

ENRAH Membership Information

What is ENRAH?

The European Network for Research on Alternating Hemiplegia (ENRAH) brings together patients and their families seeking support and improved healthcare for those suffering from Alternating Hemiplegia in Childhood (AHC). ENRAH collaborates with all patients, patient organisations, research groups, and other interested parties across Europe in order to share experiences, concerns, information, knowledge, understanding, and tools that assist AHC patients and their families.

ENRAH was initiated by the parents of an AHC-affected child through a networking project funded by the European Commission within the 6th Framework Research Programme from April 2005 through June 2007. In April 2003 ENRAH registered as not-for-profit association under the Austrian Vereinsgesetz (Reg.Nr.: ZVR 542743764).

What Is ENRAH's Mission?

The primary objective of ENRAH is to establish a platform for care and research regarding AHC in order to achieve the following objectives:

1. 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;
2. to provide a European platform for AHC patients and their families;
3. to improve quality of life for AHC affected people and their families: facilitate access and exchange of meaningful information;
4. to improve therapy: eventually leading to cure and reversal of any health afflictions caused by AHC;
5. to improve diagnosis: allowing AHC to be early on, easily, and precisely identified in patients; and
6. to develop prophylaxis: allowing for the prevention of the onset or development of AHC.
7. to develop and participate in research and education in AHC and related disorders.

In order to achieve these objectives ENRAH develops a network of communication and information sharing within an overall ethical, social, and scientific framework. ENRAH engages in activities that contribute to promoting public awareness and increase attention regarding AHC and related rare childhood neurological conditions.

What Are ENRAH's Main Achievements?

The primary achievement of ENRAH is the realisation of a pan-European platform for AHC driven by patients and working in close cooperation with caretakers and researchers. As ENRAH grows and develops toward the future, it builds on the following accomplishments:

- ✓ A network of AHC patient organisations (Italy, France, Spain, the Netherlands, Germany, UK) as well as individual patients, care takers, researchers, hospitals, and academic centres engaged in AHC patients across Europe.
- ✓ A network of Centres of Expertise for AHC in Austria, Belgium, the Czech Republic, France, Germany, Italy, The Netherlands, Spain, and the United Kingdom.
- ✓ A Web-based registry of AHC patients as well as scientific and medical information related to AHC.

- ✓ Best Practice Guidelines for related to healthcare and research in AHC.

ENRAH is driven by patient needs, based of expertise and knowledge and supported by experienced EU project managers.

What Are the Goals of ENRAH?

The primary goal of ENRAH is to improve the care and treatment of AHC patients, eventually finding effective diagnostic, therapeutic, and prophylactic interventions. ENRAH works toward this goal by

- ✓ bringing together, as much as possible, all European patients and their organisations into a single European platform;
- ✓ inviting the full participation of the medical and research community in the struggle against AHC;
- ✓ developing and maintaining a registry of patients and AHC information to promote studies and further research;
- ✓ establishing collaborations with partners having similar or related interests; and
- ✓ initiating projects to meet the needs of AHC patients.

Why Join ENRAH?

You should join ENRAH for two reasons:

1. to improve the support, care, and treatment of an ENRAH patient
2. to bring something to the support, care, and treatment of ENRAH patients

ENRAH approaches AHC as a shared concern in which all members are expected to receive from the organisation as well as giving (by sharing experience, information, and/or expertise) to the organisation. ENRAH exists for AHC patients. If this is a concern of yours, we hope you will also bring your needs and interests to ENRAH.

How Can I Participate in ENRAH?

ENRAH Membership is open to application for individuals and for legal entities looking for European-level support for AHC patients and for those who have something to bring to AHC. ENRAH recognises three levels of involvement in its activities:

1. Members

These are physical persons that make substantial contributions to ENRAH by committing to the responsible sharing of experiences, information, and expertise regarding AHC. Members contribute to ENRAH's strategic assets, critical mass, and resources.

2. Associated Members

These are legal entities that share common interests, values, and standards while contributing to the ENRAH objectives.

3. Users

These are legal entities or physical persons involved in specific projects.

A full description of ENRAH types of membership is provided in the ENRAH's Statutes and Bylaws.



The ENRAH Association Statutes (draft, version 2.1, 26 April 2007)

How Can I Join ENRAH?

1. Complete the ENRAH Membership Application Form (available at www.enrah.net or through e-mail from ts@enrah.net or by calling +43 1 9200075)
2. E-mail the completed application form along with a copy of the other information required in the application form to the ENRAH Secretariat at ts@enrah.net.

Your application will then be reviewed by the ENRAH Executive Committee according to ENRAH's Statutes and Bylaws, which can be viewed online at www.enrah.net.

How Can I Receive More Information Regarding ENRAH?

Updated information on the ENRAH Association is provided on www.enrah.net . You can also send an e-mail to the Secretary General, Dr. Tsveta Schyns, at ts@enrah.net or call +43 1 9200075.