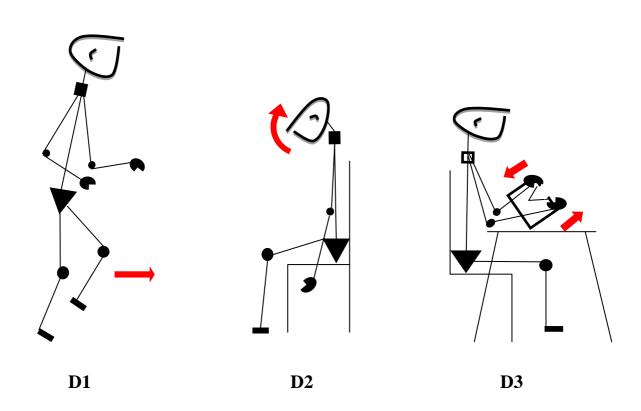


# User Manual MFM-32 & MFM-20

# 3<sup>rd</sup> Edition 2016- Erratum



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# CONSTRUCTIONS AND VALIDATIONS

# **CONSTRUCTION OF THE MFM**

Before 1998, the L'Escale pediatric rehabilitation service used the Gross Motor Function Measure (Russell et al., 1989), translated as the Evaluation Motrice Fonctionelle Globale, to objectively evaluate the motor skills of children with pathologies such as infantile spinal muscular atrophy or congenital myopathies, even though this tool has not been validated for these disorders. This tool is adapted to motor deficiency of central-nervous origin, with its specific characteristics, and not to the motor deficiency due to muscle weakness: only a few of the items concern upper limb function and no item relates to distal motor function.

An exhaustive study of the literature (Guinvarc'h, 1998) confirmed the lack of a clinical tool adapted to neuromuscular diseases for the precise evaluation of patient performance in the domain of global and segmental motor function. This review of the literature, together with advice from several international groups, encouraged us to create a new tool for the evaluation of the trunk and the upper and lower limbs which enables us to follow the motor evolution of groups of affected subjects, irrespective of the disease severity. The aim was also to create a scale that is adapted to both children and adults.

#### **VALIDATION OF THE MFM-32**

A provisional scale consisting of 75 items in both English and French, and illustrated by a video, was sent to 166 national and international groups. The criticisms expressed by 47 of these groups (Physical Medicine, Neurology and Pediatrics from both Europe and North America) were then analyzed by the MFM Francophone group which met for the first time in September 1998. The first version of the scale, which included 51 items and was written in French, was submitted for validation. The validation study for this first version of the MFM took place between May 2000 and February 2001 and included the participation of 17 centers and 376 subjects. The lessons learned from the results made it possible to produce a 2<sup>nd</sup> version with 32 items, which became the final version of the MFM-32.

The validation study for the final version of the MFM-32 took place between May 2002 and March 2003. It involved 303 subjects aged from 6 to 60 who were affected by progressive Duchenne or Becker muscular dystrophy, facio-scapulo-humeral muscular dystrophy, limb-girdle muscular dystrophies, congenital muscular dystrophy, congenital myopathies, myotonic dystrophy, spinal muscular atrophies and hereditary sensory-motor neuropathy.

The results of this validation study demonstrated the following metrological characteristics (Bérard et al., 2005):

- Inter- and inter-observer reliability ranging from good to excellent for all items
- Construct validity by factorial analysis (identification of the 3 motor functions D1, D2, D3)
- Validity against criteria
- Discriminant validity: depending on diagnosis and severity

The sensitivity to changes was studied between 2003 and 2004 in 152 neuromuscular patients (Bérard et al., 2006; Vuillerot et al., 2012), and specifically for Duchenne muscular dystrophy (Vuillerot et al., 2010) and spinal muscular atrophy (Vuillerot et al., 2013)

In 2006, demands from researchers and clinicians led to the validation of the MFM in children under 6 to be considered. After having considered the validation of the actual 32-item MFM, a study in 2007 on 4 French sites with 191 healthy children demonstrated that some items were not suitable for a child undergoing psychomotor development. By eliminating items that were failed by more than 80% of the healthy children tested, a reduced MFM with 20 items was defined. Between March 2008 and March 2009, the MFM-20 validation study involved children aged from 2 to 7. It was a multicentric study with 10 French, 1 Swiss and 2 Belgian centers involving 88 children with neuromuscular disease (de Lattre et al., 2013).

## THE DIFFERENT FRENCH EDITIONS OF THE USER MANUAL

The first edition of the user manual appeared in 2004. The second edition in 2006 featured a simplification of the scoring instructions. Important concepts were included in the text for each item, and no longer as footnotes. The later versions in 2009 and 2016 were enriched by discussions between professionals during training sessions and via the website (<a href="www.mfm-nmd.org">www.mfm-nmd.org</a>). It is preferable to use this 3<sup>rd</sup> version, which is more precise, although the earlier versions are still valid as the items and scoring have not changed.

# **CHARACTERISTICS OF THE MFM**

# THE MFM-32 AND THE MFM-20 SCALES AND THEIR CHARACTERISTICS

The MFM-32 and MFM-20 scales provide a numerical measure of the motor capacity of a subject with a neuromuscular disorder.

### THE DOMAINS

The items of the MFM-32 and MFM-20 are classified in 3 domains:

D1: Standing and transfers (13 items for the MFM-32 and 8 items for the MFM-20);

D2: Axial and proximal motor function (12 items for the MFM-32 and 8 items for the

D3: Distal motor function (7 items for the MFM-32 and 4 items for the MFM-20).

### THE ITEMS

MFM-20);

Some of the items which constitute these 2 scales are static and others are dynamic. The items are tested in supine, seated or standing positions.

They are numbered from 1-32 and arranged in a logical order. The domain of each item is noted on the user manual and on the scoring sheet.

The items of the MFM-20 are identified by a ②. These 20 items are numbered: 1, 3, 4, 5, 6, 7, 9, 10, 11, 12, 14, 18, 21, 22, 23, 24, 25, 27, 30 and 32.

Each item is scored on a 4-point scale with precise instructions detailed in this "User Manual", to be consulted constantly during testing.

To facilitate the analysis of the subject's performance, a maximum of two motor function components are taken into account for the scoring of each item. For example, in some items the examiner may control the range of the movement, and in others the position of a joint and the transition from one position to another. Furthermore, scoring is facilitated by information contained in the paragraph "Additional Instructions". Generic scoring is defined as follows:

- 0: Cannot perform the task, or cannot maintain the starting position
- 1: Initiated the task
- 2: Performs the movement incompletely, or completely but imperfectly (compensatory movements, position maintained for an insufficient duration of time, slowness, uncontrolled movement)
- 3: Performs the task fully and "normally"; the movement is controlled, mastered, directed and performed at constant speed

If the subject refuses to attempt the item, if the item is forgotten or the conditions of the examination do not enable its safe execution and the initial starting position is not respected, the score for the item is 0. A refusal can be noted on the commentary line on the scoring sheet. A score of 1 corresponds to a movement which has been initiated or partially completed. Partial achievement of a task may be due to either a weakness or a pain which limits the range of the movement, or to a retraction or ankylosis. Joint limitations prevent a maximum score for only some items. A subject who has limited function due to one or more tendon retractions or joint limitations or pain is scored in the same way as one who does not have the strength to perform the movement. For the majority of items, a score of 2 corresponds to either an achieved movement with compensatory movements or slowness, or to a position which cannot be maintained for the time required, or to a partially achieved movement. A score of 3 corresponds to the performance of an able-bodied subject.

### DISEASES FOR WHICH THE MFM CAN BE USED

In addition to the diseases which were used to validate the MFM (cf Validation of the MFM p1), the scale can be used to follow the evolution of all subjects that are affected by muscle weakness. In case of the publication of the results, it is, however, imperative to indicate that the MFM has been used, despite the fact that it has not been validated for the pathology presented by these subjects. This is because it has fulfilled a clinical need for the study of this group. The tool has been created and its use by professionals will extend its field of application.

# **TRAINING**

In order to familiarize examiners with the use of the MFM and its rigorous scoring principles, a training session is required. For routine clinical use, this training may be administered by a colleague who has already been trained, using a DVD for MFM self-training, or ideally by taking part in a training session with video support.

Between June 2004 and March 2016, more than 930 different types of therapists have participated in MFM training sessions, mainly physical therapists, occupational therapists and physicians. The training is also suggested for psychomotor specialists. During the training sessions, details provided by the trainer will improve the competence of the user. A validation test is carried out at the end of the training session to make sure the MFM is used correctly. Passing this test is imperative for using the MFM in a clinical research context.

It is recommended that the scale be practice on at least 2 subjects before taking into account the score obtained.

Since 2012, a self-training DVD on the use of the MFM has been available in French in order to allow the training of small teams who wish to use the MFM and to enable them to rigorously self-train. The information on acquiring this DVD is available on the website <a href="https://www.mfm-nmd.org">www.mfm-nmd.org</a>.

Updating the MFM user's competencies is possible by analyzing video clips on the website <a href="www.mfm-nmd.org">www.mfm-nmd.org</a>. Therapists may take as many "Competency Quizzes" as they wish. Before participating in clinical research, investigators may be required to achieve a minimal score of 8 in two "Competency Quiz" sessions.

# THE TEST

### MATERIAL

Before administering the MFM, the examiner should have a copy of the User Manual, an MFM scoring sheet and all the equipment which is listed below. The same equipment should be used for every test. If replacement equipment is used, this should be noted on the scoring sheet so it can be taken into account when the subject is tested at a later date.

- A physiotherapy mat or a wide examination table.
- Cushions for comfortable positioning of the head and limbs.
- A table set at a height that allows the subject to have their forearms resting on the table when seated and elbows flexed at 90°.
- A chair (with adjustable height if possible). The height of the seat should be such that the subject's feet touch the floor when he is seated, with the hips and knees flexed at 90°.
- Space within a corridor to enable free movement of 10 meters
- A line traced on the floor, approximately 2 centimeters wide and 6 meters long.
- A stopwatch
- A CD or CD-ROM glued onto a piece of cardboard, with the label side against the cardboard. The edge of the small circle and the circumference of the CD should be colored with a felt-tip pen.
- 10 coins about 20 mm in diameter and 2 mm thick (10 euro cents or equivalent)
- A tennis ball with a happy face © drawn on it
- A lead pencil
- Sheets of A4 paper or equivalent, 70 g or 80 g.

# **CLOTHING AND CORSETS (ORTHOSES)**

Subjects should wear light clothing which will not interfere with movement (underwear or T-shirts close to the body, tights).

They should be without orthoses and bare-footed, as shoes are considered as orthotic devices.

Under no circumstances should orthotic devices for lower limbs be used for items performed while standing, walking and during transfers.

A subject who cannot sit without a corset receives a score of 0 for items where the corset interferes with motor function.

### STARTING POSITION OF THE SUBJECT

The starting position is important to consider. If this position cannot be achieved, the score for the item is 0. The starting position is defined by the text in capital letters (upper-case) following the number of the item. It is specified in the paragraph "starting position".

For items 1 to 10, the subject should be positioned on a mat or a wide examination table, lying flat, then seated. The adjective "comfortable" used to describe the starting position signifies that cushions may be used for a better positioning of the subject. Do not place the cushion under the part of the body to be tested. Do not use the supine position allowed by a multi-position wheelchair. For items 11, 12 and 24 to 32, the subject should be able to stand on the floor or on a mat. A subject who cannot stand, even with support, obtains a score of 0 for these 11 items. For items 14 to 23, the subject may be seated in a wheelchair. The examiner should remove the armrests and the tray, which can be replaced by a table adjusted to the subject's height.

#### THE NUMBER OF ATTEMPTS AND SCORING

The "task to perform" line explains the action to be tested in the item. The examiner gives instructions as a function of the different scoring levels, expected performances, and the age and level of comprehension of the subject.

For each scoring of each item, the subject has two tries. The examiner may propose a second try if he thinks that the subject can obtain a better score than that obtained initially. The best result is the one scored. If there is hesitation about the score, the lowest one should be used.

For all items in which no special details are mentioned, all strategies used by the subject are acceptable.

### THE TEST

The test should be administered without any manual aid from the examiner or anyone else, except for items 4 and 14. However, the examiner should provide encouragement and stimulation so that the subject will achieve their best score. Spoken information, demonstrations (examiner either opposite or next to the subject) or movements performed on the subject by the examiner to better explain the task, are allowed. These demonstrations are not to be counted as part of the two authorized tries. For example, items 19 and 22 require a horizontal plane. However, a subject whose head is stabilized by a chin strap can see better if the support is tilted. In this case, it is possible to perform a demonstration with good visibility, the support remaining inclined, and then carry out the scoring on the horizontal plane.

Throughout the test, the examiner should be vigilant and consider the risk of a fall if the subject attempts motor performances beyond their ability. However, the validation study has shown that most subjects have a good understanding of their motor abilities and refuse to attempt certain tasks that would place them in danger. Finally, the subjects should be encouraged to attempt the items even if they think they cannot achieve them. During the validation study, the test revealed unexpected motor capacities in 14% of cases.

The test should be administered in a single session, if possible, or in two sessions, with a maximum interval of 7 days between the two sessions. The average time to complete the MMF-32 is 30 to 40 minutes with a cooperating subject.

## ORDER OF ITEMS AND SCORING - WHICH SIDE TO USE

The order of the items must be respected. If this order is not respected, it should be noted on page 5 of the scoring sheet.

For the items which concern one side (items 3, 4, 5, 7, 16, 17, 18, 19, 21, 22, 26 and 31), the subject chooses the side to be tested before attempting the item. If the examiner asks or the subject requests it, two

tries may be attempted on each side. For items 18, 19 and 26, two tries are possible on each side for each scoring level. The best performance is taken into account for calculating the scores; the performance on the opposite side is reported on the "commentary" line on the scoring sheet.

# **COLLECTION OF DATA AND SCORES**

## **SCORING SHEET**

Versions in French, English, German, Spanish, Italian, Dutch, Portuguese, Turkish and Arabic can be downloaded from the website <a href="www.mfm-nmd.org">www.mfm-nmd.org</a>. The scoring sheet displays the domain of each item and facilitates the transcription of scores and the calculations necessary per domain and for the total score. The "commentary" lines of the scoring sheet can be used to note specific details observed during the test. Some of the comments give information on the scores attributed and are useful for the interpretation of the scores and their evolution over time.

### **CALCULATION OF SCORES**

The scores are expressed as a percentage in relation to the maximum score. The score for each domain corresponds to the sum of the scores obtained by the subject for the items in that domain divided by the maximum score for the domain and multiplied by 100. For the MFM-32, the total score is the sum of all the scores (in all the domains) divided by 96 and multiplied by 100. For the MFM-20 the total score is the sum of all the scores divided by 60 and multiplied by 100.

### **MONITORING CURVE**

To facilitate the reading of successive results obtained by a subject over time, the results of each MFM can be transcribed in graphic form (see example at the end of this Manual). The Excel formats which produce these curves can be obtained by simple request from the website <a href="https://www.mfm-nmd.org">www.mfm-nmd.org</a>.

# MFM DATABASE

The MFM database has been collecting results of MFM tests administered to children and adults with identified or suspected neuromuscular diseases since 2007. The database was developed by D. Hamroun of the Clinical Research Directorate (Direction à la Recherche Clinique) at the CHU de Montpellier. The MFM database is freely accessible at several evaluation centers and allows all identified practitioners, therapists, or physicians to collect and consult the data. The database has been declared (N° 1255105, September 2007) to the French National Commission on Information Technology and Liberties (CNIL - Commission Nationale de l'Informatique et des Libertés). Its functioning is regulated by a charter and internal regulations which can be consulted on the website <a href="https://www.mfm-nmd.org">www.mfm-nmd.org</a>.

For the MFMs entered in the database, the scores and graphical representation (monitoring curve) are automatically calculated.

# STEERING COMMITTEE

A MFM steering committee was formed in 2007. It is responsible for the scientific quality of the MFM. It strictly monitors the studies using the data from the database, it is responsible for the diffusion of the scale on an international level, it assures the quality of the translations of the user manual and diffuses the training tools.

This committee is composed of doctors and paramedics from different French teams involved in the development of the MFM, representatives from the AFM, representatives involved in the development of the MFM database, methodologists and doctors from child and adult neuromuscular consultations.

# INTERNATIONAL DIFFUSION

Following the publication of the results of the MFM-32 validation study and the presentation of the scale at several international congresses, numerous contacts were established with several international teams. The rigor of the translations and training is the best guarantee of the homogenization of scores for an optimal reproducibility.

The adoption of the MFM by numerous groups should facilitate the follow-up of patients and international clinical research.

# TRANSLATIONS OF THE USER MANUAL

To validate a translation, as well as a reverse translation, a validation workshop is required. During this workshop, the texts of the items are checked using video clips.

Workshops have already taken place for the translation of the MFM into English (2006), Spanish (2007), Dutch (2008), Portuguese (2009), German (2010), Italian (2011), Turkish (2012) and Arbis (2012). The manuals validated in foreign languages may be downloaded from the website <a href="www.mfm-nmd.org">www.mfm-nmd.org</a>. Groups that wish to translate the MFM into another foreign language should inform contact@mfm-

## ONE CONTACT IN EACH COUNTRY

There should be one reference person identified in each country using the MFM. If you wish to appear on this reference list please contact us at contact@mfm-nmd.org.

The list of reference persons is available from the website www.mfm-nmd.org.

nmd.org to avoid translation by several groups at the same time.

Since 2007, the website <a href="www.mfm-nmd.org">www.mfm-nmd.org</a> has been facilitating the dissemination of information about the MFM and its development. The site exists in 3 languages: French, English and Spanish. On this site, individuals will find all the information about the history of the MFM, current news, publications, research projects, training possibilities with dates and locations of the sessions. The User Manual and the scoring sheet may be downloaded freely in several languages. There is a module for updating the competencies of the user which allows novice or confirmed examiners, equipped with the MFM User Manual, to score the performance of subjects presented on video clips and thereby judge their own competency in the administration of the MFM.

# **ACKNOWLEDGEMENTS**

The validation and development of the MFM-32 and the MFM-20 are the fruit of an intense and sustained collaboration of numerous French teams, two Belgian teams and one Swiss team which constituted a study group which validated this tool in several hundred patients. It was composed of the following people: Doctor M. Fournier-Méhouas, V. Tanant and C. Fafin, physiotherapists, Hôpital de l'Archet, Nice; Doctor F. Beltramo, Doctor F. Rumeau, C Marchal, C. Capello and I. Mugnier, physiotherapists, Hôpital Brabois, Nancy; Doctor D. Fort and M. Desingue, physiotherapists, Centre de Rééducation Enfants, Flavigny sur Moselle; Doctor I. Poirot, Doctor C. de Lattre, P. Rippert, Clinical Research Associate, A. Berruyer, Y. Chartier, D. Vincent-Genod, F. Girardot and F. Margirier-Locqueneux, physiotherapists, Escale, Hospices Civils de Lyon; Doctor J. Lachanat and D. Denis, physiotherapist, Fondation Richard, Lyon; Doctor J. Nielsen, Doctor V. Spehrs-Chiaffi, C. Glardon, C. Piot and S. Igolen-Augros, physiotherapists, Hôpital Orthopédique, Lausanne, Switzerland; Doctor A. Fares, Doctor G. Le Claire and Doctor J.L. Le Guiet, D. Lefeuvre-Brule, physiotherapist, Centre de Kerpape, Ploemeur; Doctor J.Y. Mahé, C. Nogues and AS. Perrau-Gouin, physiotherapists, Centre de Pen Bron, La Turballe; Doctor L. Feasson, Doctor MC d'Anjou, A. Jouve, C. Goyet and V. Henriroux, physiotherapists, Hôpital Bellevue, Saint Etienne; Doctor M. Schmuck of the Service de Soins à Domicile, Roanne; Doctor P. Kieny and G. Morel, physiotherapist, Résidence la Forêt, Saint Georges sur Loire; Doctor J.A. Urtizberea, Doctor C. Themar-Noel, Doctor F. Cottrel, Doctor V. Doppler, G. Ollivier and J. Paulus, physiotherapists, Institut de Myologie, Hôpital Pitié-Salpêtrière, Paris; Doctor F. Vandenborre, Doctor B. Estournet, Doctor S. Quijano, C. Pastorelli, N. Vedrenne and S. Morel-Lelu, physiotherapists, Hôpital Raymond Poincaré, Garches; Doctor I. Desguerre, Hôpital Saint-Vincent de Paul, Paris; Doctor E. Boulvert, Centre de rééducation Petit Tremblay, Corbeil-Essonnes; Doctor B. Pialoux, Doctor P. Gallien and F. Letanoux, physiotherapist Centre Hospitalier Régional Pontchaillou, Rennes; Doctor P. Dudognon, Doctor J.Y. Salle, F. Parpeix and P. Morizio, physiotherapists Centre Hospitalier Universitaire Dupuytren, Limoges; Doctor V. Bourg and B. Moulis-Wyndels, physiotherapist Centre Paul Dottin, Ramonville Saint Agne; Doctor JP. Gayraud Centre Hospitalier Toulouse; Doctor M. Marpeau, Doctor F. Barthel, D. Trabaud, D. Rouif and M Vercaemer, physiotherapists, Centre St Jean de Dieu, Paris; Doctor G. V. Tiffreau, Doctor G. Viet and B. Degroote, physiotherapist, Hôpital Swinghedauw, Lille; Doctor A. Carpentier and I. Bourdeauducq, physiotherapist, Centre Marc Sautelet, Villeneuve d'Ascq; Doctor F. Rivier and C. Payet-Laury physiotherapist Centre Hospitalier Gui de Chauliac, Montpellier; Doctor A. Renders and V. Kinet physiotherapist Cliniques Universitaires Saint-Luc, Brussels; Doctor N. Goemans and M. Van Den Hauwe physiotherapist, Louvain. The assistance of Jacques Paulus and Jean-Claude Riou was solicited several times.

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The development of the MFM has benefited from the financial and logistical support of the French Muscular Dystrophy Organization (Association Française contre les Myopathies) and the Hospices Civils de Lyon.

This study could not have been accomplished without the participation of hundreds of subjects who took part in the validation studies, and we would like to thank them here.

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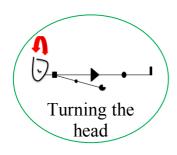
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# SCORING OF THE ITEMS MFM-32 & MFM-20





**MFM-20** 

# 1. SUPINE, HEAD IN MIDLINE POSITION

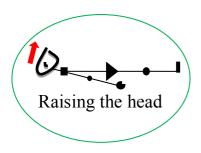
Starting position: Place the subject on the mat or the wide examination table with the upper and lower limbs in a comfortable position. Place the subject's head in the midline position<sup>1</sup>.

**Task to perform:** To hold the head in the midline position and then to turn it from one side to the other.

**Additional instructions:** "To turn the head completely" signifies that part of the ear touches the mat or the table. Turning only the eyes is a score of 0. Turning the head completely to one side is a score of 1. If the trunk of the subject participates during the movement of the head, the score is limited to 2.

- Move a small hand-held toy to encourage the child to turn their head.
- O: cannot hold the head for 5 seconds in the midline position and/or cannot turn it
- ✓ 1: holds the head for 5 seconds in the midline position and turns it partially, at least to one side
- 2: holds the head for 5 seconds in the midline position and turns it completely from one side to the other, with difficulty
- 3: holds the head for 5 seconds in the midline position and turns it completely from one side to the other

<sup>&</sup>lt;sup>1</sup> "Head and/or trunk in midline position" signifies that the head and the trunk are correctly positioned in the three dimensions. They are vertical (neither in flexion nor in extension in relation to the sagittal plane) and not tilted to the side (the eyes are at the same level in the frontal plane), and not in rotation (in the horizontal plane).



# 2. SUPINE

**Starting position:** Place the subject on the mat or on the wide examination table, the head in the midline position as much as possible<sup>1</sup>, with the upper and lower limbs in a comfortable position.

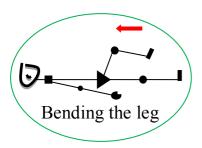
**Task to perform:** To raise<sup>2</sup> the head and to maintain the position.

**Additional instructions:** Opening the mouth to lower the chin is a score of 0. For a score of 1, any kind of head movement in flexion, which brings the chin closer to the sternum. An isolated elevation of the head without a flexion, is a score of 0. For a score of 2, the examiner should be able to place an open hand under the subject's head. If the trunk of the subject participates, or if they use their forearms as support during the movement or the maintaining of the head's position, the score is limited to 2.

- 0: cannot initiate the movement
- 1: cannot lift the head but initiates the movement
- 2: raises the head, but cannot maintain the raised position for 5 seconds
- 3: raises the head and maintains the raised position for 5 seconds

<sup>&</sup>lt;sup>1</sup> "Head and/or trunk in midline position" signifies that the head and the trunk are correctly positioned in the three dimensions. They are vertical (neither in flexion nor in extension in relation to the sagittal plane) and not tilted to the side (the eyes are at the same level in the frontal plane), and not in rotation (in the horizontal plane).

<sup>&</sup>lt;sup>2</sup> "Raise" means there is no more contact between the segment body concerned and the mat or the examination table.





# 3. SUPINE

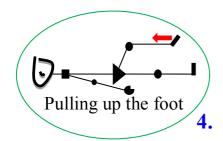
**Starting position:** Place the subject on the mat or on the wide examination table with the upper limbs in a comfortable position and with the legs resting, if possible, on the thighs, calves and feet. Do not use the wheelchair. Cushions may be used if necessary for the untested lower limb. The upper limbs should not touch the lower limb being tested.

**Task to perform:** To bring one knee to the chest.

Additional instructions: Simply changing from a position where the legs are laterally rotated to a position where the feet are flat on the mat or the table, or aiding the movement with the other lower limb is a score of 0. For a score of 1 and 2, the movement can be performed with the lower limb remaining on the mat or the table; a subject with a flexum of the knee or hip obtains a score relative to the range of movement achieved from their starting position. For a score of 1, the subject initiates the movement (< 10°). For a score of 2, the range of the movement must be between 10° and 90°. For a score of 3, the trunk and the pelvis must not raise from the supporting surface.

- ② Use a toy that the child touches with their knee.
- 0: cannot initiate the movement
- ✓ 1: initiates the movement at the hip and/or knee
- 2: partially flexes the hip and/or the knee (<90°) or the foot remains in contact with the mat or table
- ✓ 3: flexes the hip and knee more than 90° by raising¹ the foot for the whole movement

<sup>&</sup>lt;sup>1</sup> "Raise" means there is no more contact between the segment body concerned and the mat or the examination table.





SUPINE, LEG SUPPORTED BY EXAMINER

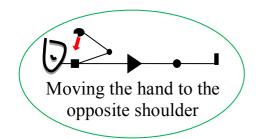
**D3** 

**Starting position:** Place the subject on the mat or the wide examination table. The subject can choose which leg is to be supported in such a way that the hip and knee are flexed at approximately 90°. The lower part of the leg should be parallel to the mat or the table and the foot should be in plantar flexion in the air.

**Task to perform:** Carry out a maximal dorsiflexion of the whole foot.

**Additional instructions:** The movement of dorsiflexion can be combined with valgus or varus of the foot. If the starting position of the foot is permanently in dorsiflexion, the maximum score is limited to 2.

- ② Use a toy that the child touches with their foot.
- 0: cannot initiate the movement
- 1: only extends the toes
- 2: partially dorsiflexes the foot but does not reach 90° in relation to the leg
- ✓ 3: from the plantar flexion, dorsiflexes the foot to at least 90° in relation to the leg





# 5. SUPINE

**D2** 

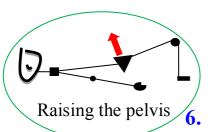
**Starting position:** Place the subject on the mat or the wide examination table with the lower limbs in a comfortable position. The upper limb to be tested should be positioned alongside the body with the hand or the fingers in contact with the mat or the table if possible.

**Task to perform:** To bring one hand to the opposite shoulder.

**Additional instructions:** The shoulder corresponds to the antero-posterior or lateral region of the upper part of the arm. The other hand or the mouth is not allowed to help. For a score of 1, either the hand or the fingers are not in contact with the mat or the table at the beginning of the task, or they fail to reach the opposite shoulder. For a score of 2, the final goal is reached but the subject either uses the hand to creep up along the trunk, or turns the trunk, or the movement is poorly controlled. For a score of 3, the upper limb must be raised for the whole task; the trunk must remain in contact with the mat or the table.

- Use a toy to lead the child's hand to the shoulder.
- 0: cannot raise the hand and elbow
- ✓ 1: partially achieves the movement by raising at least the hand and the elbow
- 2: raises the hand and moves it to the opposite shoulder using compensatory movements
- 3: raises the hand and moves it to the opposite shoulder

<sup>&</sup>lt;sup>1</sup> "Raise" means there is no more contact between the segment body concerned and the mat or the examination table.





# 5. SUPINE, LOWER LIMBS HALF FLEXED, KNEECAPS AT THE ZENITH AND FEET RESTING ON THE MAT SLIGHTLY APART

**D1** 

**Starting position:** Place the subject on the mat or the wide examination table, the lower limbs should be half flexed, the kneecap facing up and the feet resting on the mat or the table, slightly apart<sup>1</sup>. The upper limbs are in a comfortable position, not in contact with the body.

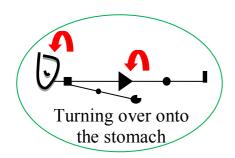
**Task to perform:** To maintain the starting position then to raise<sup>2</sup> the pelvis.

**Additional instructions:** A starting position with the feet wide apart corresponds to a score of 0. For a score of 2, the examiner must be able to pass at least one flat hand under the subject's buttocks, and the feet may be more or less apart. Lifting the pelvis past the requested alignment limits the scoring to 2.

- **②** Use a toy passed under the buttocks of the child.
- 0: cannot maintain the starting position for 5 seconds
- ✓ 1: maintains the starting position for 5 seconds
- ✓ 2: maintains the starting position for 5 seconds then partially raises the pelvis
- 3: maintains the starting position for 5 seconds then raises the pelvis; the lumbar spine, the pelvis and the thighs are aligned and the feet are slightly apart

<sup>1</sup> "with feet slightly apart" means that the separation of the feet corresponds to the width of the pelvis.

<sup>&</sup>lt;sup>2</sup> "Raise" means there is no more contact between the segment body concerned and the mat or the examination table.





D2

# 7. SUPINE

**Starting position:** Place the subject's head, trunk and limbs on the mat or the wide examination table.

**Task to perform:** To turn over onto the stomach and to free both upper limbs.

**Additional instructions:** Sitting up to turn over or grasping the edge of the mat or the table is a score of 0. For a score of 1, the subject must raise the scapular and pelvic girdles. For a score of 2 or 3, the turnover has to be completed; the abdomen may be more or less in contact with the mat or the table at the end of the movement.

The task may be done better by the child after a demonstration by the examiner.

- 0: cannot initiate rolling
- ✓ 1: rolls partially
- 2: turns over into prone with difficulty and compensatory movements and/or cannot free the upper limbs from under the trunk
- 3: turns over into prone and frees both upper limbs from under the trunk

**D1** 



# 8. SUPINE

**Starting position:** Place the subject's head, trunk and limbs on the mat or on the wide examination table.

Task to perform: Sit up<sup>1</sup>.

Additional instructions: If a subject lying on the examination table swings the lower limbs off the table to sit up, the score is 0. For a score of 1, the movement is considered as initiated if the subject raises the shoulders, or moves beyond the lateral position. For a score of 2, using one or both upper limbs for support, or using the lateral position is allowed. For a score of 3, the upper limbs may be held in front of the body for balance or to provide momentum; once seated, the subject may hold himself up with the upper limbs.

- 0: cannot initiate the movement
- 1: initiates the movement, or turns over into prone to sit up
- 2: with upper limb support<sup>2</sup>, sits up
- 3: without upper limb support<sup>3</sup>, sits up

<sup>1</sup> "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>2</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

<sup>&</sup>lt;sup>3</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.





# 9. SEATED ON THE MAT

**Starting position:** Place the subject on the mat or on the wide examination table in any seated position<sup>1</sup>, without trunk support. If the subject is seated on the table, the lower limbs are on the table. A subject who cannot sit without a brace obtains a score of 0.

**Task to perform:** Maintain the seated position then keep the hands in contact in front of the trunk.

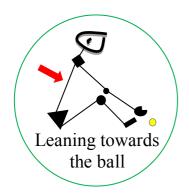
**Additional instructions:** If the trunk leans against a wall or a material, the score is 0. For a score of 2 or 3 contact may be between the two hands or any part of the two upper limbs.

- ② Ask the child to keep a small object hidden in their hands.
- 0: cannot maintain the seated position for 5 seconds
- ✓ 1: with support of one or both upper limbs², maintains the seated position for 5 seconds
- ✓ 2: without upper limb support<sup>3</sup>, maintains the seated position for 5 seconds, but does not maintain contact between the two hands for 5 seconds
- 2 3: without upper limb support, maintains the seated position for 5 seconds and is then capable of maintaining contact between the two hands for 5 seconds

<sup>&</sup>lt;sup>1</sup> "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>2</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

<sup>&</sup>lt;sup>3</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.





# 10. SEATED ON THE MAT, THE TENNIS BALL PLACED IN FRONT OF THE SUBJECT

**Starting position:** Place the subject on the mat or on the wide examination table in any seated position<sup>1</sup>. The subject must be reasonably stable in this position in order to attempt this item. If the subject is seated on the table, the lower limbs are on the table. A subject who cannot sit without a brace obtains a score of 0. The tennis ball is placed on the mat or the table in front of the subject at such a distance that the subject has to lean their trunk forward about 30° in relation to the starting position in order to touch it.

Task to perform: To lean forward to touch the ball, and then to sit back again.

**Additional instructions:** Touching the ball with both hands helps visualizing the leaning of the trunk. Only extending the upper limbs is a score of 0. If the subject supports himself using the ball, the maximum score is limited to 2.

- The task may be done better by the child after a demonstration by the examiner.
- 0: cannot lean forward far enough
- ✓ 1: with upper limb support², leans forward, touches the ball, but does not sit back again
- 2: with upper limb support, leans forward, touches the ball and sits back again
- ✓ 3: without upper limb support³, leans forward, touches the ball and sits back again

<sup>1</sup> "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>2</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

<sup>&</sup>lt;sup>3</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.

**D1** 





# 11. SEATED ON THE MAT

**Starting position:** Place the subject on the mat or on the floor in a seated position<sup>1</sup>, with the lower limbs in front of them. A subject who cannot sit without a brace obtains a score of 0.

**Task to perform:** To stand up<sup>2</sup>.

**Additional instructions:** In order to stand up, all intermediate positions between the seated and standing positions are allowed. If the subject needs to support the trunk and/or the head on material to stand up, the score is 0. For a score of 1, the piece of equipment used, table or chair, should be adapted to the subject's height and placed nearby. For a score of 2, the subject is not allowed to lean on the piece of equipment. For a score of 3, the upper limbs may be used for balance, or to provide momentum; once standing, the subject may hold himself up with a support.

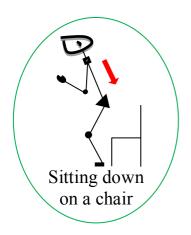
- ② Ask the child to stand up, hands in the air.
- 0: cannot stand up
- ✓ 1: stands up with upper limb support³ on a piece of equipment
- 2: stands up with upper limb support on the mat and/or on themselves
- ✓ 3: without upper limb support<sup>4</sup>, stands up

<sup>1</sup> "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>2</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower limbs may vary.

<sup>&</sup>lt;sup>3</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

<sup>&</sup>lt;sup>4</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.





# 12. STANDING

Starting position: Place the subject in a standing position<sup>1</sup> on the floor in front of the chair, with or without upper limb support depending on their ability. Leaning against the chair to support oneself using any other part of the body is not allowed.

**Task to perform:** To sit down on the chair.

**Additional instructions:** If the subject lets themselves "fall" into the chair with no control of the movement, the maximum score is limited to 1. For a score of 2 or 3, the upper limbs may be used for balance. For a score of 3, the feet must remain slightly apart throughout the movement.

- Ask the child to sit with hands in the air.
- 0: cannot sit down on the chair
- ✓ 1: with upper limb support<sup>3</sup>, sits down on the chair or lets himself fall into the chair
- ✓ 2: without upper limb support<sup>4</sup>, sits down on the chair using compensatory movements or poor control of movement
- ✓ 3: without upper limb support, sits down on the chair with the feet slightly apart<sup>5</sup>

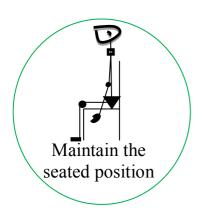
<sup>&</sup>lt;sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower

<sup>&</sup>lt;sup>2</sup> "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>3</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

<sup>&</sup>lt;sup>4</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.

<sup>5</sup> "Feet slightly apart" signifies that the separation of the feet corresponds to the width of the pelvis.



# 13. SEATED ON THE CHAIR

**Starting position:** Place the subject in a seated position<sup>1</sup> on the chair or at the edge of the table, with the feet on the floor, the upper limbs alongside the body. This item should not be performed with the subject in the wheelchair. A subject who cannot sit without a brace obtains a score of 0.

**Task to perform:** To maintain the seated position as straight as possible.

**Additional instructions:** For a score of 1, the arms may give support from the starting position. A deformity or an abnormal position of the head or trunk in one of the three dimensions limits the score to 2.

0: cannot maintain the seated position for 5 seconds

- $\sim$  1: with upper limb support<sup>2</sup> and/or leaning against the back of the chair, maintains the seated position for 5 seconds
- ✓ 2: without upper limb support<sup>3</sup> nor leaning against the back of the chair, maintains the seated position for 5 seconds, but the head and/or trunk are not in midline position
- ✓ 3: without upper limb support or leaning against the back of the chair, maintains the seated position for 5 seconds, with the head and trunk in midline position<sup>4</sup>

<sup>1</sup> "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>2</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

"Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.

<sup>4</sup> "Head and/or trunk in midline position" signifies that the head and the trunk are correctly positioned in the three dimensions. They are vertical (neither in flexion nor in extension in relation to the sagittal plane) and not tilted to the side (the eyes are at the same level in the frontal plane), and not in rotation (in the horizontal plane).

18

21





# 14. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, HEAD IN FLEXION

**Starting position:** Place the subject in a seated position<sup>1</sup>, with support if necessary. Position the subject's head in complete flexion.

**Task to perform:** To raise the head and to maintain it raised.

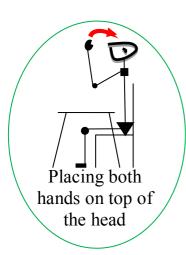
Additional instructions: A complete flexion of the head means that the chin, mouth closed, is near the sternum at a distance of less than 3 cm. A subject whose head can only be positioned by a few degrees of flexion has a score of 0. If the head cannot be positioned in complete flexion, the maximum score is 1. If the raised head is maintained in midline position for less than 5 seconds, the maximum score is 2.

- Use a toy that the child follows with their eyes.
- 0: cannot raise the head
- ✓ 1: raises the head partially
- 2: from head in complete flexion, raises the head but during the movement and/or while holding the position, the head is not in midline position
- ✓ 3: 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<sup>2</sup>

<sup>1</sup> "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>2</sup> "Head and/or trunk in midline position" signifies that the head and the trunk are correctly positioned in the three dimensions. They are vertical (neither in flexion nor in extension in relation to the sagittal plane) and not tilted to the side (the eyes are at the same level in the frontal plane), and not in rotation (in the horizontal plane).

**D2** 



# 15. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, FOREARMS ON THE TABLE BUT NOT ELBOWS

**Starting position:** Place the subject in a seated position<sup>1</sup> in front of a table adjusted to their height, with the forearms on the table but not the elbows. The subject may lean against the back of the chair. If the subject is seated in the wheelchair, the arm rests should be removed.

**Task to perform:** To place both hands on top of the head.

**Additional instructions:** Holding their hands together or using the mouth to help corresponds to a score of 0. If the subject uses compensatory movements of the head and/or the trunk, the score is limited to 2.

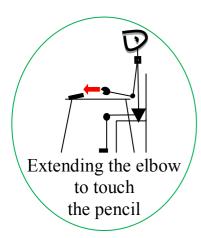
0: cannot raise both hands from the table

- ✓ 1: raises both hands from the table, but the forearms can remain in contact with the table
- 2: raises both forearms from the table but does not manage to place both hands on top of the head at the same time. The hands must at least reach the level of the mouth
- 3: places both hands on top of the head at the same time while the head remains in midline position<sup>2</sup>

1 "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

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<sup>&</sup>lt;sup>2</sup> "Head and/or trunk in midline position" signifies that the head and the trunk are correctly positioned in the three dimensions. They are vertical (neither in flexion nor in extension in relation to the sagittal plane) and not tilted to the side (the eyes are at the same level in the frontal plane), and not in rotation (in the horizontal plane).



# 16. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, THE PENCIL ON THE TABLE

**Starting position:** Place the subject in a seated position<sup>1</sup> in front of a table adjusted to their height, forearms on the table; the elbow may or may not be resting on the table. Place the pencil on the table in front of the subject at a distance equivalent to the length of the subject's upper limb - including the hand - with the elbow in maximal available extension.

Task to perform: Touch the pencil

Additional instructions: "Elbow in full extension" signifies a complete extension of the elbow without flexion contracture. "Elbow in maximal available extension" signifies that a flexion contracture of the elbow is present. The available extension of the elbow allows the positioning of the pencil. Irrespective of the score, the subject must carry out an active extension of the elbow. If the movement is limited to the fingers the score is 0. For a score of 1, a forward movement of the hand has to be observed. For a score of 1 or 2, the subject may use their fingers to help move their hand towards the pencil. For a score of 2, compensatory movements with the trunk are allowed. If a flexion contracture of the elbow is present, the maximum score is limited to 2.

- 0: cannot move forward the hand
- 1: reaching the pencil with the hand without a maximum extension of the elbow or not reaching the pencil
- 2: reaches the pencil with one hand, with the elbow in maximal available or full extension, but slowly or with compensatory movements
- ✓ 3: without moving the trunk, reaches the pencil with one hand, the forearm and hand off the table with the elbow in full extension at the end of the movement

1 "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

22 23

24 25

26

**3**0

**D3** 



# 17. SEATED ON THE CHAIR OR IN THE WEELCHAIR, 10 COINS ON THE TABLE

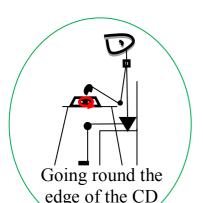
**Starting position:** Place the subject in a seated position<sup>1</sup> in front of a table adjusted to their height, forearm on the table; the elbow may or may not be resting on the table. Place ten coins next to the subject's hand.

**Task to perform:** To pick up the coins successively with one hand, one at a time, and to hold them in the same hand.

**Additional instructions:** To pick up signifies that there is no more contact between the coin and the table. The coins have to be picked up without sliding them to the edge of the table and may be stored between the fingers or in the palm of the hand. If one or more coins fall from the hand, the subject can pick it up again. The score depends on the number of coins held in the hand at the end of a 20-second period.

- 0: cannot pick up a single coin during the 20-second period
- ✓ 1: successively picks up and holds 1 to 5 coins in one hand during the 20-second period
- 2: successively picks up and holds 6 to 9 coins in one hand during the 20-second period
- 3: successively picks up and holds 10 coins in one hand during the 20-second period

<sup>1</sup>"Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.





# 18. SEATED ON THE CHAIR OR IN THE WEELCHAIR, ONE FINGER PLACED IN THE CENTER OF THE FIXED CD

**Starting position:** Place the subject in a seated position<sup>1</sup> in front of a table adjusted to their height, forearms on the table; the elbow may or may not be resting on the table. One finger, preferably the index finger is placed in the center of a CD glued to a piece of cardboard, which is held still on the horizontal plane of the table by the examiner. The position of the cardboard is chosen by the subject.

**Task to perform:** To go round the edge of the CD with a finger.

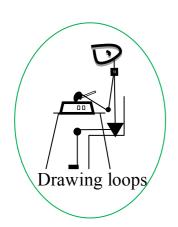
**Additional instructions:** The small circle is identified as the area in the middle of the CD measuring 3.5 cm in diameter. For a score of 2, the subject may stop one or more times and/or may change finger during the task; compensatory movements of the trunk are allowed. For a score of 3, the same finger is used for the full length of the task.

② Draw the 2 circles on the CD in color to guide the finger.

- 0: cannot go round the small circle of the CD with a finger
- ✓ 1: goes round the small circle of the CD with a finger
- 2: goes round the edge of the CD with a finger with compensatory movements or difficulty
- 3: goes round the edge of the CD with the same finger without hand support on the table

 $^{1}$ "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than  $45^{\circ}$ , irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

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# 19. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, THE PENCIL ON THE TABLE

**Starting position:** Place the subject in a seated position<sup>1</sup> in front of a table adjusted to their height, forearm on the table; the elbow may or may not be resting on the table. The subject chooses the position of the pencil and the paper held by the examiner. The item must be produced on a horizontal plane.

**Task to perform:** Pick up the pencil and draw inside the frame.

**Additional instructions:** Use the scoring-sheet with the two rectangular frames that are 1 cm high and 4 cm long. The thickness of the line is 1 mm. To help pick up the pencil the subject may use the other hand. The hand which makes a written mark is the side noted on the score sheet. For a score of 1, a visible mark on the paper is considered to be a written mark. For a score of 2, the subject may stop one or more times while drawing the loops, or the drawing of the loops may extend beyond the frame or not touch the frame. For a score of 3, the continuous series of loops must be drawn without stopping.

- 0: cannot pick up the pencil or cannot make a written mark
- 1: picks up the pencil and makes a written mark, but cannot draw one loop inside the frame touching the top and bottom lines of the frame
- ✓ 2: picks up the pencil, and draws at least one loop inside the frame touching the top and bottom lines of the frame, but cannot draw a continuous series of loops in the frame touching the top and bottom lines of the frame
- 3: picks up the pencil and draws a continuous series of loops over the full length of the frame, touching the top and bottom line of the frame

<sup>&</sup>lt;sup>1</sup>"Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

**D3** 



# 20. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, HOLDING THE SHEET OF PAPER

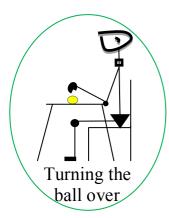
**Starting position:** Place the subject in a seated position<sup>1</sup> in front of a table adjusted to their height; the elbows may or may not be resting on the table. Place a sheet of paper in the subject's hands.

**Task to perform:** Tear the paper at least 4 cm.

**Additional instructions:** The examiner folds the sheet of paper firmly with the finger tips. It is better to use a new sheet of paper for each test. Both hands must be used to tear the paper to obtain a score above 0. For each scoring level, every manipulation to tear the sheet of paper equals one try. After this tear is started, the 4cm can be obtained by several movements.

- 0: cannot tear the sheet of paper
- 1: tears the unfolded sheet of paper
- 2: tears the sheet of paper folded in 2, beginning from the folded edge
- 3: tears the sheet of paper folded in 4, beginning from the folded edge

 $<sup>^{1}</sup>$ "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than  $45^{\circ}$ , irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.





**MFM-20** 

# 21. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, THE TENNIS BALL ON THE TABLE

**Starting position:** Place the subject in a seated position<sup>1</sup> in front of a table adjusted to their height, forearm on the table; the elbow may or may not be resting on the table. Place the tennis ball next to the hand chosen by the subject. The position of the ball is chosen by the subject. The ball must not be held by the examiner.

**Task to perform:** To pick up the ball, to raise<sup>2</sup> it, and then to turn the hand.

Additional instructions: the order of the task must be respected. "To turn the hand over completely" signifies that the back of the hand is facing the surface of the table. For a score of 1, the ball should no longer be in contact with the table. If the trunk participates, the maximal score is 2. For a score of 2 or 3, the hand may be in contact with the table at the end of the movement.

- ② Draw a face on the ball discovered by the child at the end of the movement.
- 0: cannot pick up the ball
- ✓ 1: picks up the ball but cannot turn over the hand
- 2: picks up the ball, and turns the hand over, but incompletely or completely with compensatory movements
- 3: picks up the ball, and turns the hand over completely holding the ball

**D3** 

<sup>&</sup>lt;sup>1</sup>"Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>2</sup> "Raise" means there is no more contact between the segment body concerned and the mat or the examination table.





**MFM-20** 

# 22. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, ONE FINGER PLACED IN THE CENTER OF THE DIAGRAM

**Starting position:** Place the subject in a seated position<sup>1</sup> in front of a table adjusted to their height, forearm on the table; the elbow may or may not be resting on the table. One finger, chosen by the subject (or the thumb) is placed at the center of the diagram below, on the word "start". The user manual is held still on the horizontal plane of the table by the examiner.

**Task to perform:** To place the finger on the drawings.

**Additional instructions:** For all scoring levels, the hand and/or the other fingers may give support. If the finger touches the lines, the score is limited to 2

- ②Ask the child to hide each drawing with their finger.
- ✓ 0: cannot raise² the finger, nor slide it onto a drawing
- 1: cannot raise the finger to place it on a drawing, but can slide it on at least one drawing
- 2: raises the finger and places it imprecisely on 1 to 8 drawings of the diagram
- 3: raises the finger and places it successively on the
   8 drawings of the diagram without touching the lines

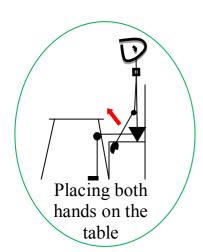
Start

Start

55

<sup>&</sup>lt;sup>1</sup>"Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>2</sup> "Raise" means there is no more contact between the segment body concerned and the mat or the examination table.





# 23. SEATED ON THE CHAIR OR IN THE WHEELCHAIR, UPPER LIMBS ALONG THE TRUNK

**Starting position:** Place the subject in a seated position<sup>1</sup>, the upper limbs alongside the body. If the subject is seated in the wheelchair, the arm rests should be removed. The table, adjusted to the appropriate height, is placed at a distance equivalent to the length of the subject's forearm when the elbow is beside the body.

**Task to perform:** To place both hands on the table.

Additional instructions: A subject with a flexion contracture of the elbow greater than 90° obtains a score of 0. For a score of 1, at least one finger of one hand should touch the top of the table. For a score of 2, the forearms and/or the hands may be placed, one after the other, on the table.

- ② Ask the child to sit still like a statue so that they don't move their trunk
- 0: cannot touch the top of the table with one finger
- ✓ 1: achieves the movement with only one upper limb, or only the fingers of one or both hands placed on the table
- ✓ 2: places the two forearms and/or the hands on the table slowly or with compensatory movements
- → 3: places the two forearms and/or the hands on the table at the same time without moving the trunk

<sup>1</sup>"Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

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# 24. SEATED ON THE CHAIR

**Starting position:** Place the subject in a seated position<sup>1</sup> on a chair adjusted to their height, feet on the floor slightly apart<sup>2</sup>. The table, adjusted to the appropriate height, may be placed nearby if the examiner feels that the subject will need it for the task.

**Task to perform:** To stand up.

**Additional instructions:** For a score of 1, the subject may take support on different places of the body, with the table and/or the chair adjusted to the subject's height. For a score of 1 or 2, the feet may be wide apart. The use of the upper limbs for maintaining balance or providing momentum limits the score to 2. For a score of 3, the upper limbs cannot be used for balance or to give momentum during the movement.

Ask the child to stand up with their hands in the air.

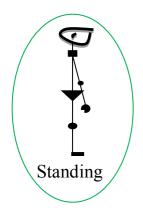
- 0: cannot stand up
- ✓ 1: stands up with support³ using the nearby table or the chair and/or the body
- 2: without upper limb support<sup>4</sup>, stands up with compensatory movements
- 3: without upper limb support, stands up with the feet slightly apart

<sup>&</sup>lt;sup>1</sup> "Seated" is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

<sup>&</sup>lt;sup>2</sup> "Feet slightly apart" signifies that the separation of the feet corresponds to the width of the pelvis.

<sup>&</sup>lt;sup>3</sup> "With support" signifies that the subject may use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.

<sup>&</sup>lt;sup>4</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.





# 25. STANDING WITH UPPER LIMB SUPPORT ON EQUIPMENT

**Starting position:** Place the subject in a standing position<sup>1</sup> on the floor with the upper limbs<sup>2</sup> resting on a piece of equipment for support. A subject who cannot stand without an orthotic support obtains a score of 0.

**Task to perform:** To release the support if possible and to stand straight.

**Additional instructions:** For a score of 2, "Poor alignment" signifies that the trunk the head or the lower limbs are not aligned in the three dimensions. If the subject puts the feet too wide apart, or if he uses the upper limbs for balance, the score is limited to 2.

- ② Ask the child to stand still like a statue.
- 0: cannot maintain a standing position for 5 seconds
- ✓ 1: with support of one or both upper limbs, maintains the standing position for 5 seconds
- ✓ 2: without upper limb support<sup>3</sup>, maintains a standing position for 5 seconds with poor alignment or compensatory movements
- ✓ 3: without upper limb support, maintains a standing position for 5 seconds with the feet slightly apart<sup>4</sup>, the head, trunk and limbs in midline position<sup>5</sup>

<sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower limbs may vary

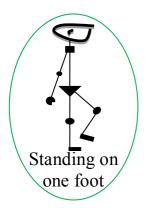
<sup>4</sup> "Feet slightly apart" signifies that the separation of the feet corresponds to the width of the pelvis.

D1

<sup>&</sup>lt;sup>2</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

<sup>&</sup>lt;sup>3</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.

<sup>&</sup>lt;sup>5</sup> "Head and/or trunk in midline position" signifies that the head and the trunk are correctly positioned in the three dimensions. They are vertical (neither in flexion nor in extension in relation to the sagittal plane) and not tilted to the side (the eyes are at the same level in the frontal plane), and not in rotation (in the horizontal plane).



# 26. STANDING WITH UPPER LIMB SUPPORT ON EQUIPMENT

**Starting position:** Place the subject in a standing position<sup>1</sup> on the floor with the upper limbs<sup>2</sup> resting on a piece of equipment for support. A subject who cannot stand without an orthotic support obtains a score of 0.

**Task to perform:** To release the support if possible, then to raise one foot.

**Additional instructions:** "To raise one foot" signifies that the foot does not touch the floor nor is supported by the other leg. The foot which supports the weight of the subject is the side noted on the score sheet. For all scoring levels, all compensatory movements are allowed; what matters is the amount of time the subject stands on one foot. For a score of 2 or 3, the subject must let go of the upper limb support before lifting the foot.

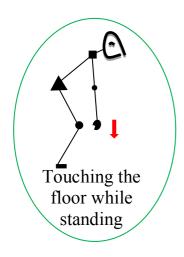
- O: with support from one or both upper limbs, cannot raise one foot for 3 seconds
- 1: with support from one or both upper limbs, raises one foot for 3 seconds
- without upper limb support<sup>3</sup>, raises one foot between 3 to 9 seconds
- 3: without upper limb support, raises one foot for 10 seconds

D1

<sup>&</sup>lt;sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower limbs may vary.

<sup>&</sup>lt;sup>2</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

<sup>&</sup>lt;sup>3</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.





# 27. STANDING

**Starting position:** Place the subject in a standing position<sup>1</sup> on the floor, if possible without support<sup>2</sup>.

**Task to perform:** To touch the floor with one hand, and to stand up again.

**Additional instructions:** Any strategy to achieve the task is allowed except that of sitting on the floor. To give a score higher than 0, a part of the hand, at least one finger, must touch the floor. A support<sup>3</sup> during the task limits the score to 1.

- ② Ask the child to touch a drawing set on the floor.
- 0: cannot touch the floor with one hand or cannot stand up again
- 1: with support, touches the floor with one hand and stands up again
- 2: without support, touches the floor with one hand and stands up again, slowly or with compensatory movements
- 3: without support, touches the floor with one hand and stands up again

D1

<sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower limbs may vary

<sup>&</sup>lt;sup>2</sup> "Without support" signifies that the subject does not use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.

<sup>&</sup>lt;sup>3</sup> "With support" signifies that the subject may use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.



Starting position: Place the subject in a standing position on the floor. In order to perform this task, the subject must be able to walk without support<sup>2</sup>.

**Task to perform:** Walk 10 steps on the heels.

**Additional instructions:** The steps should follow each other by no more than 2 seconds. For a score of 1, "lifting the toes" signifies that the subject raises all the toes for the length of the task but the front part of the feet remain in contact with the floor. For a score of 2 or 3, "on the heels" signifies that the subject supports himself exclusively on the heels without support from the front part of the feet; the front part of the feet must not touch the floor between steps.

- ✓ 0: takes less than 10 steps forward³, lifting the toes of one or both feet
- ✓ 1: takes 10 steps forward lifting all the toes of one or both feet
- ✓ 2: takes less than 10 steps forward on both heels, or 10 steps forward, including 5 on only one heel
- 3: takes 10 steps forward on both heels

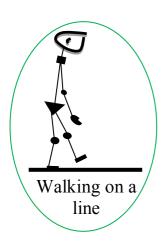
D1

<sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower limbs may vary.

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<sup>2 &</sup>quot;Without support" signifies that the subject does not use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.

<sup>&</sup>quot;A step forward" indicates the forward movement of one lower limb.



**Starting position:** Place the subject <sup>1</sup> in a standing position<sup>2</sup>, without support, in front of a straight line about 6m long and 2cm wide, drawn on the floor. In order to perform this task, the subject must be able to take at least one step without support.

**Task to perform:** To walk on the line.

**Additional instructions:** The steps should follow each other by no more than 2 seconds. If the subject's foot is no longer on the line, only the steps taken before the foot deviated from the path are counted.

- ✓ 0: cannot take 1 step forward³ on a line
- ✓ 1: takes 1 to 3 steps forward on a line
- 2: takes 4 to 9 steps forward on a line
- 3: takes 10 steps forward on a line

**D1** 

Ä

32

<sup>&</sup>lt;sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower limbs may vary.

<sup>&</sup>lt;sup>2</sup> "Without support" signifies that the subject does not use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.

<sup>&</sup>quot;A step forward" indicates the forward movement of one lower limb.





Starting position: Place the subject in a standing position on the floor without support<sup>2</sup>. In order to perform this task the subject must be able to walk without support.

**Task to perform:** To run.

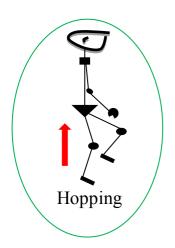
Additional instructions: "To run" signifies that at a certain moment, both feet are off the floor at the same time.

- © Encourage the child to run by running with him.
- 0: cannot increase walking speed
- increases walking speed but cannot run 10 meters
- 2: runs 10 meters with compensatory movements
- 3: runs 10 meters

<sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower

**D1** 

<sup>&</sup>lt;sup>2</sup> "Without support" signifies that the subject does not use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.



# 31. STANDING ON ONE FOOT WITHOUT SUPPORT

Starting position: Place the subject in a standing position<sup>1</sup> on one foot, without support<sup>2</sup>, the other foot off the ground.

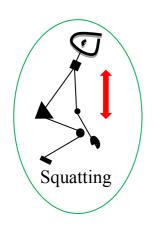
**Task to perform:** To hop in place.

**Additional instructions:** In order to complete the instructions for the hop, the subject may be placed in a 60 cm diameter circle drawn on the floor. "To hop" signifies to jump on one foot. At some point both feet are off the floor at once. The foot that is in the air must not touch the floor at any time. The hops should follow each other by no more than 2 seconds, without falling, and the subject should not use a support. The foot which is on the floor, is noted on the score sheet

- 0: cannot initiate hopping
- 1: initiates a hop, the heel is raised from the floor but the toes remain in contact with the floor
- 2: hops 1 to 9 times
- 3: hops 10 times in place

<sup>&</sup>lt;sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower

<sup>&</sup>lt;sup>2</sup> "Without support" signifies that the subject does not use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.





**Starting position:** Place the subject in a standing position<sup>1</sup> on the floor without support<sup>2</sup>.

**Task to perform:** To squat and to stand up again.

**Additional instructions:** "A squatting position" is defined as a position near the floor, supported by the two feet, the body in a hunched position, the hips and knees flexed more than 90°. The buttocks are not in contact with the floor. The subject must stand up from the squatting position without placing a knee on the floor.

- ② Ask the child to squat, hands in the air.
- 0: with upper limb support<sup>3</sup>, cannot squat or cannot get up
- 1: with upper limb support, manages to squat and gets up once
- 2: without upper limb support<sup>4</sup>, manages to squat and gets up once
- 3: without upper limb support, manages to squat and gets up twice in a row

<sup>1</sup> "Standing position" is defined as an upright position supported by both feet. The alignment of the trunk and the lower limbs may vary.

**D1** 

<sup>&</sup>lt;sup>2</sup> "Without support" signifies that the subject does not use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.

<sup>&</sup>lt;sup>3</sup> "With upper limb support" signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

<sup>&</sup>lt;sup>4</sup> "Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.

# **DEFINITION OF TERMS**

**"Seated":** is defined as an upright position of the trunk supported by the buttocks. The alignment of the pelvis and the trunk can vary but the trunk must not be inclined by more than 45°, irrespective of the direction. Unless otherwise stated, the position of the legs is unimportant.

"With support" signifies that the subject may use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.

**"With upper limb support"** signifies that to reach or maintain the position, the subject is allowed to use their upper limbs, in any way, on the body, the floor, or any material. Supporting oneself on any material with any part of the body other than the hand or the arm is not allowed.

**"Standing position"** is defined as an upright position supported by both feet. The alignment of the trunk and the lower limbs may vary.

"Feet slightly apart" signifies that the separation of the feet corresponds to the width of the pelvis.

**"Without support"** signifies that the subject does not use one or both upper limbs or any other part of the body to provide support, on the floor, the body or any material.

"Without upper limb support" signifies that to reach or maintain the position, the subject is not allowed to use their upper limbs on the body, the floor or any material.

"Raise" means there is no more contact between the segment body concerned and the mat or the examination table.

"Head and/or trunk in midline position" signifies that the head and the trunk are correctly positioned in the three dimensions. They are vertical (neither in flexion nor in extension in relation to the sagittal plane) and not tilted to the side (the eyes are at the same level in the frontal plane), and not in rotation (in the horizontal plane).

"A step forward" indicates the forward movement of one lower limb.

# EXAMPLE

Born in January 1992, Julien is affected by Duchenne muscular dystrophy (DMD). He lost the ability to walk in January 2002 (aged 10 years) and uses an electric wheelchair.

His motor function was first assessed using the MFM in December 2002. Julien is participating in the validation study and the sensitivity to change study of the MFM.

Julien was 10 years and 10 months old at the time of the first MFM test and his Total Score was 50.00%.

When he was 11 years old, he broke his femur and was treated by cast immobilization for 45 days. This femoral break was painful for 6 months, and corresponds to the lower scores.

After this painful period, recovered his axial and proximal (D2) and distal (D3) motor abilities. The scores increase gradually to reach 49% for the Total Score in February 2004, when he was 13 years and 3 months old. At the age of 14 and 14 years and 2 months old respectively, the MFM shows rapid deterioration of motor function, especially for D2 (axial and proximal motor function) with a loss of 30.56% in a 14-month period. This decrease in scores corresponds to a clinically evident loss of function, which was noticed by his parents and during consultations.

At the age of 14 years and 3 months, Julien was started on steroid treatment.

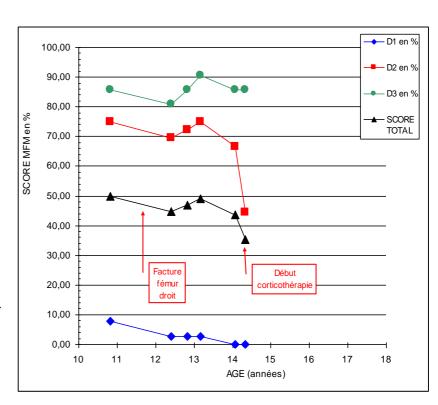
After 3 months on steroid treatment, the D2 and D3 scores increased. Over a 6-month period, the Total Score improved from 35.42% to 44.79%.

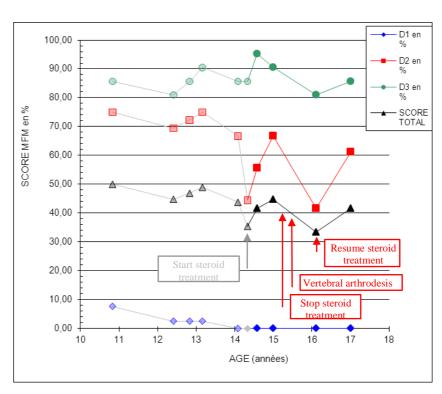
When Julien was 15 years and 4 months old, steroid treatment was stopped one month before vertebral surgery.

At the age of 16 years and 1 month, 8 months after the surgery, there was a decrease in the scores, especially for D2 (axial and proximal motor ability).

Steroid treatment was resumed at the age of 16 years and 2 months.

When Julien was 17 years and 2 months of age, he recovered some of his axial and proximal (D2) and distal (D3) abilities. The Total Score of the MFM improved to 41.67%.





Julien's successive MFM scores show the evolution of motor abilities during the period from the age of 10 years and 10 months to 17 years and 2 months. The graph of the MFM scores shows losses and motor recovery based on medical and surgical events in Julien's life.

After DMD patients loss the ability to walk, the natural history of the disease shows an average annual loss of 5.80 % [-9.14, -2.46] for the Total Score, -7.86 % [-12.42, -2.94] for D2 (axial and proximal motor). What is the role of steroid therapy in this adolescent in light of the low degradation observed in the MFM D2 and Total Score?



