**A transition medicine model in Congenital Central Hypoventilation Syndrome (CCHS) patients**

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***Background***

Transition medicine is defined as “the deliberate, coordinated process of moving a patient from paediatric-oriented healthcare to adult-oriented healthcare with the goal of optimizing the young adult’s ability to assume an adult role and function”.

Two models are usually considered: the young-adult based model and the disease-based model:

The former is based on the use of adolescent-centred models irrespective of the illness, the latter envisages a multidisciplinary approach provided by physicians from different paediatric and adult medical fields. Several barriers, including the different approaches of paediatric and adult-oriented carers, plus legal and the economic issues, may however hinder the process.

When passing from childhood into adulthood, transition to adult-oriented providers is necessary in children with special healthcare needs (CSHCN), particularly those affected by congenital disorders, in order to cope with the complexity of their care.

The CCHS entails the typical features of a complex life-long disease that greatly benefits from the harmonization of the carers. Consequently, the transition from a paediatric environment to adult oriented medical care is a key process.

# *Development of the project:*

In Italy transition medicine is an emerging issue in that it is very fragmented and therefore depends mainly on the spontaneous volunteer services provided by healthcare workers in the individual local setups.

With these crucial aspects in mind, we are carrying out a project involving the Health Department of Regione Toscana, the Department of Respiratory Medicine of the University of Florence and the Department of Pediatrics of Meyer Children’s Hospital, aimed at improving the transition process in CCHS patients.

Our project foresees that patients be admitted to the paediatric hospital irrespective of their age. A personalized approach is established based on their special care needs (i.e. ventilation mode, laboratory examinations, clinical evaluations etc.), as well as on the role that each adult or paediatric clinician plays in the joint-clinic.

This disease-based model could have an impact on a potential population of 20 Italian CCHS patients (34% of all Italian cases) who are now beyond the pediatric age and who are not currently included in any transition medicine programmes.