



Towards comprehensive health care and management for children with rare conditions in Europe

Brussels, December 2011,

Because the low prevalence, the specificity and the high total number persons affected by a rare disease, the Council of the European Union calls for a global approach to improve the quality of life and socio economic potential of persons with a rare diseases based on special and combined efforts to prevent significant morbidity and avoidable premature mortality (June 2009).

The majority of rare conditions presents in childhood. Therefore, optimal care including early screening, identification, diagnostic confirmation, management and treatment must be a pediatric priority.

Some children with rare conditions are identified at birth through newborn screening. Others are identified as characteristics of the condition become apparent during childhood. Most rare conditions involve diagnostic confirmation and a pro-active multidisciplinary approach. During the focus on specialty care for the child, fragmentation may occur in which the role of primary care may be neglected. Chronic and rare conditions require holistic, comprehensive and coordinated joint management among primary care, specialists, and families.

The World Health Organization states that a collaborative management approach at the primary health care level involving patients, their families and other health care providers may reduce the burden of disease for the child, family, and society. The family-centered chronic care management originated in pediatric care.

Within the care model for child health, a process of coordinated co-management among specialists, primary care providers, and families promotes timely, explicit, bi-directional communication, clear articulation of management responsibilities, and specific definition of the locus of management for chronic and rare conditions. The chronic care model also incorporates all components of the health care system including specialty care as well as the surrounding community organizations, policies, and other resources impacting health. The care model describes processes intended to lead towards the best possible health outcomes. Appropriate early identification, diagnostic confirmation, and longitudinal management provide the gateway to the prevention of illness and optimal overall health for children with rare and chronic conditions. The chronic care model will reduce fragmented care and enhance disease management including participation and support of families in the care process. Therefore, promotion of the chronic care model should be adopted as a framework for improved systems of health care for children with rare and chronic conditions in Europe and beyond.

Children have a right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health (the Convention on Rights of the Child, adopted by the United Nations).

European Academy of Pediatrics endorses the principles of chronic care management for children and will support their harmonization and implementation.