

NAME AND SEAT

Article 1.

1. The foundation bears the name: Stichting UPPMD Data Foundation.
2. The foundation is seated in Zeist, Netherlands.

PURPOSE

Article 2.

1. The foundation has as its purpose:

Worldwide collaboration between Duchenne Parent organisations in order to enhance the understanding of the course of DMD/BMD, the effects of treatments, the needs and preferences of DMD/BMD patients and all other aspects relevant to the lives of DMD/BMD patients.

2. The foundation will in particular devote itself to the realisation of this task by way of the following goals:

- a. Collect data from PROs, PROMs, PMR etc in a data collection hub;
- b. Integrate worldwide sources of information for DMD such as databanks, biobanks and registries in one unified environment;
- c. Provide solid and safe information to parents, clinicians, regulators and other stakeholders;
- d. Promote and support research;
- e. Develop tools for better use of existing data.

COMMITTEE

Article 3.

1. The committee of the foundation consists of at least three persons, the first committee will be established by this deed. The number is determined by the Committee.

2. The members of the committee are appointed by the Committee for a period of three years; they are immediately eligible for re-election.

Article 4.

The functions of the committee members, including that of the chairman, secretary, treasurer and deputies, are decided upon by the committee.

COMMITTEE TASK AND REPRESENTATION

Article 5.

1. The committee is entrusted with fulfilling the business of the foundation.
2. The committee is authorised to enter into all agreements.

Article 6.

The foundation is represented by the committee as well as by two members of the committee jointly.

COMMITTEE MEETINGS

Article 7.

1. The committee meetings are held as often as the chairman, or two members of the committee deem necessary.
2. The committee decides by majority vote in a meeting where at least two thirds of the number of committee members is present.

3. The committee has the right to make decisions without a meeting, provided all committee members declare themselves in favour of the proposition concerned.

TERMINATION OF THE MEMBERSHIP OF THE COMMITTEE

Article 8.

The membership of the committee terminates:

- a. by the expiration of the term of office.
- b. by resignation.
- d. by dismissal upon the decision of the Committee.

FOUNDATION YEAR – ANNUAL REPORT AND ACCOUNTS AND ACCOUNTABILITY

Article 9.

1. The foundation year runs from January first up to and including December thirty-first.
2. Within six months of the expiration of the foundation year the committee shall issue an annual report of the past financial year and the accounts.
3. Approval by the Committee of the accounts and report absolves the treasurer.

FINANCIAL MEANS

Article 10.

The financial means of the Foundation are obtained from contributions of the members, gifts of sponsors, testamentary dispositions, legacies, subsidies, other contributions and benefits from property.

RULES AND REGULATIONS

Article 11.

The Committee decides on the rules and regulations which cannot contain stipulations that are contrary to these articles of foundation and in which arrangements are made that are necessary or desired in the view of the committee.

AMENDMENT TO THE ARTICLES OF FOUNDATION

Article 12.

1. Amendment of these articles of association can only take place by a decision of the Committee, which has been called with the announcement that an amendment of the articles of association will be proposed there, a copy of the proposed amendment must be included.
2. A decision to make amendments to the articles of foundation needs a majority of at least three quarters of the number of votes cast by members of the committee.

DISSOLUTION

Article 13.

1. Dissolution of the foundation can be resolved upon by the Committee.
2. What is stipulated in article 12 applies here likewise.
3. A decision for dissolution should also contain:
 - a. Appointment of a commission of liquidators, consisting of three persons
 - b. appointment of the means to cover a possible liquidation deficit
 - c. a possible liquidation surplus should be allocated in accordance with the purpose of the foundation mentioned in article 2.

FINAL CONDITION

Article 14.

In all cases not covered by these articles of foundation or the rules and regulations, or where there is disagreement concerning the foundation