MHFMS and MHFMS-EXTEND
FOR CHILDREN WITH SPINAL MUSCULAR ATROPHY

GENERAL TESTING DIRECTIONS

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Developed in collaboration with Project Cure SMA Team
### MHFMS and MHFMS-Extend General Directions

#### Testing Methods

1. Evaluator must observe actual activity, not score based on parent report. Parent report should be documented on Clinical Report Form (CRF) form only.

2. Allow only 3 attempts for each item. Proceed to next item after 3rd attempt. Score is based on the best performance of the 3 trials.

3. Parents may be present and may give verbal encouragement, but they cannot provide any physical contact that supports the trial.

4. Assure parents that variability is part of the tested issue. This will allay their concerns that you may not be observing their child's best performance on every item.

5. Test instructions: Test instructions are defined for each test item. The evaluator should provide instructions as noted for each item without additional directions as to how to specifically perform task. You want to assess the individual's natural and typical everyday performance. Providing instructions as to specific strategy to use or quality of movement is not allowed unless indicated for a test item. Verbal directions may be provided and examples of such are provided within the manuals. The evaluator may also provide a demonstration if necessary.

6. Start position: Evaluators should try to place child in the start position for an item if child cannot attain that position independently. In order to accurately assess the child and score an item the correct starting position must be achieved either independently or with assistance.

7. Parental Assistance: If child will not cooperate without parental assist, the parent may place child in positions as needed (e.g. #13 holds position when placed). Clearly instruct or show the parent/guardian the correct position in which to place the child. Parental assist should be limited and used only when absolutely necessary.

8. Behavioral compliance: If it is felt that the child's best performance is not being observed during your test session this should be noted in the appropriate section of the score sheet or on the Clinical Report Form (CRF).

9. Timing of tasks: Counting is one second per digit (one one thousand, two one thousand...). Although a stopwatch is not necessary you may use a stopwatch to be sure you are timing accurately.

10. Order of test items: Perform items in the order listed on the score sheet. Item order minimizes position changes. In addition, maintaining a consistent order of items from one test to the next will minimize fatigue and is essential if the test is to be used for research purposes to limit the effects of fatigue on performance.

11. Clothing: The child should wear a bathing suit or underwear or short sleeve shirt with shorts. Hair should be tied back. No socks or shoes should be worn unless specifically indicated for a specific test item. Placing armbands on subject's R ankle and subject's R wrist prior to initiation of testing will make it easier to distinguish right and left sides during testing.

12. Orthoses: No orthoses (AFO's, TLSO's or other bracing, etc) should be used during testing unless specifically indicated for an item. If the task cannot be completed without the use of an orthosis on an item that specifies no orthosis should be used the score should be recorded as 0 (unable to perform).

13. Subject should attempt **ALL** items even if you think they may not succeed based on performance on previous items.
14. It is important to give lots of positive feedback to the child, whether they achieve the requested item or not.

15. Rest breaks are allowed between items if necessary. Please be sure to include rest breaks in the overall time required for test completion.

16. Safety: Sound judgment by the subject and clinical evaluator must be used to determine the safety risks involved with each task. If the subject feels uncomfortable with a task, reports pain that will limit performance of a task or the risk of falling during task performance is significantly increased, the test should not be performed. Falls can result in serious injuries in this subject population, especially in those persons with inadequate strength and function of upper extremities. If parent reports that the child may fall, do not attempt task. All subjects must be guarded appropriately for safety during all tasks, but especially during upright and timed task performance.

17. Safety: Remember to provide head support to the child when necessary for safety.

**Test Environment**

1. Limit the use of toys. If possible, use toys only after testing, as a reward, rather than during testing.

2. Limit distractions to greatest degree possible during testing.

3. Clean all toys and mats between subjects.

4. Two high density, 4' by 6' blue or green* floor mats or treatment plinths should be placed together as a test surface. *The color of the mats is not important unless you are filming the child for research purposes. Blue and/or green mats will film best.

**Scoring**

1. Evaluator should rate all items during actual testing session.

2. When in doubt of the scoring of an item, repeat the item up to 3 times.

3. If you think it is not the child's best performance (e.g. they do a 1, but can probably achieve a 2), you may repeat the item up to 3 times to see if their performance improves.

4. The best performance score of the 3 trials is recorded.

5. If a subject cannot/does not physically attempt a task, score should be recorded as 0 on the CRF.

**Score Sheet/Data Collection**

1. Evaluator may use test item booklet with descriptors during testing. Testing scores should be recorded directly in test booklet. After testing scores should be transferred to the Case Report Form (CRF). Evaluator should complete comment column on CRF during testing.

2. On skills where start or end position is requested (1, 3, 4, 5, 15, 17) or where other additional info is requested (3, 7, 16) please be sure to document in comments column on the CRF.

3. Evaluator completes all items in the Test Booklet during testing. Be sure to code accurately for all missing or incomplete data collection.

4. CRF and Test Booklet should be turned in at end of test or rating session to site coordinator. Evaluator should not have access to CRFs after testing/scoring is completed. The evaluator should not have access to or review previous test results prior to reassessing an individual as this may bias your assessment.
5. Record on the CRF the density of the mat used for this assessment: low, medium or high density.

6. Record on the CRF the start time and end time of testing.

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**MHFMS-Extend modules general directions**

1. All tests should be performed in an area that has good lighting and is free of distractions. Tests may be videotaped.

2. Subject should wear bathing suit (preferred) or shorts and short sleeve or sleeveless T-shirt.

3. Place athletic armband on right wrist and right ankle. These should stay on for the duration of testing and will assist the evaluator in distinguishing right from left sides for several tasks.

4. **Gross Motor and Timed Tasks:** Use of shoes, socks and braces is item specific. No shoes, socks, or braces should be used unless item specifies that these items are allowed. No assistive devices allowed unless specified under test item.

   **Fine Motor:** Items are performed sitting in an appropriate size chair and table. Feet should be touching the floor. Adjust benches and Table-mate (adjustable table) appropriately or use foam blocks to accommodate sitting posture for individual subject. Elbows and forearms may be resting/supported on the table. For tasks that are tested at the tabletop may use wheelchair if needed and/or chest strap. Please note on CRF and on CE Reminder Sheet if wheelchair is used. No assistive devices or upper extremity splints allowed unless specified under test item. The only exception is a TLSO, which may be worn only if required by a post-op protocol for a child that may have had a recent spinal fusion. If TLSO used please mark on CRF and CE Reminder Sheet.

5. Demonstrations by the Clinical Evaluator (CE) are allowed. If the person being tested does not understand directions, the evaluator may demonstrate the task.

6. For **fine and gross motor**, if the subject does not perform the task by the third trial, discontinue and move on to the next item. For **timed tasks** time to perform is measured in seconds with a stopwatch. All test scores are reflective of the task achievement, not the motor performance process.

7. Safety: Sound judgment by the subject and clinical evaluator (CE) must be used to determine the safety risks involved with each task. If the subject feels uncomfortable with a task, reports pain that will limit performance of a task or the risk of falling during task performance is significantly increased, the test should not be performed. Falls can result in serious injuries in this subject population, especially in those persons with inadequate strength and function of upper extremities. If a parent/guardian says the subject may fall, do not attempt task. All subjects must be guarded appropriately for safety during all tasks, but especially during upright and timed task performance.

8. No physical assist or physical prompting that supports the trial should be given by the CE or family/guardian. Verbal encouragement may be provided using suggested directional cues. Specific, detailed directions as to how to move limbs or body to complete tasks are not allowed.

9. If a subject cannot or does not physically attempt a task, record as a 0 on the CRF.