

# nEUroped

## European Network for Rare Paediatric Neurological Diseases

### Coordinator

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Lyon University Hospital

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**European Network of Reference for Rare Paediatric Neurological Diseases (nEUroped): a network of communication and information sharing across the field of rare nervous system disorders in children characterised by paroxysmal attacks.**

nEUroped focused on diseases which affect children from early infancy. Most patients have a better chance of being treated if diagnosed in the first year of life. Unfortunately, due to the fact that they are rare and sporadic, many of these cases go undiagnosed until the teenage years. Moreover, they are often symptomatically diagnosed or are mistreated because of poor knowledge of the natural evolution of the disease. The project focused on a number of these conditions, amongst which Alternating Hemiplegia of Childhood (AHC), Narcolepsy and Rare Surgically Treatable Epileptic Syndromes (RSTES), that include Cerebellar hamartomas, Hypothalamic hamartomas, Landau-Kleffner syndrome, Nodular heterotopias, Sturge-Weber syndrome, Tuberos Sclerosis and Rasmussen syndrome. The study built European-wide patient registries on AHC, Narcolepsy and RSTES and aimed to develop guidelines for early diagnosis and treatments for the selected diseases. The project also served to identify specific ethical issues and best practices in this field and spread the network's expertise throughout Europe. nEUroped comes from patient groups' strong conviction that by networking and sharing information about their particular disease they can improve diagnosis and help develop new therapeutic interventions. This project gave renewed hope of finding new clues into these diseases and a unique opportunity to complement clinical expertise with patients' real life experience'. nEUroped led to the creation of an International Consortium for the Research on Alternating Hemiplegia of Childhood ([www.iahcrc.net](http://www.iahcrc.net)) coordinated by Prs Arzimanoglou (Hospices Civils de Lyon, France) and Mikati (Duke University, USA), which contributed to the identification of the genetic causes at the origin of AHC. It also served as one of the models for the creation of the European Reference Networks.

More information on: <https://www.eurordis.org/content/european-network-rare-paediatric-neurological-diseases-neuroped>

### Timeline of the project

24th April 2008

36  
months

13  
beneficiaries

23th December 2011



### Total Budget

1.25 M€

Hospices Civils de Lyon  
Budget

476 700€

