Condition” column. Record more than 1 family member, if applicable.
* Alive/Deceased – Record if the individual is alive or deceased
* Year of Birth – Record the year the individual was born using the format YYYY. If unknown, record as “9999”
* Age at first symptoms – Record the age in years the individual first experienced symptoms of the condition. If unknown, record as “UNK”
* Age at Death – Record the age in years the individual died using the format YYYY. If unknown, record as “9999”.