The role of the Nurse practitioner in optimizing care for children with Congenital Adrenal Hyperplasia


Radboud university medical center / Amalia Children’s Hospital, Nijmegen, the Netherlands. Department of Pediatrics endocrinology

Congenital Adrenal Hyperplasia (CAH) is a group of rare congenital conditions. The care for children with CAH not only consists of medical treatment. Education of the parents and adolescents, close follow-up and approachable accessibility for questions are also important to improve the individual care for these children. We are working on optimizing patients care with several projects such as: Transitional care, Parents and patient satisfaction, measuring Quality of life.

The nurse practitioner plays a key-role in every part of the care for children with CAH

The role and tasks of the NP

Organizing outpatient care

Coordinating transitional care

Providing information for schools

Training and coaching of children and parents to prevent Addison crisis

Easy accessibility by email and telephone

Measuring Quality of life

Patients and parents needs and Questions

Collaboration within a multidisciplinary team: pediatric endocrinologist, pediatric urologist, gynecologist and clinical psychologist

Contact with and collaboration within national and international endocrine nursing groups

Contact with patient support group: AdrenalNET

BijnierNET

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Contact information:
Viviane vd Crommert, NP pediatric endocrinology
Viviane.vandecrommert@radboudUMC.nl

Amalia Children’s Hospital
Radboudumc