



**European Network for Research on
Alternating Hemiplegia in Childhood**

**ENRAH
ASSOCIATION**

THE ENRAH ASSOCIATION STATUTES

(adopted by the General Assembly 23 June 2007 Prague, Czech Republic)

Article 1 - Name and Registration

1. Following the Austrian Laws, as modified beginning 01.07.2002, ENRAH is established as a European not-for-profit organisation (“Verein”) under the name ‘European Network for Research on Alternating Hemiplegia (in Childhood)’, abbreviated ‘ENRAH’.
2. ENRAH is registered in Vienna to actively forward scientific research on Alternating Hemiplegia in Childhood (AHC).

Article 2 - Objectives

ENRAH aims to develop a network of communication and information sharing within an overall ethical, social, and scientific framework aimed at achieving the following objectives:

- A. to promote public awareness of AHC and increase the priority given to AHC and related rare childhood neurological conditions by policy and decision-makers and health care providers;
- B. to provide a European platform for AHC patients and their families;
- C. to improve quality of life for AHC affected people and their families: facilitate access and exchange of meaningful information;
- D. to improve therapy: eventually leading to cure and reversal of any health afflictions caused by AHC;
- E. to improve diagnosis: allowing AHC to be early on, easily, and precisely identified in patients; and
- F. to develop prophylaxis: allowing for the prevention of the onset or development of AHC.
- G. to develop and participate in research and education in AHC and related disorders

Article 3 - Means to Achieve Its Objectives

1. The association engages in activities that contribute to its objectives in the ways it deems most appropriated, including participation in international projects and collaborations, the organisation of conferences and meetings, and publications. The activities of ENRAH are considered, set out, and reviewed by the Executive Committee.
2. In order to achieve its objectives, the association receives and manages funds in the forms of subsidies, donations, legacies, sponsorships. The association also disposes of all contributions, grants, loans and other income or funds, whether periodically paid or not.

Article 4 - Members

1. The Association is composed of members.
2. Members are founding and elected individual members that together direct the Association toward achieving its objectives by developing and managing activities and resources.
3. Associate Members are organisations that share the objectives, values and interests of the Association and contribute expertise from areas outside the Association. Users are individuals or organisations that are involved in specific projects using the Registry under specific conditions. Associate Members and Users have no voting rights.

Article 5 -Acquiring ENRAH Membership

1. ENRAH Membership is open to application to all persons interested in Alternating Hemiplegia in Childhood and who are willing to contribute constructively to the goals and activities of the Association.
2. A prospective candidate must apply in writing to the Executive Committee. The Executive Committee evaluates the application and decides on acceptance or non-acceptance in accordance with the ENRAH Membership Policy (published separately).

Article 6 - Ending ENRAH Membership

1. Membership ends in the case of death, loss of civil rights, resignation, or the closing of the Association.
2. Members may resign at any time by notifying the Executive Committee in writing.
3. Membership may be withdrawn by a two-thirds vote of those present at an Executive Committee meeting. A member must be notified one month in advance of a proposal to withdraw his or her membership, and the member must be allowed to present arguments in writing or otherwise as determined by the Chairperson to the Executive Committee. A member whose membership has been withdrawn may appeal to the next General Assembly. The membership remains withdrawn unless reversed by a majority vote of the General Assembly.
4. Failure to pay the annual subscription fee may result in the withdrawal of membership.

Article 7- Rights and Responsibilities of the Members

1. Members are entitled to take part in all activities of the Association and to benefit from any of its acquisitions and achievements.
2. Members should contribute to the ENRAH objectives as well as engaging in the Association in a manner that respects its Statutes and decisions. Members are responsible for the fulfilment of the ENRAH mission and promoting its vision through their activities in the Association and in their activities outside the Association.
3. Members must pay an annual contribution, which amount will be determined each year by the General Assembly on the proposition of the Executive Committee.
4. A member who dies or who no longer belongs to the Association no longer has decision-making rights or rights to any of the assets of the Association.

Article 8 – Decision-making Bodies

The decision-making bodies of ENRAH are the General Assembly and the Executive Committee.

Article 9 – General Assembly

1. The General Assembly is the overall decision-making body in ENRAH. It is be composed of the members. The Executive Committee may invite guests to attend the General Assembly in a non-voting capacity.
2. The General Assembly has the following the competencies:
 - reviewing the past activities of ENRAH and the strategic plan of ENRAH for the future;
 - reviewing the annual accounts;
 - electing President, Vice President, Treasurer , Secretary and Executive Committee members;
 - amending to the Statutes; and
 - dissolving ENRAH (by a two-thirds majority vote of those present).
3. The General Assembly meets at least once a year. Each General Assembly takes place at a time and place indicated by the Executive Committee by email to each member at least 30 days prior to the meeting. The invitation should include a preliminary agenda.
4. The Association may meet in Extraordinary General Assembly if decided by the Executive Committee or at the request of not less than one quarter of the members of the General Assembly. An Extraordinary General Assembly must follow the same procedures as in 9.3 above.
5. The General Assembly is presided over by the President of the Executive Committee or, in the President's Absence, by the Vice President or by another Executive Committee member nominated by the President.

6. The decisions of the General Assembly are made by a simple majority vote. Only those members attending may vote. Decisions of the General Assembly are taken by simple majority vote.
7. Decisions of the General Assembly are recorded in formal minutes, signed by the person presiding at the meeting and by one other Committee member. All members will receive by e-mail a copy of the draft minutes of the General Assembly. The minutes of the general assembly are approved at the following meeting of the General Assembly and a copy of the minutes are circulated to all members by e-mail.

Article 10 – Executive Committee

1. The Executive Committee of ENRAH is responsible for the management and administration of the Association. It comprises not less than five and not more than ten members.
2. The Executive Committee is elected by the General Assembly by a simple majority vote and chosen from among the candidates of the members. Members of the Executive Committee are appointed for a three year term; they may be re-elected at the end of three years. In the event of a vacant post occurring during a year, a co-opted member is nominated by the Executive Committee. The co-opted member fulfils the mandate of an elected Committee member to complete the remaining term of office of the member he/she replaces.
3. The Secretary General of ENRAH is an *ex officio*, non-voting member of the Executive Committee.
4. The members of the Executive Committee appoint from among themselves the officers, including President, Vice-President, Secretary, and Treasurer.
5. The Executive Committee oversees all the work of ENRAH, including that of the ENRAH Working Parties.
6. The Executive Committee establishes an Advisory Council of experts to advise the Executive Committee on its strategic planning and to review the progress of ENRAH.
7. The Executive Committee meets as required, but at least twice a year, at the request of at least two members of the Executive Committee.
8. An Executive Committee meeting may be held in person or through telephone or Internet conferencing facilities.
9. The Executive Committee may take decisions only if at least half of its members are in the meeting.
10. Decisions of the Executive Committee are taken by simple majority of those present.
11. At the next Executive Committee meeting the minutes of the previous meeting are presented for approval and, once finalised, signed by the Secretary of the meeting and kept in a register. The minutes are sent by e-mail to the members and are considered as a form of regular notification of the decisions of the Executive Committee.
12. The Executive Committee has the powers and authority to decide and implement the Executive Committee's acts in pursuance of the objectives of the present Statutes. All matters not expressly reserved by the law or the Statutes to the General Assembly falls under the competency of the Executive Committee.
13. The Executive Committee carries out, or causes to be carried out, all activities of ENRAH and ensures that the decisions of the General Assembly are fulfilled.
14. Any documents that commit the Association to an obligation are signed by the President and the Secretary General.
15. All members of the Executive Committee may represent ENRAH in an official capacity. All such representations should be reported to the Executive Committee.

16. The Executive Committee may establish any bylaws it considers necessary for the proper functioning of the Association.
17. Any legal action as plaintiff or as defendant are pursued by the Executive Committee represented by the President or a member designated by the President.
18. The official language of the Association is English.

Article 11 – Administration

1. One or more Secretariat offices with paid administrative support may be established by the Executive Committee for the day-to day management of ENRAH. The Secretariat office(s) can be at any location determined by the Executive Committee.
2. The Executive Committee may appoint staff, either as employees or as consultants.
3. The Secretariat is managed and coordinated by the Secretary General.

Article 12 – Finances

1. The financial year commences on 1st January and end on the 31st December.
2. The Treasurer prepares a balance-sheet and the accounts which the Executive Committee then submits to the General Assembly following the end of the financial year.
3. An annual audit of the books and records of the Association is carried out by an independent auditor.

Article 13 – Amendments and Dissolution

1. Each proposition that calls for an amendment to the Statutes or calls for the dissolution of ENRAH must be made by a voting member of ENRAH. The Member submits the proposal to the Executive Committee and Secretary General at least 60 calendar days prior to the General Assembly at which the proposal is to be voted upon. The Secretary General sends the proposal to the voting members of ENRAH at least 30 calendar days prior to the General Assembly at which the proposal is to be voted upon. The General Assembly decides proposals for amendments to the Statutes or for the dissolution of the Association by a two-thirds majority vote by those present at the General Assembly.
2. In case of dissolution, at whatever time or for whatever reason, the Executive Committee determines the manner of the liquidation of the Association. The remaining assets of the Association, after payment of any debts and charges, are to be donated to a not-for-profit organisation as decided by the Executive Committee.