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”.