Extra-corporal membrane oxygenation (ECMO) is a rescue therapy for newborns with severe but reversible respiratory failure. Although ECMO has significantly improved survival, it is associated with substantial complications of which intracranial injuries are the most important. These injuries consist of haemorrhagic and non-haemorrhagic, ischaemic lesions. Different from the classical presentation of haemorrhages in preterm infants, in ECMO treated newborns haemorrhages are mainly parenchymal and with a high percentage in the posterior fossa area. There are conflicting data on the predominant occurrence of cerebral lesions in the right hemisphere. The existence of intracerebral injuries and the classification of its severity are the major predictors of neurodevelopmental outcome. This section will discuss the known data on intracranial injury in the ECMO population and the effect of ECMO on the brain.

### Rare Diseases, Common in Paediatrics

**IS-043** **COMPREHENSIVE COORDINATED CARE FOR CHILDREN WITH RARE CONDITIONS**

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Most of the chronic conditions of childhood occur relatively rarely, and many of those rare conditions require complex care. Children with the most complex conditions comprise 5% or less of the paediatric population but account for as much as 70% of paediatric care expenditures. These children are particularly vulnerable to the effects of fragmented care and services resulting in less than optimal health outcomes and higher health care costs. Developed by paediatricians, the medical home model has been promoted by the United States Maternal and Child Health Bureau and the American Academy of Paediatrics as a locus of proactive, coordinated care in the context of an integrated system of child health services and supports. The medical home has now been adopted as a model of care across the life span and occupies a critical position in United States health care reform efforts. This presentation provides an overview of the medical home model and its place in an integrated care model of child health for children with rare and complex conditions. The critical functions of care coordination, written and shared care plans, and explicitly articulated co-management roles for primary care providers, specialists, other ancillary service providers, and families will be explained.
The newborn human infant particularly the preterm infant was previously regarded as a sensory-motor organism without consciousness. By the introduction of developmental care neonatal nurses and doctors commenced to regard the preterm patient as an autonomous person with consciousness although at a minimal level. The thalamocortical connections from the sense organs are established from about the 23rd gestational week, indicating that the neuronal global workspace can function (see ref 1). From established from about the 23rd gestational week, indicating that the neuronal global workspace can function (see ref 1). From established from about the 23rd gestational week, indicating that the neuronal global workspace can function (see ref 1). From established from about the 23rd gestational week, indicating that the neuronal global workspace can function (see ref 1). From established from about the 23rd gestational week, indicating that the neuronal global workspace can function (see ref 1).

At the moment we have data to different aspects of the haemodynamic situation in human studies, including ductal shunting (van Vonderen et al, Arch Dis Child Fetal Neonatal Ed 2014) behaviour of stroke volume and cardiac output (van Vonderen et al, Pediatr Res 2014, Noori et al J Pediatr 2013). The presentation will give an overview of all these publications, adding data that are about to be published.

There are many parameters that influence the haemodynamic situation, including heart rate, stroke volume, cardiac output, and blood pressure. As transition of the newborn is a very dynamic situation, studies have to follow a timeline in order to cover all changes over time. Furthermore, it has been shown that the main driving force for establishing lung perfusion is aeration of the lungs. A further important aspect, it has been shown in animal experiments that clamping the cord results in a significant decrease in the haemodynamic situation, as by clamping the cord there is a loss of blood volume of the placenta resulting in a significant drop in venous return to the right atrium. A quick switch of the shunt flow direction via the open ductus arteriosus from right-to-left to left-to-right is able to compensate for that. If there is no left-to-right shunt via the duct in this situation this may impair blood flow to organs, as for instance the brain (Urlesberger et al, Neonatology 2013). All these data have resulted in a more profound discussion of the possible benefits of delayed cord clamping.

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Shaping the Brain with Developmental Care? (Symposium Organised by the European Association for Developmental Care (EADCare))

1 Lagercrantz H, Hanson, M., Ment, L., Rodeck, C. (Eds) The Newborn Brain 2nd ed. Cambridge University Press, 2010


IS-044 Appraisal Of Disability In Rare Diseases With The Icf-cy: The Orphanet Disability Project
M de Chalendar, S Bee, A Oly and A Rath

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