



nEUroped is for children with rare nervous system disorders. The European Network on Rare Paediatric Neurological Diseases, nEUroped, brings together patients and their families, patient organisations, research groups, and other interested parties across Europe. nEUroped is currently co-funded by the European Union Public Health Program 2007 in a project aiming to improve diagnosis, management and dissemination of information on a number of rare nervous system disorders in children.

Extended Network Meeting nEUroped

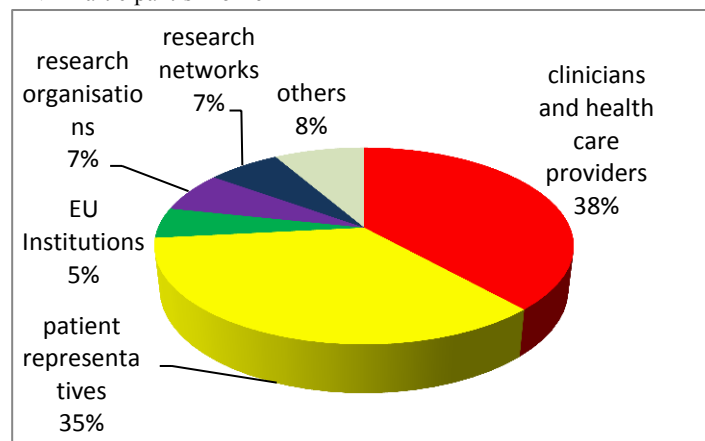
21-23 November 2010, Fondation Universitaire, Brussels, Belgium

From the ENM Organising Committee

The Extended Network Meeting of nEUroped in Brussels was an important milestone in the nEUroped project. Over 60 invited patient, clinical, and research experts participated in an intensive 3 days of varied programmes and events.

The ENM organisers were particularly pleased by the level of discussion and contributions from patients and professionals alike. We also thank the European Commission and the EMA for their support and contributions to the ENM.

ENM Participant's Profile



Patient Network Workshop 21 November 2010

The majority of the ENM participants also attended the preliminary workshop focusing on the role of patients in patient registries. The sessions included:

- Capacity Building and Patient Network Integration into nEUroped
- Using the nEUroped Disease Registry to Address Rare Paediatric Neurological Diseases need
- Working Groups on the Progress, Expectations, and Challenges in AHC, Narcolepsy, and RSTES

Recommendations from the Workshop Patient Network participants

Survey on Patient Needs

Include the input of patient groups on the structure and content of surveys on patient needs to best encourage feedback and guarantee that feedback is useful.

Streamline the survey to allow for easier translation into various languages.

Survey on Ethical Issues

Discuss and share the survey with the extended network and larger audiences.

The survey should be used to support the development of ethical guidance for patient registries.

Guidelines

Feedback from the patient perspective should be considered in the final publication of existing care management guidelines for Narcolepsy, RSTES and Alternating Hemiplegia.

Patient Registry

Regular updates on the progress and development of the registry should be communicated to the patient networks.

Overall Integration of Patients in the Project

Identification of patients not followed by specialists in this network

Evaluation of patient needs and expectations

Education and training for patients

Contribution to items to be documented in the registry such as patient satisfaction and quality of life data.

Patients should contribute to ethics committees as well as to the development of informed consent forms.

[Read the detailed Report on the ENM Workshop](#)

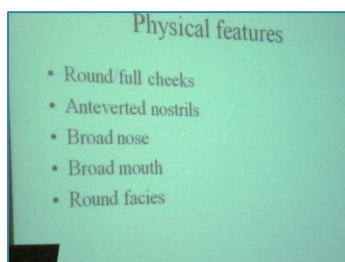
Conference Day 1: Building the nEUroped Network for Research and Health, 22 November 2010

Recommendations from the Conference Sessions Participants:

Session 1: The Patient's Health, Ethics, and Patient Registries for Rare Diseases in Europe

We should strive for harmonisation of European standards on patient registries with multistakeholders involvement.

Patient registries should increase knowledge and share research on rare diseases.



Session 2: Best Practices for Developing & Using Patient Registries

Patient's needs and interests should be expressed in the patient registries to improve their own understanding of disease.

Link the development of patient registries to the increasing standardisation of patient health records, clinical trial registries, and other patient data systems under development in the European Union.

Session 3: Making Use of the nEUroped Patient Registry for Research

Greater communication and capacity-building is needed within patient organisations and between patients and researchers in order to improve the value and use of the nEUroped Registry.

Secure long-term funding so that the work developed by a project is not lost.

[Read the detailed report on the Conference day 1](#)

nEUroped Registry Training Workshop

Altogether 28 participants from the nEUroped network participated in this valued Registry Training Course. The course focused on the development and use of a patient registry, including overall objectives, field designations, identifying relevant clinical data, the relationship between data from varying diseases and the expression of those diseases, as well as data input, control, and oversight. The nEUroped Centres of Expertise play a key role in the registry development, data entry, and data management. The training course examined the accomplishments of nEUroped with regard to developing a European patient registry for rare neurological disorders. The course was held primarily as an interactive workshop with experts from the registry provider on hand to assist the participants and the discussion. The course also offered the nEUroped experts their first hands-on opportunity to engage the registry.

Day 2: The Accomplishments and Future Engagements of nEUroped 23 November 2010

The second day of the ENM focused on reviewing core nEUroped documents in development as well as receiving input from patients, clinicians, researchers and other stakeholders (inside and outside nEUroped) with regard to disease guidelines, the nEUroped surveys, the nEUroped EU Guidelines, the nEUroped Registry, and the future development of the network within the European framework for research and health in rare diseases.

Recommendations from the Conference Sessions Participants:

Session 4: Disease Guidelines for nEUroped

Publish the guidance's developed during the nEUroped project and ensure that a system is in place to collect feedback from experts and patients as well as to update the drafts regularly.



Session 5: Integrating Disease and Best Practice Guidelines into European Patient Registries

The nEUroped registry and Guidelines should include health indicators such as mandatory fields for data collection and for analysis and reporting.

The nEUroped European Best Practice Guidelines for Patient Registries should be completed and published.

Session 6: Future Perspectives on the nEUroped Networks' Organisation and Sustainability

nEUroped should contribute to, and adopt, the European standards for patient registries (e.g., the draft nEUroped Guidelines, the evaluation criteria of Enpr-EMA).

nEUroped needs to develop further its network, organisation, and sustainability.

[Read the detailed Report on the Conference day2](#)