

European Network for Research on Alternating Hemiplegia in childhood -

ENRAH Association

2008 REPORT

1. ORGANISTAION

2. ACTIVITIES

3. PUBLICATIONS

4. FINANCIAL REPORT



ORGANIZATION

1.1. Registration

ENRAH is a patient driven non-profit non-governmental organisation founded in 2003 in Vienna, Austria to actively forward scientific research on Alternating Hemiplegia in Childhood (AHC) and related very rare disorders. The Association is registered under the Austrian Vereinsgesetz Reg.Nr.: ZVR 542743764 .

1.2. Members

Full members :

Schyns Tsveta	Poncelin Dominique	Sange Guenter
Neville Brian	Nevsimalova Sona	Casaer Paul
Vavassori Rosaria	Panagiotakaki Eleni	Crawley Francis
Ebinger Friedrich	v/d Maagdenberg Arn	Arzimanoglou Alexis
Spiel Georg	Martinelli Filippo	Gianotta Melania
Laan Laura	Bassi Maria Teresa	Campistol Jaume
Gobbi Giuseppe	Nicole Sophie	

Associated Members: AISEA, AESHA

Secretary General: Tsveta Schyns

Auditor and Tax Advisor: Mag. Irene Wiesinger, Steuerberaterin

1.3. General Assembly

2008 General Assembly took place in London 26th April 2008 ,

ATTENDEES:

Brian Neville , Sona Nevsimalova , Tsveta Schyns, Georg Spiel,
Paul Casaer , Guenter Sange, Francis Crawley, Friedrich Ebinger,
Rosaria Vavassori, Claudio Zucca, Maria Teresa Bassi, Sophie Nicole,
Eleni Panagiotakaki, Arn van den Maagdenberg





APOLOGIES:

Arzimanoglou Alexis, Campistol Jaume, Gianotta Melania, Gobbi Guiseppe, Laan Laura, Martinelli Boneschi Filippo, Kemlink David, Poncelin Dominique

AGENDA:

1. Activities report 2007
2. Financial report 2007
3. Membership- New Members and Fee 2008.
4. ENRAH in 2008- new projects and co-funding:
 - nEUroped ,-proposal for Associated Members – to be submitted to the PHP call May 2008, -new research and projects
5. GA 2009
6. Any other issues

DECISIONS:

1. Approved the Activities Report 2007 and the Financial Report 2007 and the audited accounts, and gave discharge to the Board.
2. Membership fee for 2009 will be 10 euro's.
3. The next GA will be held in at the same place- Wolfson center, London on March 21st Saturday 2009. The Agenda and the Reports 2008 will be send out in January 09.

1.4. Membership and membership fee

In 2008 ENRAH had 23 Full Members/Individuals.

The annual Fee 2007 is fixed to 10Euro's and should transferred to Esybank AG, Quellenstraße 51-55, A-1100 Vienna, Austria

ENRAH

IBAN: AT511420020010398003

BIC: EASYATW1



2. ACTIVITIES in 2008

2.1. Partner in nEUroped project (start 24 April 08) . WP Leader nEUroped Network and WG AHC Chair

- ✚ Organized SB and AHC WG meeting London 25th -26th April 08
- ✚ Organized a one day WG meeting on AHC Leuven , 13th October 2008
- ✚ Financial managing
- ✚ Eurordis Membership meeting Copenhagen 16-17th May 08
- ✚ Networking European Research and Innovation Exhibition , Paris 5-th June 2008, Invited speaker session on rare diseases organized DG Research and INSERM, France
- ✚ FENS Satellite Symposium ERA-Net NEURON July 11th, 2008 – Geneva, Switzerland

2.2. Representation at the PDCO, EMEA

- ✚ Tsveta Schyns, supported by Eurordis, EGAN and EFNA was elected as a full member of the PDCO, EMEA from August 2008. Participation in the monthly meetings (3 days) of the PDCO at the EMA since September 2008.

2.3. Policy

- ✚ Submission of comments on the European Commission public consultation regarding a European action in the field of rare diseases, 13th February 2008
- ✚ Representation at the Task Force Rare Diseases, DG Sanco - Tsveta Schyns is invited member of the TFRD since June 2008

2.4. Networking

- ✚ DIA European meeting, 2-6th March 08, Barcelona.
- ✚ Workshop on modelling in paediatric drug development and use 14-15th April 2008, EMEA, London





✚ Round Table of Companies, Barcelona 20th June 2009.

4. PUBLICATIONS

4.1. Transparency Measures in the Paediatric Regulation. DIA European meeting, 2-6th March 08, Barcelona.

4.2. Optimized Communication Between Industry, Investigators and Patients: Repositories of Patient Data. DIA European meeting, 2-6th March 08, Barcelona.

4.3. European Network of Expertise for Rare Pediatric Neurological Diseases nEUroped. Eurordis Membership meeting Copenhagen 16-17th May 08

4.4. Patients in Rare Diseases Research, Networking European Research and Innovation Exhibition, Paris 5th June 2008.

4.5. The Role of Patients in the EU Paediatric Legislative and Non-legislative Framework RTC Barcelona 20th June 2009.

5. FINANCIAL REPORTS

Profit and Loss 2008 (attached)

