



**Mesure de la Fonction Motrice**  
pour les maladies neuromusculaires

## **DATABASE**

### **Case Report Form**

#### ***MFM Study Group***

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## PATIENT'S ID

Family Name (birth name) : |\_|\_|\_|\_|\_\_\_\_\_

(At least 3 first letters – eventually full name)

Married Name : |\_|\_|\_|\_|\_\_\_\_\_

(At least 3 first letters – eventually full name)

First name |\_|\_|\_|\_\_\_\_\_

(At least 2 first letters – eventually full name)

Date of birth : I\_|\_| I\_|\_| I\_|\_| I\_|\_| I\_|\_|  
                  dd      mm      yyyy

Gender :       M I\_| I 1       F I\_| I 2

Handedness : Right I\_| I 1       Left I\_| I 2       Not determined/both I\_| I 3

Clinical Diagnosis (code) : I\_|\_| I\_|\_| I\_|\_| or specify if not in list : .....

(Check at each visit in case of change of diagnosis)

Genetic information: Mutated gene if known (eg, COL6, LMNA...), number CTG repeats for DMI, number SMN copies for SMA, or other : .....

Age at onset of signs (that have led to first visit) |\_|\_|\_|, |\_|\_| years (0= at birth, ND=unknown)

Date of Death : I\_|\_| I\_|\_| I\_|\_| I\_|\_| I\_|\_|

~~Participation to the validation study of the 2nd version – French and Swiss centers only: yes I\_| I 1 no I\_| I 0~~

## VISIT DATA

Name of Physician : .....

Consent signed : yes I\_| I 1 no I\_| I 0

(recommended, can be obtained at further visit if not at 1st visit)

Date of completion of the MFM scale : I\_|\_| I\_|\_| I\_|\_| I\_|\_| I\_|\_| (last day if MFM done over 2 days)  
  dd      mm      yyyy

Diagnosis : Confirmed : I\_| I 1   suspected : I\_| I 0

Genetic testing : yes I\_| I 1   no I\_| I 0       If yes : year of samplings : I\_|\_| I\_|\_| I\_|\_|

Participation to a clinical trial presently or previously (or since last visit) ? yes I\_| I 1   no I\_| I 0

If yes, specify : DMD steroids I\_| I 1, ASIRI I\_| I 2, MFM-20 validation I\_| I 3, PTC 124 I\_| I 4, TROPHOS1 I\_| I 5,  
NM Grades of Severity I\_| I 6 ULENAP I\_| I 7 DM1DEXA I\_| I 8 TROPHOS2 I\_| I 9

Other I\_| I : specify ..... (contact Dr C Payan)

Date of inclusion in the trial : :I\_|\_| I\_|\_| I\_|\_| I\_|\_| I\_|\_|   Date of end: I\_|\_| I\_|\_| I\_|\_| I\_|\_| I\_|\_|  
  dd      mm      yyyy   dd      mm      yyyy

Ongoing I\_| I

Medications ongoing (or modified or initiated since last visit) ? yes I\_| I 1   no I\_| I 0

Si yes, complete the table «Concomédications» page 9

## MEDICAL HISTORY AND PRESENT CLINICAL FEATURES

**Ambulation acquired** (10 steps without human help)      yes I\_\_ I 1      no I\_\_ I 0

If yes, age of walking acquisition : I\_\_ I\_\_ I\_\_ I\_\_ months      Unknown I\_\_ I 9

**Loss of ambulation** : yes I\_\_ I 1      no I\_\_ I 0      Not applicable I\_\_ I 9

If YES, Age of loss of ambulation (cannot walk 10 steps without human help) : I\_\_ I\_\_ I years      I\_\_ I months

Date unknown I\_\_ I

**Ventilation** : yes I\_\_ I 1      no I\_\_ I 0

If YES, Continuous I\_\_ I 1      Intermittent I\_\_ I 2

Non invasive I\_\_ I 1      Invasive (tracheostomy) I\_\_ I 2

### Orthopedic surgical history:

			dd	mm	yyyy
Upper limbs	no I__ I 0	yes I__ I 1	date of last intervention	I__ I__ I__ I__ I__ I__ I__ I__	
Hips	no I__ I 0	yes I__ I 1	date of last intervention	I__ I__ I__ I__ I__ I__ I__ I__	
Knees	no I__ I 0	yes I__ I 1	date of last intervention	I__ I__ I__ I__ I__ I__ I__ I__	
Feet	no I__ I 0	yes I__ I 1	date of last intervention	I__ I__ I__ I__ I__ I__ I__ I__	
Spine	no I__ I 0	yes I__ I 1	date of last intervention	I__ I__ I__ I__ I__ I__ I__ I__	

### Surgery other than orthopedic:

			dd	mm	yyyy
Tracheostomy	no I__ I 0	yes I__ I 1	date:	I__ I__ I__ I__ I__ I__ I__ I__	
Gastrostomy:	no I__ I 0	yes I__ I 1	date:	I__ I__ I__ I__ I__ I__ I__ I__	
Cardiac surgery:	no I__ I 0	yes I__ I 1	date:	I__ I__ I__ I__ I__ I__ I__ I__	
Other (that could interfere with motor function) :	no I__ I 0	yes I__ I 1	date:	I__ I__ I__ I__ I__ I__ I__ I__	

Specify:.....

### Vignos grade: \_\_\_\_\_

- 1 - walks and climbs stairs without assistance
- 2 - walks and climbs stairs with aid of railing
- 3 - walks and climbs stairs slowly with aid of railing (over 12 seconds for 4 standard steps)
- 4 - walks unassisted and rises from chair but cannot climb stairs
- 5 - walks unassisted but cannot rise from chair or climb stairs
- 6 - walks only with assistance or walks independently with long leg braces
- 7 - walks in long leg braces but requires assistance for balance
- 8 - stands in long leg braces but unable to walk even with assistance
- 9 - is in wheelchair.
- 10 - is confined to bed.

### Brooke Grade: \_\_\_\_\_

- 1 - starting with arms at the sides, the patient can abduct the arms in a full circle until they touch above the head.
- 2 - can raise arms above head only by flexing the elbow (i.e. shortening the circumference of the movement) or using accessory muscles.
- 3 - cannot raise hands above head but can raise an 180ml glass of water to mouth (using both hands if necessary).
- 4 - can raise hands to mouth but cannot raise an 180ml glass of water to mouth.
- 5 - cannot raise hand to mouth but can use hands to hold pen or pick up pennies from the table.
- 6 - cannot raise hands to mouth and has no useful function of hands.

**Wheelchair use** : yes I\_\_ I 1 no I\_\_ I 0

If yes :      manual      I\_\_ I 1      electrical      I\_\_ I 2      manual + electrical      I\_\_ I 3

The overall severity of the motor disability is :      Mild      moderate      severe      very severe  
I\_\_ I      I\_\_ I      I\_\_ I      I\_\_ I  
1      2      3      4

## DATA AT COMPLETION OF THE MFM

### INFORMATIONS CONCERNING THE MFM EXAMINER:

First Name and last name: .....

Year of first experience in the evaluation of Neuromuscular disorders : I\_\_I\_\_I\_\_I\_\_I yyyy

Date of initial training validated (test of validation passes) with the MFM I\_\_I\_\_I I\_\_I\_\_I I\_\_I\_\_I\_\_I\_\_I dd mm yyyy

Date of last participation to a training session of reactualisation of the MFM : I\_\_I\_\_I I\_\_I\_\_I I\_\_I\_\_I\_\_I\_\_I dd mm yyyy

**Fatigue/tiredness** of patient at start of completion compared to usual state :

Ask : «How do you feel compared to your usual state of wellbeing? »

Better than usual	I__ I 1
As usual	I__ I 2
More tired than usual	I__ I 3
Far more tired than usual	I__ I 4

**Completion of the MFM:** 32 items I\_\_ I 1

20 items I\_\_ I 2 (for subjects younger than 7 years – the items highlighted in grey in the scale)

Are both sides tested systematically? yes I\_\_ I 1 no I\_\_ I 0





*Si YES, complete for items tested both sides, first the side chosen by the patient then the other side*

**MOTOR FUNCTION MEASURE (MFM)**

For each item, report in comments in case of refusal, pain, technical aid during completion....

Items of the MFM scale	Rating		
	D1 =	D2 =	D3 =
1. 😊 SUPINE, HEAD IN MIDLINE POSITION: holds the head for 5 seconds in midline position and turns it completely from one side to the other. comments : .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
2. SUPINE: raises the head and maintains the raised position for 5 seconds comments : .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
3. 😊 SUPINE: flexes the hip and knee more than 90° by raising the foot during the whole movement. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 comments : .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
4. 😊 SUPINE, LEG SUPPORTED BY EXAMINER: from the plantar flexion, dorsiflexes the foot to at least 90° in relation to the lower part of the leg. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 comments : .....			<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3
5. 😊 SUPINE: raises the hand and moves it to the opposite shoulder. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 comments : .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
6. 😊 SUPINE, LOWER LIMBS HALF-FLEXED, KNEECAPS AT THE ZENITH AND FEET RESTING ON THE MAT SLIGHTLY APART: maintains for 5 seconds the starting position then raises the pelvis ; the lumbar spine, the pelvis and the thighs are aligned and the feet slightly apart. comments: .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
7. 😊 SUPINE: turns over into prone and frees both upper limbs from under the trunk. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 comments : .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
8. SUPINE: without upper limb support sits up. comments: .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
9. 😊 SEATED ON THE MAT: without upper limb support, maintains the seated position for 5 seconds and is then capable of maintaining contact 5 seconds between the two hands. comments: .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
10. 😊 SEATED ON THE MAT, THE TENNIS BALL PLACED IN FRONT OF THE PERSON: without upper limb support, leans forward, touches the ball and sits back again. comments: .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	

Items

	D1=	D2=	D3=
11. 😊 SEATED ON THE MAT: without upper limb support, stands up. <i>comments:</i> .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
12. 😊 STANDING: without upper limb support, sits down on the chair with the feet slightly apart. <i>comments:</i> .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
13. SEATED ON THE CHAIR: without upper limb support nor leaning against the back of the chair, maintains the seated position for 5 seconds, with the head and trunk in midline position. <i>comments:</i> .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
14. 😊 SEATED ON THE CHAIR OR IN THE WHEELCHAIR, HEAD IN FLEXION: from head in complete flexion, raises the head then maintains it raised for 5 seconds, the head stays in midline position throughout the movement and the holding position. <i>comments:</i> .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
15. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, FOREARMS ON THE TABLE BUT NOT ELBOWS: places both hands on top of the head at the same time while the head and trunk remain in midline position. <i>comments:</i> .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
16. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, THE PENCIL ON THE TABLE: without moving the trunk, reaches the pencil with one hand, forearm and hand off the table with the elbow in full extension at the end of the movement. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <i>comments :</i> .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
17. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, 10 COINS ON THE TABLE: successively picks up and holds 10 coins in one hand during the 20-second period. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <i>comments :</i> .....			<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3
18. 😊 SEATED ON THE CHAIR OR IN THE WHEELCHAIR, ONE FINGER PLACED IN THE CENTER OF THE FIXED CD: goes round the edge of the CD with the same finger without hand support on the table. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <i>comments :</i> .....			<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3
19. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, THE PENCIL ON THE TABLE: picks up the pencil and draws a continuous series of loops inside the frame and over its full length touching the top and bottom line of the frame. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <i>comments :</i> .....			<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3
<b>Trial n°1</b>  <b>Trial n°2</b> 		contralateral trial n°1  contralateral trial n°2 	

Items

Items	D1=	D2=	D3=
20. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, HOLDING THE SHEET OF PAPER: tears the sheet of paper folded in 4, beginning from the fold edge. <i>comments:</i> ..... .....			<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3
21. 😊 SEATED ON THE CHAIR OR IN THE WHEELCHAIR, THE TENNIS BALL ON THE TABLE: picks up the ball, and turns the hand over completely holding the ball. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <i>comments :</i> ..... .....			<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3
22. 😊 SEATED ON THE CHAIR OR IN THE WHEELCHAIR, ONE FINGER PLACED IN THE CENTER OF THE DIAGRAM: raises the finger and places it successively on the 8 drawings without touching the lines. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <i>comments :</i> ..... .....			<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3
23. 😊 SEATED ON THE CHAIR OR IN THE WHEELCHAIR, UPPER LIMBS ALONG THE TRUNK: places the two forearms and/or the hands on the table at the same time without moving the trunk. <i>comments:</i> ..... .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	
24. 😊 SEATED ON THE CHAIR: without upper limb support, stands up with the feet slightly apart. <i>comments:</i> ..... .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
25. 😊 STANDING WITH UPPER LIMB SUPPORT ON EQUIPMENT: without upper limb support, maintains a standing position for 5 seconds with the feet slightly apart, the head, trunk and limbs in midline position <i>comments:</i> ..... .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
26. STANDING WITH UPPER LIMB SUPPORT ON EQUIPMENT: without upper limb support, raises the foot for 10 seconds. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <i>comments :</i> ..... .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
27. 😊 STANDING: without support, touches the floor with one hand and stands up again. <i>comments:</i> ..... .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
28. STANDING WITHOUT SUPPORT: takes 10 steps forward on both heels. <i>comments:</i> ..... .....	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		

Items	Report page 7	D1=	D2=	D3=
29. STANDING WITHOUT SUPPORT: takes 10 steps forward on a line. <i>comments:</i> ..... .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
30. 😊 STANDING WITHOUT SUPPORT: runs 10 meters. <i>comments:</i> ..... .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
31. STANDING ON ONE FOOT WITHOUT SUPPORT: hops 10 times in place. side: right : <input type="checkbox"/> left : <input type="checkbox"/> contralateral score: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <i>comments :</i> ..... .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
32. 😊 STANDING WITHOUT SUPPORT: without upper limb support, manages to squat and gets up twice in a row. <i>comments:</i> ..... .....		<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3		
<b>TOTAL</b>		<b>D1=</b>	<b>D2=</b>	<b>D3=</b>

Duration of completion : I\_\_I\_\_I\_\_I Minutes

Cooperation of patient : none I\_\_I 0, moderate I\_\_I 1, optimal I\_\_I 2

Comments on overall testing and results obtained: (if nothing particular, report NAD )

.....

.....

## SUMMARY OF RATINGS

### MFM 32 ITEMS

#### DIMENSION

#### TOTAL COTATIONS IN % PER DIMENSION

D1. Standing and transfers  $\frac{\text{Total Dimension 1}}{39} = \frac{\quad}{39} \times 100 = \dots\dots\dots \%$

D2. Axial and proximal motor function  $\frac{\text{Total Dimension 2}}{36} = \frac{\quad}{36} \times 100 = \dots\dots\dots \%$

D3. Distal motor function  $\frac{\text{Total Dimension 3}}{21} = \frac{\quad}{21} \times 100 = \dots\dots\dots \%$

**TOTAL SCORE** =  $\frac{\text{total of ratings}}{32 \times 3} \times 100$

=  $\frac{\quad}{96} \times 100$

=  $\dots\dots\dots \%$



## MFM 20 ITEMS

### DIMENSION

### TOTAL COTATIONS IN % PER DIMENSION

**D1.** Standing and transfers       $\frac{\text{Total Dimension 1}}{24} = \frac{\quad}{24} \times 100 = \dots\dots\dots \%$

**D2.** Axial and proximal motor function       $\frac{\text{Total Dimension 2}}{24} = \frac{\quad}{24} \times 100 = \dots\dots\dots \%$

**D3.** Distal motor function       $\frac{\text{Total Dimension 3}}{12} = \frac{\quad}{12} \times 100 = \dots\dots\dots \%$

**TOTAL SCORE**      =  $\frac{\text{total of ratings}}{20 \times 3} \times 100$   
=  $\frac{\quad}{60} \times 100$   
=  $\dots\dots\dots \%$

**PRESENT MEDICATIONS OR TAKEN WITHIN THE LAST 3 MONTHS**

Report medications taken regularly by patient within the last 3 months (at first MFM) or modified since last evaluation  
 The shaded boxes will be completed by the CRA or the curator

Brand Name or ICD <i>completed par CRA</i>	Indication **	Daily Dose ***	Route (*)	date of start	date of end
..... CODE I I I I I I I	..... I I I I I I I		I _ I _ I	I _ I _ II _ I _ II _ I _ I	I _ I _ II _ I _ II _ I _ I Ongoing <input type="checkbox"/> 1 Stopped <input type="checkbox"/> 0
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(\*) 1= oral, 2= intravenous, 3= intramuscular, 4= topical, 5= subcutaneous, 6= rectal,  
 7= intra-nasal, 8= transcutaneous, 9= eye drops, 10= vaginal, 11=by inhalation, 12= other,  
 99= unknown

\*\* NO ABBREVIATION Please

\*\*\* Use « PRN » (Pro Re Nata – as needed) where necessary