EUROPEAN AND INTERNATIONAL INITIATIVES

Children’s Rights in Primary Paediatric Care: European Study

1Martin-Alvarez, 2Ahtarzaei, 3Kovacs, 4M Katz

Background and aims In response to a WHO discussion paper, in December 2013 the European Academy of Paediatrics Working Parties on Ethics and Rare Diseases created a position paper on the early identification, diagnostic confirmation, and longitudinal management of disease in early childhood. The presentation examines the EAP’s research engagement in developing infrastructure in primary and specialist care as well as at national and European levels.

Methods The EU Rare Disease Programmes and actions, have encouraged the EAP to engage in research on the pooling and structuring of data on child health that can improve global chronic disease prevention and management in paediatric practice. The EAP supports the development of a repository of existing rare disease guidelines. Rare diseases are usually chronic, and in 75% affect children and or present in childhood. An EU model will be developed that includes both preventive child health care and rare disease management. For cross-border collaboration is needed to compile patient registries, the development of a shared platform for European patients within the framework of the developing EU eHealth policy is essential: as part of an Open Access Paediatric Healthcare Resource as a child health reference for rare, chronic, and/or disabling diseases.

Results An overview of the current European and international frameworks for rare, chronic, and/or disabling diseases within eHealth is presented.

Conclusions Improved access to knowledge about early diagnosis and disease management for primary and specialist paediatric health care professionals, can bring the EAP experience and expertise to bear on current European and international research.