



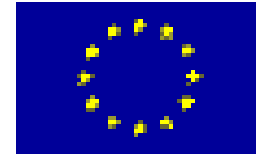
EUROPEAN NETWORK OF EXPERTISE FOR RARE PAEDIATRIC NEUROLOGICAL DISEASES

European Actions to improve the life of patients living with rare diseases : Building on the achievements of the HP 2007-2013

Session 2: Pilot European Reference Networks on Rare Diseases

Luxembourg, 25 – 26 October 2011

Setting up nEUroped



Rare nervous system disorders in children characterized by paroxysmal attacks

- ❑ Alternating Hemiplegia of (in) Childhood

- ❑ Narcolepsy (Narcolepsy-cataplexy and narcolepsy without cataplexy)

- ❑ Rare Surgically Treatable Epileptic Syndromes
 - Hypothalamic hamartomas
 - Landau-Kleffner syndrome and related disorder
 - Sturge-Weber syndrome
 - Rasmussen syndrome



Executive
Agency for
Health and
Consumers



Other Commonalities

- onset in early childhood
- chronic and long life
- under-recognized and misdiagnosed
- mistreated because of poor diagnosis
- poor knowledge on their natural evolution or, anecdotal treatment strategies (medical or surgical)
- under researched with no clear concept on their pathophysiology
- often, devastating impact on quality of live
- information on the diseases is generally lacking.

nEUroped Project Partners

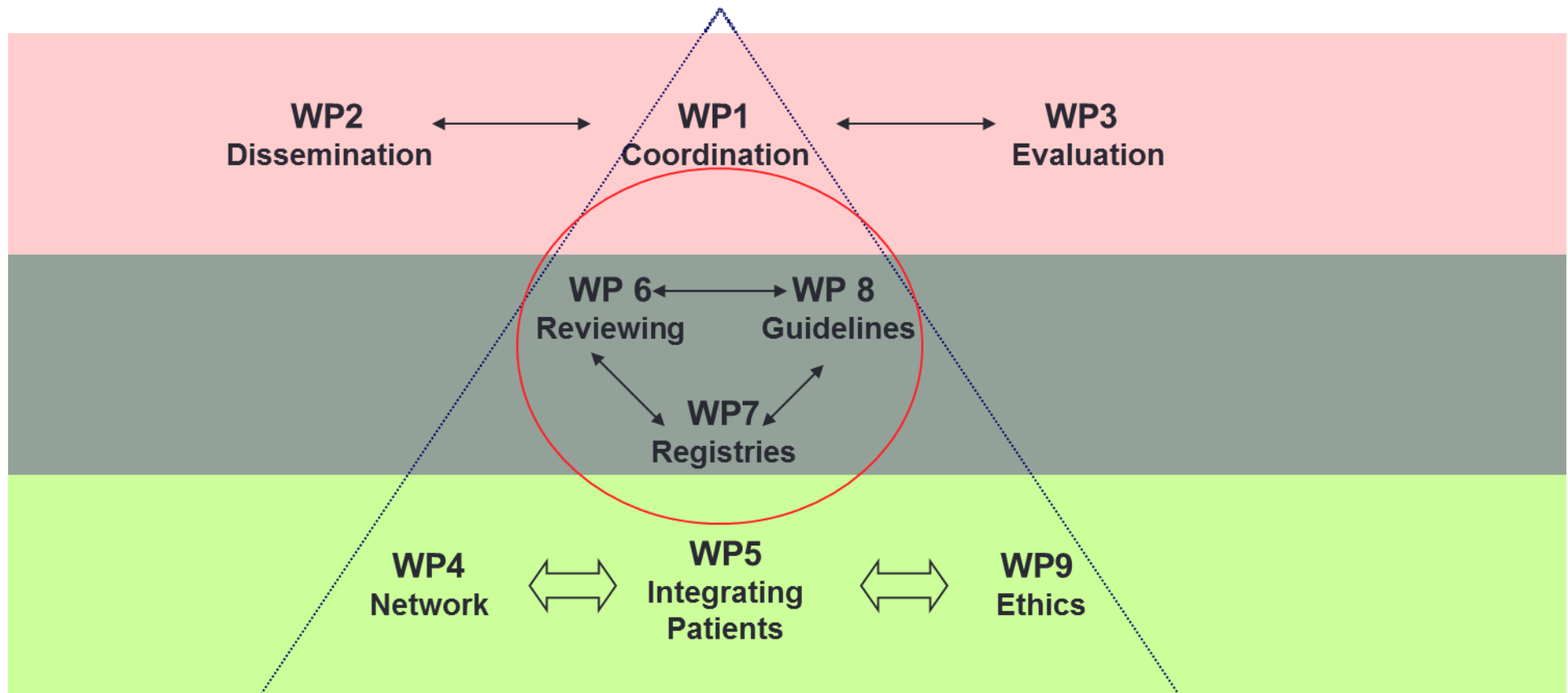
- Hospices Civils de Lyon, [France](#) – Main Partner
- University College London, [UK](#)
- Univerzita Karlova v Praze, 1. lekarska fakulta, [Czech Republic](#)
- European Network for Research on Alternating Hemiplegia
- University of Bologna, [Italy](#)
- EURORDIS, France
- GCPA, Belgium
- AISEA Onlus, Italy
- Universitätsklinikum Heidelberg, [Germany](#)
- IRCCS E.MEDEA, [Italy](#)
- Leiden University Medical Center, [The Netherlands](#)
- Hospital de Sant Joan de Déu, [Spain](#)
- University Medical Centre Ljubljana, [Slovenia](#)



nEUroped Objectives

- ❑ **A platform in Europe, in a Form of a Extended Network** for patients and their families affected by these conditions, for clinicians, health carers and researchers
- ❑ **Tools for research** in the form of Patient's Registry
- ❑ **Guidelines** for diagnosis and management of the diseases concerned
- ❑ **Highest ethical and scientific standards**

nEUroped Project structure



nEUroped Main Outcomes

- Critical mass of patients and researchers for collaborative and sustainable European research in the field of rare paediatric neurological diseases
 - ✓ Extended Network
 - ✓ Patient Registry
- Improved diagnosis and management of the concerned diseases
 - First Draft Guidelines
 - Higher awareness on the selected diseases among both clinicians and general public
- Sense of community for the people affected by these diseases



nEUroped after the PHP project

The need of legal structure to support :

- ✓ Network Coordination Centre
 - Updating the Guidelines
- ✓ Governance of the patient registry
- ✓ Setting up research projects and fundraising

WWW.NEUROPED.EU

Thank you!

Tsveta Schyns

On behalf of the nEUroped Consortium