

Pediatric Primary Care in Slovenia, a medical home

Date: February 2-3th 2018

Place: Maribor , Slovenia

Subject:

Pediatric primary care a medical home for children with disabilities

Suggested Twitter message:

Pediatric primary care in #Maribor offers a #medicalhome for disabled children appreciated by Dutch #raredisease patient representatives.

Suggested Twitter links:

@ngorarediseases @eurowhosvn@who.int @UNICEF_EU @eurordis

Most rare and disabling conditions manifest in early childhood. To exchange information on early diagnosis of rare and disabling condition, a Dutch group of patient representative visited the ambulatory pediatric clinic in Maribor, Slovenia.

At ambulatory pediatric health services, the awareness of recognizable features of rare conditions can reduce the diagnostic delay. By early diagnosis and intervention the child a with a rare and disabling condition may achieve the maximal potential throughout its life. 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 a multidisciplinary primary pediatric care child, a process of coordinated co-management among specialists, primary care providers , and families timely, explicit, bi-directional communication, clear articulation of management responsibilities, and specific definition of the locus of management for chronic and rare conditions should be promoted.¹

The child with a rare condition may end up with the numerous Healthcare Providers. The child's data are in paper files or locked in vendor dependent IT systems, governed by health institutions. To facilitate patient centered care, patients and their families should carry their own data securely safe in a personal health record. Computer science is needed to make the shift from institutional thinking to self-management, and an improved a sense of well-being and better understanding of the patients own condition.

Information

Jernej Završnik, Primary Care

Dutch rare disease patient representatives :

Petra Poulissen and

Marinus Vermeulen

Liesbeth Siderius, EAP Rare Disease WG

<http://eapaediatrics.eu/wp-content/uploads/2015/12/EAP-Statement-11-12-2011-.pdf>

