Was CRF information collected:  At visit  By phone  By Mail (letter)

## Medication Changes

Review Medication List on Prior and ConMed form with family

1. Have you had any medication changes since your last visit?  Yes  No

## Interval History Change

(If Yes is answered to any of the questions below, update appropriate CRF)

### Interval Illness or Hospitalization

Review Hospitalization list on Surgical and Hospital History with family

1. Have you had any illnesses since your last study visit(s)?  Yes  No
2. Have you had any hospitalizations since your last study visit(s)?  Yes  No
3. Have you had any ER visits since your last study visit(s)?  Yes  No
4. Have you had any wheezing since your last visit?  Yes  No
5. Have you been intubated since your last visit?  Yes  No
6. Have you had a tracheostomy since your last visit?  Yes  No

### Interval Change in Noninvasive Ventilation (NIV) or Ventilator Settings?

Review NIV (BiPAP) and Ventilator Settings on Intake Medical History with family

1. Have your BiPAP/Ventilator settings been adjusted since your last visit?

Yes  No

If Yes, NIV settings: IPAP: EPAP:

If Yes, ventilator settings: Tidal Volume (ml): PEEP: Backup rate:

1. Have you had any aspiration or choking episodes since your last visit?

Yes  No

1. Have you started using mechanical in/ex-sufflation (cough assist) since your last visit?

Yes  No

### Interval Surgery

Review Surgical History on Surgical and Hospital History with family

1. Have you had any scoliosis surgeries since your last study visit?  Yes  No
2. Have you had any other surgery since your last study visit?  Yes  No
3. Have you had a G-Tube placed since your last study visit?  Yes  No

### Interval Disease Progression or Accidents?

1. Have you had any new contractures since your last study visit?  Yes  No
2. Have you broken a bone since your last study visit?  Yes  No
3. Have you dislocated a joint since your last study visit?  Yes  No
4. Have you noticed any change in strength since your last study visit?

Yes, I feel weaker

No change

Yes, I feel stronger

1. Are you able to roll over in bed unassisted?

Yes, I can roll over completely from back to front

Yes, I can roll to my side

No, I cannot roll over on my own

1. If walking, have you been falling or stumbling (tripping) more often since your last visit?

Yes  No

1. Has it become more difficult to feed yourself?  Yes  No
2. Have you had a change in how much physical therapy you receive since your last visit?

Yes  No

If Yes, how much change in physical therapy since your last visit?

Increased  Decreased  Don’t go to physical therapy

1. Have you had a change in how much speech therapy you receive since your last visit?

Yes  No

If Yes, how much change in speech therapy since your last visit?

Increased  Decreased  Don’t go to speech therapy

1. Have you had a genetic confirmation of CMD to LGMD spectrum disorder since your last visit?

Yes No

If Yes, which gene has been identified as mutated?

## History by System

(If Yes is answered to any of the questions below, add to AE form)

1. Have you had any arrhythmias (heart rhythm problem) since your last study visit?  Yes  No
2. Have you had cardiomyopathy (enlarged heart) since your last study visit?  Yes  No
3. Have you had frequent urinary tract infections (UTI) since your last study visit?  Yes  No

If Yes, how frequent?

0

1-2

3-4

> 5

1. Have you developed scoliosis since your last study visit? Yes  No
2. Have you had any seizures since your last study visit?  Yes  No
3. Have you had behavioral issues since your last study visit?  Yes  No
4. Have you developed depression since your last study visit?  Yes  No
5. Have you developed anxiety since your last study visit?  Yes  No
6. Have you had frequent upper respiratory infections (URI) since your last study visit?  Yes  No

If Yes, how frequent?

None

1-2

3-4

> 5

1. Have you had pain in a new location since your last study visit?  Yes  No

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If Yes, which joints had pain?

Neck

Shoulder

Elbows

Wrists

Fingers

Hips

Knees

Ankles

### Current Motor Function

Table Current Motor Function

| Motor Function | Still maintained? | Age lost (years) | Date Lost (YYYY‑MM) |
| --- | --- | --- | --- |
| 1. Able to run | Yes  No | Data to be entered by site | Data to be entered by site |
| 1. Able to climb stairs using a handrail | Yes  No | Data to be entered by site | Data to be entered by site |
| 1. Able to walk outdoors without assistance > 10 steps | Yes  No | Data to be entered by site | Data to be entered by site |
| 1. Able to walk indoors without assistance > 10 steps | Yes  No | Data to be entered by site | Data to be entered by site |
| 1. Able to walk with assistance (including walker, calipers, of KAFOs) | Yes  No | Data to be entered by site | Data to be entered by site |
| 1. Able to sit when placed | Yes  No | Data to be entered by site | Data to be entered by site |
| 1. Able to hold head up | Yes  No | Data to be entered by site | Data to be entered by site |

### Missing Value Codes:

A = Lab or equipment failure

M = Ran out of time

N = No data

X = Unknown

E = Examiner error

O = Obsolete CRF

D = Not applicable

P = Unable to test due to permanent disability

T = Unable to test due to temporary condition

S = Scheduling problem

## General Instructions

Interval Medical History data are collected to assess changes in disease progression or health status from study visit to study visit. This captures new conditions/symptoms that occurred from the last study visit to this visit.

## Specific Instructions

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

* Missing Value Codes – Please use these codes for all questions where a value is requested but no value is available. The purpose of these codes is to prevent any blanks on the CRF.