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## FORMATION OF AN ASSOCIATION

On this twenty-third day of May in the year two thousand and eleven, there appeared before me, Mr Martijn Frederik Le Coultre, a civil-law notary practising in Laren, the Netherlands:

1. Mr Marcellinus Franciscus Theodorus Timmen, born in Winterswijk, the Netherlands, on the twenty-fifth of March one thousand nine hundred and fifty-nine, holder of a Dutch driving licence with number 4466965307, residing at Pyreneeën 47, 3524 VM Utrecht, the Netherlands, married, here acting as the authorized signatory (*procuratiehouder*) and, in that capacity, as duly authorized representative of **Vereniging Spierziekten Nederland**, an association having its registered office in Baarn, the Netherlands, maintaining business offices at Van Heutszlaan 6, 3743 JN Baarn, and recorded in the Trade Register under number 40000172;
2. Mr Rafique Jabri, associated with the undersigned civil-law notary's notarial offices at Hilversumseweg 37, 1251 EW Laren, born in Kenitra, Morocco, on the twenty-sixth of October one thousand nine hundred and eighty-three, here acting pursuant to written powers of attorney from:
  - (a) Mr Alexander Vriesendorp, born in Groningen, the Netherlands, on the seventh of January one thousand nine hundred and fifty-three, holder of a Dutch passport with number NMK856HR4, residing at Bremhorstlaan 7, 2244EN Wassenaar, the Netherlands, married;
  - (b) Mr Marc Cornelis van Hal, born in Leersum, the Netherlands, on the twenty-first of May one thousand nine hundred and sixty-nine, holder of a Dutch passport with number NP7RP4726, residing at Harderwijkkade 15, 3826 BE Amersfoort, the Netherlands, married to Petra Verwaaij;

who granted said powers of attorney in their capacities of treasurer and Executive Board member and, as such, as the jointly authorized representatives of **FSD Stichting**, a foundation having its registered office in Wassenaar, the Netherlands, maintaining business offices at Kievietslaan 34, 2243 GD Wassenaar, and recorded in the Trade Register under number 41160397.

The persons appearing before me declared that they hereby formed an association on behalf of the entities represented by them and that said association would be governed by the following:

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## ARTICLES OF ASSOCIATION

NAME, REGISTERED OFFICE, LANGUAGE

### Article 1

The name of the Association is: **FSHD Europe**.  
It has its registered office in Baarn, the Netherlands.  
The official language of the Association is English.

## OBJECTS

### Article 2

The objects for which the Association has been formed are:

- (a) To find a cure for facio-scapulo-humeral dystrophy (FSHD) through successful cooperation;
- (b) To promote awareness, understanding, and knowledge of FSHD;
- (c) To stimulate, promote, and share knowledge and experiences in the field of care, welfare, support, and diagnostics of individuals struck by FSHD and their families;
- (d) To stimulate, facilitate, and financially or otherwise support research into the causes of FSHD in order to find a cure or medicine for FSHD;
- (e) To raise funds to finance scientific research into FSHD as such and into support activities in the broadest sense of the word;
- (f) To work towards the attainment of the Association's goals in collaboration with national and international FSHD and other organizations, whether private or governmental, that have any involvement with muscular disorders;
- (g) To protect the interests of people suffering from FSHD and their families, in the broadest sense of the word.

## MEMBERSHIP

### Article 3

1. The Association shall have ordinary members, candidate members, and honorary members. Except where expressly provided otherwise or where the context clearly dictates otherwise, any reference to members or to a member in these Articles or in any internal rules or resolutions adopted pursuant to these Articles shall be deemed to refer to both ordinary and honorary members.
2. Ordinary members are legal entities that have registered for membership with the Executive Board and have been accepted by the Executive Board. The maximum number of ordinary members per country shall be two: the relevant national organization in the field of muscular disorders and the national organization in the field of FSHD. Any resolution by the Executive Board to deny membership may be overruled by the General Assembly.
3. Candidate members are private individuals from countries not represented in the Association by any organization, who aspire to be accepted as full members within three years of commencement of their candidate membership. The maximum number of candidate members per country shall be one.

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4. Honorary members are private individuals who have been elected by the General Assembly, on the recommendation of the Executive Board, for their exceptional contributions to the Association or in the field of FSHD and who have accepted said election. Honorary members are appointed for life.

#### Article 5

Individual membership is non-transferable.

#### Article 6

1. Membership or candidate membership of the Association ends:
  - (a) Upon the Association giving notice of termination;
  - (b) Upon a member giving notice of termination;
  - (c) Upon liquidation or dissolution of a legal-entity member or upon its involvement in any merger or de-merger;
  - (d) Upon the death of a member;
  - (e) Upon expulsion.
2. Members can only terminate their membership at four weeks' written notice prior to the end of a financial year. However, notice of termination with immediate effect shall be possible:
  - (a) For members who cannot reasonably be required to continue their membership;
  - (b) Within one month of the date on which a member becomes aware or is informed of the adoption of a resolution restricting the rights of members or increasing their obligations, except where any such change concerns monetary rights and obligations;
  - (c) Within one month of the date on which a member is informed of the adoption of a resolution for the Association to enter into a merger or to be converted into another legal form.

In the event of any late notice of termination, membership will continue until the end of the next financial year.

3. The Association can terminate a member's membership only at four weeks' written notice prior to the end of a financial year. Any such notice of termination must be given by the Executive Board. The Association may only give notice of termination if it cannot reasonably be expected to allow the membership in question to continue. In the event of any late notice of termination, membership will continue until the end of the next financial year.
4. Members may exclusively be expelled for having acted in breach of the Articles of Association or any internal rules or resolutions adopted by the Association - for example by having failed to pay the annual fees in a timely fashion or at all after having received a relevant reminder - or for having caused unreasonable harm to the Association's interests. Members are expelled by the Executive Board, which shall notify the member concerned of the expulsion resolution and the charges made as soon as possible. Upon receipt of any such notification, the member shall have one

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month to file an appeal with the General Assembly. Both during the term for filing an appeal and pending the appeal procedure, the member concerned will be suspended. Any resolution by the General Assembly to expel a member must be carried by a minimum two-thirds majority of the votes cast.

5. Any termination of membership in the course of a financial year shall not in any way affect the member's obligation to pay the annual fee for the year in full. The Executive Board may suspend members who have acted in breach of the Articles of Association or any internal rules or resolutions adopted by the Association or who have caused unreasonable harm to the Association's interests for such a period of time as the Board may determine, subject to a maximum of six (6) months. An appeal to any such suspension resolution may be filed with the General Assembly. The appeal provisions in Article 6.4 shall apply accordingly.
6. Any notice of termination by candidate members, if given in writing, shall have immediate effect.

#### SPONSORS

##### Article 7

Sponsors are those parties whom the Executive Board has accepted as sponsors. The Executive Board may terminate any sponsorship by giving written notice of termination. Sponsors are under an obligation to make an annual financial donation to the Association, the minimum amount of which shall be determined by the Executive Board.

#### FINANCIAL MEANS

##### Article 8

1. The Association's financial means consist of the annual fees paid by the members, the annual donations of the sponsors, specific legacies, testamentary dispositions, gifts, and other income.
2. Each member shall pay an annual membership fee the amount of which shall be determined by the General Assembly. Honorary members are released from this obligation.

#### EXECUTIVE BOARD

##### Article 9

1. The Executive Board shall consist of no less than four and no more than seven private individuals.
2. The members of the Executive Board shall be appointed by the General Assembly. Executive Board members must be private individuals, which means that they are not members of the Association. However, they may be persons who vote at meetings of the General Assembly as representatives of a member. Members of the Executive Board are required to have a great affinity with FSHD, and one member at the very least should have a scientific involvement with FSHD. The General Assembly shall determine the number of Board members.

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3. The Executive Board shall elect from its midst a President, a Vice-President, a Secretary, a Treasurer, a Research Coordinator, and a Coordinator of Patient Interests. The positions of Secretary and Treasurer may be held by one Board member.
4. The General Assembly may suspend or dismiss an Executive Board member at any time by means of a reasoned decision. The affirmative vote of a two-thirds majority of the General Assembly shall be required for the adoption of any such resolution.
5. A suspension shall end if the General Assembly fails to adopt a resolution on the relevant Board member's dismissal within three months of the date of the suspension. The Board member in question shall be afforded an opportunity to defend his or her case before the General Assembly and to be counselled by a lawyer on any such occasion.
6. Members of the Executive Board shall be appointed for a period of no more than three years. For purposes of this provision, a year shall be construed as the period between two successive annual meetings of the General Assembly. The Board members shall resign in accordance with a resignation schedule to be drawn up by the Executive Board. Resigning Board members are immediately eligible for re-election, but no Board member shall serve on the Board for a total period, whether consecutive or not, of more than nine years.
7. Vacancies shall be filled as soon as possible. The Board shall continue to constitute a valid quorum even when not all seats are filled.

#### Article 10

1. The Executive Board shall be charged with the Association's management. It may delegate powers and duties to third parties until further notice and grant them a fee or expense allowance in consideration for their services.
2. The Executive Board shall meet at least twice a year, either in person or by teleconference or other electronic means of communication, and may adopt resolutions without a meeting provided that no less than three fourths of the number of Board members in office have spoken in favour of the proposed resolution. Any other resolutions shall require a simple majority of the votes cast.
3. Subject to Article 10.4 below, the Executive Board shall be authorized to adopt resolutions to enter into agreements: (i) pertaining to the acquisition, transfer or encumbrance of registered property as defined in the Dutch Civil Code; or (ii) in which the Association stands surety or accepts joint and several liability for the debts of others, guarantees performance by a third party, or agrees to provide security for the debts of a third party.
4. The Executive Board shall require approval from the General Assembly for adopting any resolution to enter into an agreement as described in Article 10.2 above.

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Without approval, the Association cannot be deemed to be duly represented in concluding the relevant transactions.

5. The business transacted and resolutions adopted in each meeting of the Executive Board shall be recorded in minutes, which are to be adopted at the next meeting and shall then be sent to the members and candidate members.
6. The members of the Executive Board shall not receive any remuneration other than an expense allowance of such amount as shall be determined by the Executive Board.

#### Article 11

1. The Association shall be represented by the Executive Board.
2. The power to represent the Association shall also vest in the President acting together with the Secretary or Treasurer, or the Secretary acting together with the Treasurer (if these positions are separated).
3. The Executive Board may also authorize one or more members of the Executive Board or third parties to represent the Association within the limits of the power conferred on them.

#### STUDY GROUPS

##### Article 12

The Association shall have two study groups:

1. The Research Group, under the direction of the Research Coordinator: this Group is in charge of coordinating all activities in the field of research, as well as presenting proposals for research and subsidies and reporting to the Executive Board. Members of this Group must be scientific researchers or physicians. They will be approached by the Research Coordinator and are appointed by the Executive Board. They are eligible to receive an expense allowance, the amount of which shall be determined by the Executive Board, but no remuneration.
2. The Patient Interests Group, under the direction of the Coordinator of Patient Interests: the purpose of this Group is to act as a liaison for patients and their families and to protect their interests. In addition, this Group informs the Executive Board of proposals and insights of patients and their families. Members of the Patient Interests Group are recruited primarily from the community of patients and their families. They will be approached by the Coordinator of Patient Interests and are appointed by the Executive Board. They are eligible to receive an expense allowance, the amount of which shall be determined by the Executive Board, but no remuneration

No intervention of the Executive Board will be required for these two Groups to interact.

#### GENERAL ASSEMBLY

##### Article 13

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The annual meeting of the General Assembly shall be held in the month of May in the municipality in which the Association has its registered office or in Amsterdam, at Schiphol Airport or in Rotterdam, or in any city of a country represented in the Association by a member. At the same time and venue, the Executive Board and the Study Groups shall hold meetings.

#### Article 14

1. All non-suspended members, candidate members, and parties invited by the Executive Board and/or the General Assembly shall be admitted to the annual meeting. A member may be represented at a meeting exclusively by one duly authorized private individual appointed in writing who is associated with the relevant legal-entity member. Suspended members shall have access to meetings in which the suspension resolution is to be discussed, and may then and there present their views on the matter.
2. Only members shall have voting rights in the annual meeting. Candidate members shall have an advisory vote. Each voting member shall have one vote and may authorize another voting member in writing to represent him or her. Voting members may represent no more than two other members.
3. A resolution adopted unanimously by all voting members, even if they have not met, shall have the same force and effect as a resolution adopted by the General Assembly, provided that such resolution is adopted with the prior knowledge of the Executive Board.
4. The President shall determine the voting procedure to be followed at general meetings.
5. All resolutions for which no qualified majority is required by law or under these Articles of Association must be carried by an absolute majority of the votes cast. In the event of a tie of votes on a motion other than for the election of persons, the motion shall be rejected. If the votes are tied in an election, lots shall be drawn. If none of the candidates in an election between more than two candidates have gained an absolute majority, a revote shall be held between the two candidates who polled the highest number of votes. Where necessary, such a revote shall be preceded by an interim voting round.

#### Article 15

1. Meetings of the General Assembly shall be chaired by the President or, in his or her absence, by the oldest Executive Board member present. If no members of the Executive Board are present, the General Assembly shall elect its own chairperson.
2. The chairperson's decision at a meeting of the General Assembly concerning the results of a vote shall be conclusive. The same shall apply as regards the contents of a resolution, in so far as it is adopted on the basis of a motion not recorded in writing. If any such decision by the chairperson is disputed immediately after it is made, however, a new vote shall be taken if the majority of the General Assembly or,

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in case the original vote was not a vote by call or by ballot, one of the voting persons present so requires. This new vote shall render the legal effects of the original vote null and void.

3. The Secretary or a person designated by the chairperson of the meeting shall take minutes of all business transacted. Said minutes shall be adopted and signed by the chairperson and the relevant secretary. The minutes may also be adopted at the next meeting of the General Assembly and be signed in evidence thereof by the chairperson and secretary of that meeting.

#### Article 16

1. The Association's financial year shall correspond to the calendar year. The General Assembly shall meet at least once every year, in the month of May. At said meeting, the Executive Board shall present its report on the affairs of the Association and the management conducted. The Executive Board shall submit a balance sheet and a statement of income and expenses, plus notes, for approval by the General Assembly. These documents shall be signed by all Board members; if the signature of any of them is missing, that fact and the underlying reason shall be duly reported.
2. If the documents referred to above are not audited by an accountant as referred to in Section 2:393(1) of the Dutch Civil Code, the General Assembly shall each year appoint a committee consisting of no less than two members who may not be members of the Executive Board.
3. The Executive Board shall send the documents referred to in Article 16.1 to the committee no later than one month prior to the meeting of the General Assembly. The committee shall review the documents and report its findings to the General Assembly.
4. The Executive Board shall be under an obligation to furnish all information requested by the committee, to show all cash values and assets on request, and to allow the committee to inspect all accounts and records of the Association.
5. If the committee takes the position that special accounting expertise is required to complete the review, it may retain the services of an expert at the Association's expense.

#### Article 17

1. Apart from the annual meeting of the General Assembly referred to in Article 16, extraordinary meetings shall be called whenever the Executive Board so requires.
2. If so requested in writing by such a number of members as are empowered to cast one tenth or more of the votes in a full meeting of the General Assembly, the Executive Board must call a general meeting at a maximum of four week's notice from the date of the request. If no action is taken within fourteen days of the request, the requesting members may proceed to call the meeting and to ask people outside the Executive Board to chair the meeting and take minutes.

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3. Meetings of the General Assembly shall be called by one month's written notice to be sent to the voting members. The notice of each meeting shall state the business to be transacted.
4. In cases where no written notice is given of a meeting of the General Assembly, valid resolutions can still be adopted, provided that the meeting is attended by such a number of voting members as are empowered to cast one half of the number of votes in a full meeting of the General Assembly and, further, provided that neither any of the voting members nor the Executive Board object to this decision-making procedure. If a meeting of the General Assembly is called at a shorter period of notice than prescribed, valid resolutions can be adopted unless such a number of members as are empowered to cast one tenth of the votes at said meeting object. The first sentence of this Article 17.4 shall apply equally to any decision-making by the General Assembly in respect of any business not included in the agenda for the meeting.

#### AMENDMENT TO THE ARTICLES OF ASSOCIATION

##### Article 18

1. Amendments to these Articles of Association require a resolution adopted by the General Assembly at a meeting specifically and expressly convened for that purpose.
2. Those who have called a meeting of the General Assembly for purposes of discussing a motion to amend these Articles shall deposit a copy of the motion, containing a verbatim rendition of the proposed amendment, for inspection by the members at an appropriate location from the fifth day prior to the meeting, at the latest, until the end of the day on which the meeting was held.
3. Any resolution to amend the Articles of Association must be carried by an affirmative majority of no less than three fourths of the number of votes cast at the meeting.
4. Amendments to these Articles shall not take effect until a notarial instrument reflecting the relevant amendments has been executed. All members of the Executive Board are authorized to sign the document in question.
5. Articles 18.1 and 18.2 shall not apply if the meeting of the General Assembly is attended by or on behalf of all voting members and the resolution to amend the Articles is adopted unanimously.
6. The members of the Executive Board shall be obliged to deposit an authentic copy of the deed of amendment, together with a copy of the full consecutive text of the Articles of Association, as amended, at the office of the Chamber of Commerce.

#### MERGER, DE-MERGER, DISSOLUTION, LIQUIDATION

##### Article 19

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1. The provisions laid down in Articles 18.1 to 18.3 and 18.5 shall apply equally to any resolution of the General Assembly to enter into a merger or de-merger transaction or to dissolve the Association.
2. When adopting a resolution as referred to in Article 19.1, the General Assembly shall appropriate the liquidation balance in such a manner as is commensurate, to the fullest extent possible, with the objects for which the Association has been formed.
3. The assets of the Association shall be liquidated by the Executive Board.
4. Following its dissolution, the Association shall continue to exist in so far as necessary with a view to the liquidation of its assets. These Articles shall remain in force to the fullest extent possible during the liquidation process. In all documents and communications sent by the Association, the words "in liquidation" shall be added to its name.
5. The Association shall cease to exist when all assets known to the Association or the liquidator(s) have been disposed of. The liquidators shall register the Association's discontinuation with the Chamber of Commerce referred to in Article 18.6.
6. The accounts and records of the Association, once dissolved, shall be kept for a period of twenty years after completion of the liquidation process by a person designated by the liquidators.

#### INTERNAL RULES

##### Article 20

1. The General Assembly, acting on a motion presented by the Executive Board, may adopt and amend internal rules containing provisions on subject-matters not (fully) provided for in these Articles of Association.
2. The internal rules may not contain any provisions that are in breach of the law or these Articles of Association.
3. The adoption of any resolution to adopt or amend internal rules shall be governed by the provisions laid down in Articles 17.1, 17.2 and 17.5.

#### POWERS OF ATTORNEY

The powers of attorney granted by the persons referred to under 2(a) and 2(b) on the first page hereof are evident from two non-notarial documents which have been attached to the original copy hereof.

#### FINAL PROVISION

The following persons have been elected to the Association's initial Executive Board:  
The position of President is still vacant;  
Ms Fabiola Maria Bertinotti, born in Monza, Italy, on the first of August one thousand nine hundred and sixty-five: as Vice-President;

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Mr Frank Johan Claude van Zimmeren, born in Malang, Indonesia, on the tenth of November one thousand nine hundred and seventy-nine: as Treasurer;  
Mr Manuel Cabral, born in Rapoula do Coa Sabugal, Portugal, on the twelfth of November one thousand nine hundred and sixty-seven: as Secretary.

#### CONCLUSION

The persons appearing are known to me, the undersigned civil-law notary, their identities having been duly established by means of the aforesaid identity documents intended for that purpose.

IN WITNESS WHEREOF, the original of this instrument was executed in Laren on the date stated in the first paragraph hereof.

The substance of this document was briefly summarized and explained to the persons appearing. They then declared that they had taken note of the provisions hereof well before the time of execution and that they agreed to the same, and that they had also been informed of the legal consequences arising for the parties hereunder and waived a full reading of this instrument. Subsequently, after a limited reading, this instrument was immediately signed, first by the persons appearing before me and then by me, the civil-law notary.

(signatures followed)

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ISSUED AS A TRUE COPY  
[signature]