

THE CONSTITUTION  
OF THE  
EUROPEAN HUNTINGTON'S DISEASE NETWORK

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## ARTICLE 1 – NAME, MISSION AND PRINCIPLES

- 1.1. Name. This network shall be known as the European Huntington’s Disease Network and referred to in this Constitution as “EHDN”.
- 1.2. Mission. The EHDN is a nonprofit research network for clinicians, scientists, patients, and families committed to advancing research and facilitating the conduct of academic and industrial clinical trials to improve quality of life of people with Huntington’s disease and their families.
- 1.3. Principles. EHDN is committed to
  - open and full scientific communication,
  - broad sharing of scientific data,
  - collaborative planning and implementation of both non-clinical and clinical projects,
  - compliance with applicable good research and clinical practice in all non-clinical and clinical projects, referred to in this Constitution as ‘Study’ or ‘Studies’,
  - peer review,
  - prompt publication of all valid results of scientific enquiry,
  - full and open disclosure of potential conflicts-of-interest,
  - democratic governance of its organization and activities,
  - working with other professional organizations, government and industry sponsors, and lay organizations,
  - recognition and protection of the interests of people with Huntington’s disease and their families, and
  - working to advance its mission as quickly as possible consistent with the foregoing.

## ARTICLE 2 - ORGANIZATION

- 2.1 Network. EHDN is an independent and not-for-profit network. EHDN serves as a platform for clinicians, scientists, patients and families affected by Huntington’s disease to collaborate in support of both non-clinical and clinical research on Huntington’s disease.

- 2.2 Limitation. Nothing contained in this Constitution shall constitute or be deemed to constitute EHDN either a partnership between the members or a formal business organization or legal entity. Each member is acting as an independent person and not as the agent of any other member. Nothing contained in this Constitution shall be construed as entitling any member to share in the profits or losses arising out of the efforts of any other member.

### ARTICLE 3 – MEMBERSHIP

- 3.1. Regular Members. Any individual actively contributing to Huntington’s disease care and/or research in Europe is eligible to be a regular member of EHDN. Each regular member of EHDN shall have one vote on any matter submitted to the membership.
- 3.2. Associated Members. Any individual actively contributing to Huntington’s disease care and/or research outside Europe is eligible to be an associated member of EHDN. Except as otherwise specifically provided in this Constitution, associated members shall not have voting rights.
- 3.3. Opportunities Associated with Membership. All members have
- the opportunity to take part in the activities of EHDN,
  - the opportunity to access the members-only areas of the EHDN web portal,
  - the opportunity to attend Plenary Meetings of EHDN,
  - the opportunity to participate in EHDN working groups,
  - the opportunity to propose studies for review and endorsement by the Scientific and Bioethics Advisory Committee (referred to as ‘SBAC’), and
  - the opportunity to qualify as an EHDN investigator eligible to participate in clinical studies and trials endorsed by EHDN.
- 3.4. Adherence to Rules and Policies. All members of EHDN are expected to adhere to this Constitution and to the by-laws, rules and policies adopted by EHDN pursuant hereto.
- 3.5. Application for Membership. Any individual desiring to become a member of EHDN shall make application for membership in such form as may be prescribed by the Executive Committee. Questions of eligibility for membership shall be determined by the Executive Committee.
- 3.6. Resignation. Any member may terminate membership in EHDN by written notice to the Executive Committee.

- 3.7. Removal of Member. The Executive Committee may terminate an individual's membership in EHDN for violation of this Constitution or the by-laws, rules and policies adopted by the EHDN pursuant hereto or for other scientific, professional or individual misconduct that may be expected to bring the reputation of EHDN into disrepute.
- 3.8. Dues; Fees. The Executive Committee may propose annual dues or other fees payable by EHDN members in order to support EHDN activities. Any such proposal for dues or other fees will not come into effect until approved by a majority of votes cast by the regular members either at a Plenary Meeting or in a mail-in/online ballot distributed for that purpose.

#### ARTICLE 4 – EXECUTIVE COMMITTEE

- 4.1. Executive Committee. The activities of EHDN shall be coordinated by an Executive Committee consisting of eleven voting members as follows:
- nine persons elected by the EHDN membership (the “Elected Members”),
  - one person representing the European community of families affected by HD appointed by the European Huntington’s Disease Association or another organization as determined by the Executive Committee, and
  - one person appointed by CHDI Foundation, Inc.

The chairs of EHDN standing committees, and representatives of EHDN Central Coordination, shall be ex officio members of the Executive Committee and shall not have voting rights for Executive Committee business.

4.2. Elected Members.

- 4.2.1 The Elected Members must be regular members of EHDN.
- 4.2.2 The Elected Members shall be divided into two, as nearly equal as possible, classes. The term of each class of Elected Members shall be staggered so that one class is elected at each Plenary Meeting.
- 4.2.3 Except as otherwise provided in this Constitution, each Elected Member shall serve for a term ending on the date of the second Plenary Meeting following the Plenary Meeting at which such Elected Member was elected, provided, that the term of each Elected Member shall be subject to the election of her or his successor and to the earlier vacancy in her or his office as further described in this Constitution.
- 4.2.4 A person may serve for no more than two terms, whether or not consecutive, as an Elected Member.

- 4.2.5 The Executive Committee may temporarily extend the term of Elected Members in the event of unforeseen circumstances such as a natural catastrophe or global pandemic.
- 4.3. Chair and Deputy Chair. As soon as practicable following the election of new Elected Members, the members of the Executive Committee shall elect from among themselves a person to be the Chair and a person to be the Deputy Chair. The Executive Committee may extend the term of the Chair or the Deputy Chair or both of them as Elected Members to ensure the continuity of EHDN leadership. The Executive Committee may remove the Chair or the Deputy Chair or both of them by majority vote of the Executive Committee.
- 4.4. Vacancies; Replacements.
- In the event of vacancy of the Chair, the Deputy Chair shall succeed the Chair for the balance of his or her elected term.
  - In the event of vacancy of the Deputy Chair, the Executive Committee may appoint a replacement from among the other members of the Executive Committee.
  - In the event of vacancy of an Elected Member of the Executive Committee, the position may be replaced by the next available member with the next highest vote count from the last election for the remaining term period.
  - In the event of vacancy of an appointed member of the Executive Committee, a replacement member may be appointed by the organization that appointed the departing member.
- 4.5. Meetings. The Executive Committee shall meet at least three times a year. Members of the Executive Committee may attend such meetings through conference calls and other means of communication. A majority of the Executive Committee present at a meeting may act unless a greater number is required by this Constitution. The Executive Committee may act without a meeting if, prior to or subsequent to the action, each member of the Executive Committee consents to the action.
- 4.6. Responsibilities. The EHDN Executive Committee shall
- oversee the activities of EHDN, including Central Coordination and Language Area Coordination,
  - oversee the development and maintenance of the infrastructure of EHDN,
  - ensure continued funding of the infrastructure of EHDN including proposing and overseeing potential dues, fees or surcharges for EHDN,

- evaluate and, if appropriate, endorse studies as set forth in Article 8,
- evaluate and, if appropriate, grant access to data or biomaterials or both as set forth in Article 9,
- convene Plenary Meetings and report to the members thereat, and
- adopt such by-laws, rules and policies not inconsistent with this Constitution as considered necessary or useful to further the mission of EHDN.

## ARTICLE 5 – EHDN COMMITTEES

- 5.1. Committees. The EHDN shall have a standing Scientific and Bioethics Advisory Committee (SBAC). The Executive Committee may establish other committees and task forces to assist with the oversight of the activities of EHDN with such mandates and responsibilities as the Executive Committee may determine.
- 5.2 Elected and Appointed Members.
- 5.2.1 The Executive Committee may appoint, or arrange the election of, members to committees. Committee members must be regular members of EHDN. Any committee member appointed by the Executive Committee may be removed by the Executive Committee with or without cause.
- 5.2.2 Nominations. The Executive Committee may seek nominations for membership on committees from EHDN regular members. The Executive Committee may appoint members to the committees from the nominations received, hold elections, or add members on an *ad hoc* basis as needed.
- 5.3. Scientific and Bioethics Advisory Committee.
- 5.3.1. Responsibilities. The SBAC shall facilitate Huntington’s disease research in Europe by acting as a source of scientific and bioethical knowledge and advice to members of the EHDN network. As such the SBAC may consider and provide recommendations to members and the Executive Committee concerning:
- 5.3.1.1. applications for access to EHDN resources including data or biomaterials,
  - 5.3.1.2. applications for EHDN endorsement of studies,
  - 5.3.1.3. applications for seed fund projects, and
  - 5.3.1.4. such other scientific and bioethical questions as members may raise.

5.3.2. The SBAC shall consist of twelve members intended to include a broad representation of the research and clinical interests of EHDN. Each member of the SBAC shall serve for a term ending on the date of the second Plenary Meeting following the appointment or election of such member, provided, that the term of each member of the SBAC shall be subject to the appointment or election of her or his successor and to the earlier vacancy in her or his office as further described in this Constitution.

5.3.3. Chair and Co-chair: As soon as practicable following each Plenary Meeting, the members of the SBAC shall elect from among themselves a person to be the Chair and a person to be the Co-chair.

5.4 The Executive Committee may temporarily extend the term of Elected Members of EHDN Committees in the event of unforeseen circumstances such as a natural catastrophe or global pandemic.

#### ARTICLE 6 – ADMINISTRATION

6.1. Central Coordination. Central Coordination shall be managed by an administrator designated by the Executive Committee.

6.2. Responsibilities of Central Coordination. Central Coordination shall manage the day-to-day activities of EHDN including,

- the coordination of the development of the information technology tools available to EHDN as directed by the Executive Committee,
- the development, management and execution of contractual relationships with EHDN staff, collaborators and vendors;
- the coordination and instruction of the work of the Language Area Coordinators of EHDN who shall be native speakers ensuring the fast dissemination and prompt implementation of the EHDN activities and endorsed studies, and
- the financial administration, accounting, and reporting of the EHDN budget.

6.3. Language Area Coordination. Language area coordinators shall be located in Language Area Coordination Centers as appropriate and shall organize, assist and conduct the practical aspects of EHDN within their area of language coordination; the language area coordinators are accountable to Central Coordination of EHDN.

6.3.1. Responsibilities. The tasks of language area coordination include but are not limited to

- translating written materials of EHDN into the respective languages,
- identifying researchers and sites interested in and capable of participating in EHDN activities and endorsed studies,
- providing support to EHDN working groups,
- providing support to study sites active in EHDN endorsed studies,
- assisting sites with Ethical Review Board applications and in conducting EHDN endorsed studies in accordance with ICH GCP guidelines, and
- providing on site monitoring for EHDN endorsed studies according to the guidelines of Central Coordination in accordance with ICH GCP guidelines.

6.4. Finances. Any income or property provided by EHDN shall be applied solely towards the promotion of the mission of EHDN as set forth in Article I, and no portion shall be paid or transferred to any officer, member or employee of EHDN, except for reasonable and proper remuneration, including repayment of out-of-pocket expenses, for any services rendered to EHDN. All income and expenses of EHDN shall be recorded and transacted in a discrete, designated account for which there are minimal administrative or overhead charges. An auditable accounting shall be kept of all income and expenses of EHDN.

6.5. Policies, Practices and Procedures. The Executive Committee is authorized to adopt such policies, practices and procedures not inconsistent with this Constitution as they consider necessary or useful for the administration of EHDN. Any policies, practices or procedures so adopted will be reduced to writing and incorporated in the minutes of the Executive Committee meeting at which they were adopted.

## ARTICLE 7 – MEETINGS OF EHDN

7.1. Plenary Meetings. EHDN shall hold a Plenary Meeting not less frequently than every second year to provide an opportunity for meetings of EHDN members and working groups, and Executive, standing and *ad hoc* committees. The Plenary Meeting may also include scientific presentations, reviews and other sessions related to Huntington's disease. At the Plenary Meeting there shall be a meeting of the EHDN membership for the purpose of

- receiving the report of the Executive Committee,
- holding elections,

- if necessary, amending this Constitution
- 7.2. Working Groups; Meetings. Members of EHDN are invited to organize peer groups to address particular topics of relevance to the mission of the EHDN. Proposals may be submitted to Central Coordination. The Executive Committee will decide on support for the Working Group meetings and other activities.
- 7.3. Science and Education Meetings. EHDN may organize and sponsor scientific and educational meetings as directed by the Executive Committee.

#### ARTICLE 8 – ENDORSEMENT OF STUDIES

- 8.1. Principles. EHDN is committed to enabling Huntington’s disease research by endorsing Studies which meet its standards of scientific rigour and ethical conduct. Members conducting Studies endorsed by EHDN are expected to comply with the provisions of this Constitution and to the policies and procedures adopted by EHDN pursuant hereto including the provisions relating to Publication and Authorship and Ethics and Conflicts-of-Interest.
- 8.2. Application for Endorsement. Any person may make application to EHDN for endorsement of a Study related to Huntington’s disease by submitting such information as the Executive Committee may, by policy and procedure, prescribe.
- 8.3. Science; Bioethics Recommendation. The SBAC shall review each application and submit a report thereon to the Executive Committee, including such conditions for endorsement.
- 8.4. Endorsement Criteria. In deciding whether to endorse a Study the Executive Committee shall consider the report of the SBAC and may consider any other factors it deems appropriate in the circumstances.
- 8.5. Conduct. All EHDN endorsed Studies shall be conducted in accordance with this Constitution, the policies and procedures adopted by EHDN pursuant hereto and all applicable laws and regulations.
- 8.6. Policies and Procedures. The Executive Committee may adopt policies and procedures to give effect to these endorsement principles, including specification of the information to be included in an application for EHDN endorsement of a Study.

#### ARTICLE 9 – ACCESS TO EHDN DATA AND BIOMATERIALS

- 9.1. Principles.
- 9.1.1. Ownership of Clinical Data and Biomaterials. Clinical data and biomaterials remain the personal property of the research participant providing them. Such data and biomaterials may only be used by

investigators for research upon and subject to the terms of the informed consent of the research participant providing them.

- 9.1.2. Sharing Data and Materials. EHDN is committed to enabling well-powered, informative Studies of Huntington's disease by making data and biomaterials provided by patients and collected through the efforts of contributing sites available to competent scientific investigators who propose ethically sound Studies. In exchange for receiving the data and biomaterials, when ethically feasible EHDN may require researchers to promptly submit Study-level data derived in the course of the project back to EHDN to further annotate the data and biomaterials used.
- 9.1.3. Other Compliance. Members conducting Studies using data or biomaterials obtained from EHDN are also expected to comply with the provisions of this Constitution and to the policies and procedures adopted by EHDN pursuant hereto including the provisions relating to Publication and Authorship and Ethics and Conflict-of Interest.
- 9.2. Application for Access to EHDN Resources. Any member of EHDN may make application to EHDN for access to EHDN data or biomaterials or both by submitting such information as the Executive Committee may, by policy and procedure, prescribe and by providing such other information as the SBAC or the Executive Committee may request.
- 9.3. Science; Bioethics Recommendation. The SBAC shall review each application for access to EHDN data or biomaterials and submit a report thereon to the Executive Committee, including such conditions for granting access as the SBAC deems appropriate in the circumstances. In deciding whether to recommend giving access to data or biomaterials or both, the SBAC may consider the aims, objectives, scientific and clinical adequacy of the Study, the availability of the biomaterials sought, the qualifications and capabilities of the investigators, the mechanism for funding, the sponsorship of the proposed study, ethical issues and any other factors it deems appropriate in the circumstances.
- 9.4. Access Criteria. In deciding whether to grant access to data or biomaterials or both, the Executive Committee shall consider the report of the SBAC and may consider any other factors it deems appropriate in the circumstances.
- 9.5. Conduct. All EHDN data and biomaterials shall be used in accordance with this Constitution, the policies and procedures adopted by EHDN pursuant hereto and all applicable laws and regulations.
- 9.6. Policies and Procedures. The Executive Committee may adopt policies and procedures to give effect to these data and biomaterial access principles, including specification of the information to be included in an application for access to EHDN data and biomaterials.

## ARTICLE 10 – PUBLICATION AND AUTHORSHIP

### 10.1. Principles. EHDN is committed to

- prompt publication of all valid results of scientific enquiries,
- recognition of the contribution of research participants and their families,
- fairness to all contributors, including providing opportunities for authorship and proper acknowledgement of all investigators contributing data or materials,
- recognition of sponsor support for EHDN and EHDN endorsed Studies.

10.2. Policies and Procedures. The Executive Committee may adopt policies and procedures to give effect to these publication and authorship principles, including pre-publication review of any publication of results from an EHDN endorsed studies.

## ARTICLE 11 – ETHICS AND CONFLICTS-OF-INTEREST

### 11.1. Principles. Members of EHDN shall

- maintain the highest personal and professional standards in conducting studies. Real and perceived conflicts-of-interest should be avoided,
- fully disclose their research support and any significant financial interest in any manufacturer(s) of commercial products related to the topic of any presentation for education events in which they participate, and insist on full and meaningful disclosure of financial support for educational events to which they are invited to participate.
- not in any way or manner benefit financially from the information obtained as a result of their participation or knowledge of EHDN studies. In particular:
  - not own or trade in the equity of a company whose drugs or products are being investigated by EHDN or EHDN endorsed studies (an “involved company”) or inform or influence relatives, friends or others in financial transactions regarding an involved company.

11.2. Education; Confidential Information. EHDN members have an obligation to act in the public interest and should be willing to educate the scientific and lay communities so long as doing so does not disclose confidential information or jeopardize the successful outcome of any Study which is in progress.

11.3. Policies and Procedures. The Executive Committee may adopt policies and procedures to give effect to these ethical and conflict-of-interest principles,

including the timing of the application of these principles to Studies, permitted activities and the annual disclosure of certain relationships.

ARTICLE 12 – AMENDMENTS; DISSOLUTION; EFFECTIVE DATE

- 12.1. Amendments. Amendments to this Constitution may be proposed by any regular member, must be made in writing, must be signed by six other regular members, and must be submitted to the Executive Committee at least two months prior to a meeting of the Executive Committee, at which time the proposed amendment will be considered and voted upon. If the proposed amendment is approved by the Executive Committee, it will be submitted to a vote of the regular members of EHDN. Affirmation by at least two-thirds of the votes cast shall be required for the amendment to be adopted.
- 12.2. Ibid. At the request of the proposer, amendments not approved by the Executive Committee may be placed on the agenda at least one month prior to a Plenary Meeting of EHDN where the proposal may be enacted by an affirmative vote by at least two-thirds of votes cast by voting members at the meeting.
- 12.3. Dissolution. The dissolution of EHDN shall be decided by the affirmative vote of at least three-fourths of votes cast. The procedure for proposing the dissolution of EHDN shall follow that outlined for proposing amendments in section 12.1.
- 12.4. Effective Date. The Amendment of the Constitution was adopted on September 12, 2024.