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ENRAH for SMEs EC FP6 funded project

LSSM-CT-2005-516513

Specific Supported Action

April 2005-March 2007

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European Network for Research on Alternating Hemiplegia in Childhood ENRAH



enrah 
EUROPEAN NETWORK FOR RESEARCH ON
ALTERNATING HEMIPLEGIA

Alternating Hemiplegia in Childhood (AHC)

Alternating Hemiplegia in Childhood (AHC) is a rare neurological disorder characterized by frequent, temporary episodes of paralysis on one side of the body (hemiplegia). Symptoms usually begin before the age of 18 months. This syndrome may be characterized by temporary (transient) hemiplegia of varying degrees; temporary paralysis of the muscles that control eye movement (transient ocular palsies); sudden, involuntary movements of limbs and facial muscles (choreoathetosis); and/or excessive sweating with changes in skin color and body temperature (autonomic nervous system dysfunction). Mental capacity may be affected. The exact cause of AHC is unknown. Some cases of AHC may be inherited as an autosomal dominant trait.

ENRAH is a non-profit organisation which was founded in 2003 in Vienna, Austria. Enrah is a partnership of patient organisations, academia and industry in Europe to support the research on Alternating Hemiplegia in Childhood (AHC).

The ENRAH Network

- Involves clinical and academic centres and patient organisations active in the field of AHC.
- Members are spread all over Europe (more than 15 countries).
- Combines know-how from science and industry.
- Supports the co-ordination of research activities in the field of AHC.
- Initiates further research projects.
- Communicates relevant research results and project ideas.
- Informs the public about AHC and other similar rare diseases.
- Know-how transfer between the industry, academia and policy-makers.
- Organises events and PR activities.



European Project - Specific Support Action
Funded by the 6th Framework Programme for Research, Technology and Demonstration of the European Union

Goals of the **ENRAH for SMEs (Small and Medium sized Enterprises)** project:

- Establish a web-based European registry of AHC patients.
- Establish a multidisciplinary research network on AHC.
- Organise workshops on AHC.
- Identify partners from industry and SMEs to participate in the network and in further European research projects.
- Identify research topics for the 7th Framework Programme..
- Conduct studies using the collected information on the disease
- Develop specific ethics and GCP standards and applications for research involving AHC patients.
- Communicating information on the project results and the studies to the scientific community and the public.

