

# **Bylaws of the EU-NN e.V., European Narcolepsy Net**

## **§ 1 Name and location**

1. The name of the association is „European Narcolepsy Net (EU-NN)”. It shall be registered in the chamber of registers and is then named „e.V.” (registered association).
2. The association is based in Marburg, Germany.
3. The association was founded on February 9, 2008.
4. The association remains neutral on politics, races and religions.
5. The fiscal year is the calendar year.
6. The association is founded exclusively and directly for non-profit purposes according to the part „tax-privileged purpose“ of the German fiscal code.

## **§ 2 Objectives of the association**

1. Objective of the association is the promotion of the European scientific research in narcolepsy, hypersomnia, and related fields and the optimization of medical care for patients by improving diagnostic and therapeutic measures. A close co-operation of those involved in treatment, management and research, as well as patients and their family members is to be developed further and will facilitate a fast knowledge and information exchange in the field. Therefore the association wants to contribute to and improve the European information and communication structures and to support the establishment of a standardized patient data base.

The statute’s purpose in particular will be carried out by the following measures

- a) Interaction, collaboration, and integration of European experts in the area mentioned in § 2.1
- b) initiation and execution of scientific projects in basic and clinical research as well as research in health care of the areas mentioned in § 2.1 which are not or only partly supported by public organisations or industrial sponsoring

- c) organising scientific meetings, seminars, and advanced training activities
- d) co-operation with European and non-European scientists and scientific organisations, research projects or consortia, that could support the objectives of the association in the areas mentioned in § 2.1
- e) collaboration with other research institutions
- f) To provide grants to members and non-members for participation in scientific and educational meetings
- g) publication of research results, guidelines, and recommendations for socio-legal aspects and unmet needs
- h) transfer of results into applicable tools
- i) cooperation and support with public organisations, patient groups and the pharmaceutical industry

### **§ 3 Non-profit entity**

1. In all its activities, the association will maintain non economic interest and will be organized and function as a non-profit entity.
2. The funds of the association may only be used for achieving the purposes of the association. The members do not receive any remuneration from the funds of the association.
3. No person may benefit from spending money that is at odds with the purposes of the association.
4. Persons in a honorary capacity may only receive reimbursement of their documented expenses.
5. EU-NN is going to create a database consisting of three parts:
  - a. Core database
  - b. extended database
  - c. Biosample bank

The contents of the core database and any change of it is based on the unanimous decision of the Assembly of members.

The association is the owner of the core database. All regular members of the association have access to the core database only. It is not permitted to use the data of the core data base

by any member in case the Board has disapproved it. Members who want to have access to other than their own data will inform the Board for admission to this data. The extended database remains the individual property. The member is owner of the biosamples and may contribute his samples after local ethical approval to the Biosample Bank

Materials collected in the Biosample Bank are owned by the association. There will be separate bylaws for the Biosample Bank that meet national and European requirements.

#### **§ 4 Membership**

It is to be differentiated between regular members, associate and supporting members of the association. Natural and juridic persons (corporations), legal entities of the public and private law, can become members as well as in law and order recognized organisations which support and promote the scientific and health-referred purposes of the association actively. For that purpose it requires the willingness to promote scientific research and knowledge in the areas mentioned in § 2.1 actively or support these tasks appropriately. Each sleep center is represented by one regular member only. Regular members must provide core data of at least five patients with narcolepsy or hypersomnia at their own expense. With each five new patients included the number of regular members of one sleep center can be increased by one to a maximum of three regular members. The quality of the data will be reviewed by the data base management committee and must be considered adequate for inclusion into the database.

Only regular members have a right to vote. To practice the right to vote another member can be authorized in writing. The authorization is to be given for each Assembly of the members separately. However, one member may represent no more than one additional voice by authorization. Natural and legal entities of the public right who become active in the sense of the aforementioned statute purposes or who will support the objectives of the association by financial, idealistic, and other achievements actively can become sustaining members of the association. They do not have a right to voting (non-voting members).

The application for membership is to be addressed in writing to the Board which finally decides on each request in the next board meeting. The decision is to be communicated to the applicant in writing, it requires no justification and cannot be contested.

## **§ 5 Termination of membership**

The membership ends

- a) with the death of a member
- b) by voluntary termination of the membership
- c) by exclusion from the association

The voluntary termination is declared with a written statement to a member of the board. It is only allowed at the end of the calendar year within a 3-month term of notice.

Membership of any member may be terminated in case of violation of the association's interests by a decision of the Board. Before a decision can be made, the member has to be offered the opportunity to justify any reasons personally. In case a written declaration to the membership has been submitted it has to be read within the Assembly of members.

## **§ 6 Membership fees**

There will be membership fees. The Board decides on the amount. The Board can abstain from raising membership fees.

## **§ 7 Organs of the association**

1. The organs of the association are

- a) The Board
- b) The Assembly of all members

2. Further organs can be formed or dissolved by resolution of the Assembly. If the new organs have only advisory function, it therefore requires no amendment of the by-laws, if the Assembly of members as an organ at the same time issues an agenda obligatory for the new organ.

## **§ 8 The Board**

The Board according to German law consists of the

- a) President
- b) Vice-president
- c) Secretary

- d) Treasurer
- e) One to three members at large

#### Committees

One of the board members must be the chair of a permanent committee. The Board decides which member is chair of the respective committee.

The president has to be a European citizen.

It is not allowed that one person takes over more than one position of the board.

### **§ 9 Representation**

The association is represented legally and extra-legally by two board members conjointly. Legal documents must be signed by two Board members. Signatures of either president/vice-president or treasurer are required.

The right of representation of the Board is limited to the property of the association and its databank.

### **§ 10 Duties and responsibilities of the Board**

The Board is responsible for

- a) The current business of the association
- b) The execution of resolutions of the Assembly
- c) To develop the financial plan
- d) To record book keeping on incomes and expenditures of the association (total revenue)
- e) Decision on admission of further members
- f) Task distribution and control of business activity
- g) Control of projects for accordance to the ethical principles of the Helsinki Declaration
- h) Access to database
- i) Use of databank material for scientific purpose
- j) The applicants for scientific projects need consent of 2/3 of the members of the Scientific Committee

Committees: The board can nominate committees for important board tasks. The

committees must not be approved by the assembly; There are 3 permanent Committees:

- a. A Scientific Committee
- b. B Data base management Committee
- c. C Funding Committee

The president is allowed to assign tasks to board members.

### **§ 11 The term of office of the board**

All terms of office will be for two years beginning with the day of election. The board holds office until the re-election of the board.

If a member of the board leaves the board during the turn, the board elects a substitute member from the pool of members for the remaining duration of the turn.

The re-election of a board member in the same position is possible for further two years. The maximum membership in the board in a sequence will be 6 years.

### **§ 12 Decision-making of the board**

The Board seizes its resolutions generally in board meetings, which will be announced by the president or vice-president in writing, by phone or via email. In each case a fourteen-day announcement is to be kept. The announcement does not require the agenda. The Board can make decisions if at least two members of the board, among them the president or the vice-president, are present. During the procedure on adoption of resolutions the majority of the delivered valid voices decides. With equality of votes, the voice of the president/vice-president as the leader of the board meeting decides.

The board meeting is chaired by the president, if not available by the vice-president.

Resolutions of the board are to be proofed in minutes and signed by the chair of the meeting and by the secretary of the meeting.

A decision of the board can be done in a written form or by phone if all board members agree on that mode of action.

The board meets at least once per year.

### **§ 13 Honorary work of the board**

The Board leads its business honorary. Personal expenses which result from Board activities can be reimbursed in appropriate form.

### **§ 14 Rules of internal procedure**

The Board can give itself rules of internal procedure.

### **§ 15 Liability of the Board**

The Board is liable for practice of the office by willful intent or gross negligence.

### **§ 16 Administrative Office**

For the realisation of the current business the Board is authorized to establish an office and employ regular staff.

### **§ 17 Financial auditor**

The auditor is selected by a simple majority of votes for the duration of two years by the Assembly of members. He/She examines all book keepings of the association and verifies the accounts. The auditor may not belong to the Board, and is not subject to the Board instructions and should therefore examine the financial business independently.

### **§ 18 Assembly of all members**

Each regular member present has one vote in the Assembly of the association.

The obligatory items on the agenda are:

- a. Annual reports, financial statements, and auditor's reports of the two years preceding the meeting

- b. Ratification of the financial statements and decision about granting an exemption from liability to the members of the Board. Ratification of the choice of the Auditor for the coming period
- c. Election and dismissal of Board members
- d. Decisions on changes of the bylaws and termination of the association
- e. Nomination of honorary members

### **§ 19 Announcement of the Assembly of members**

The Assembly of the association's membership has to take place at least once every two years.

The Board has to ensure that the members are informed about the meeting by mail or e-mail at least 30 days prior to the date of the meeting including the announcement of the agenda.

The period begins with the working-day following the dispatch of the invitation. The announcement has to be sent to the e-mail address of the member that has been announced in a written form by each member. The Board determines the agenda.

### **§ 20 Decision-making process by the Assembly of members and quorum**

1. The Assembly of the association's membership will be chaired by the president or in case of being prevented by the vice-president or another Board member. If no Board member is present, the Assembly decides on a chair.

2. The minutes are taken by the secretary. If he/she is not present, the chair determines a deputy for taking the minutes.

3. The minutes have to be taken on the decisions of the Assembly of the association and have to be signed by the chair of the meeting and the secretary. The minutes have to include the following information: Place, date of the meeting, name of the chair and secretary and the

number of the members present at the meeting, the agenda, the decisions and the mode of voting. In case of changes on the bylaws the changed article has to be indicated.

4. The Assembly is not a public meeting. The chair can admit guests. The Assembly has to decide on the admission to press, the broadcast network or TV.

5. The mode of voting is decided by the chair. The voting has to be in a written form, if 1/3 of the members present insist on that.

6. Each duly announced Assembly of members constitutes a quorum independent of the absolute number of members present.

7. The Assembly decides on proposals in general by majority of the valid votes; abstentions are not relevant. For changing the bylaws a two-thirds majority of the valid votes is necessary, for the termination of the association a majority of 4/5.

8. If no candidate has received a majority in elections in the first ballot, a second ballot is performed between those two candidates who have received the highest number of votes in the first ballot. The voting can take place by email independently from the Assembly of the members. In case of equal number of votes the vote of the chair of the Assembly will be relented.

## **§ 21 Additional requests for agenda**

Each member can apply to the Board in written form that additional proposals will be included in the agenda one week before the day of the Assembly of members of the association at the latest. The chair of the meeting has to add those proposals to the agenda at the beginning of the meeting. The membership decides on the application of additional proposals to the agenda that may be initiated within the Assembly of the association. A 3/4 majority is needed to accept an additional application on that day.

Proposals for termination of the association as well as the voting and dismissal of Board members can only be decided if the application of that proposal has been announced to all members together with the agenda.

## **§ 22 Extraordinary Assembly (EA) of all members**

The Board can announce an extraordinary Assembly of the association at any time. It has to be announced if the interest of the association demands an Assembly of the association or if the Board demands a written form signed by 1/10 of all members indicating the reasons and purpose. The rules according to §§ 18, 19, 20, and 21 are applied accordingly in extraordinary Assemblies of the association.

## **§ 23 Termination of the association**

A proposal to terminate the association must be initiated by a vote of two-thirds of the Board. The proposed termination must be included in the agenda of an Assembly of the association and announced to the membership at least 30 days prior to the meeting. The association may be terminated if at least four fifths (4/5) of the votes at the Assembly are in favor of such termination (§ 20).

The president and the vice-president are both to accomplish the liquidation if not decided otherwise by the Assembly of the association members. The same regulations apply accordingly if the association is terminated or dissolved because of other reasons or has lost its legal capacity.

If the association is terminated or has lost the non-profit purpose, all remaining assets (funds) and properties must be conveyed to the European Sleep Research Society [ESRS] under the condition that it is to be used directly and exclusively non-profit for the narcolepsy and hypersomnia research. This regulation is effective only if the responsible tax office agrees or gives otherwise to recognize that there are no fiscal doubts regarding the non-profit character.

All belongings of the association will be transferred to the ESRS if the EU-NN e.V. loses its non-profit status.

## **§ 24 Currency of the association**

The currency of the association is the Euro.

These bylaws have been agreed on in the founding meeting (Assembly of the association) in Zurich on February 9, 2008.