insufficiency, mostly complicated by persistent pulmonary hypertension. However, cerebral damage, intracerebral haemorrhage as well as ischemia belong to the most devastating complications of ECMO.

Objectives Objectives of the presentation are to give insights into what is known from literature concerning cerebral damage related to neonatal ECMO treatment for pulmonary reasons.

Methods A short introduction in ECMO indications and technical aspects of ECMO are provided for better understanding of the process. Against the results of the only multicentre randomised trial of ECMO versus conservative treatment, the presentation will focus on (potential) risk factors for cerebral haemorrhage and ischemia during ECMO treatment.

Results and conclusion Although neonatal ECMO treatment shows improved outcome compared to conservative treatment in cases of severe respiratory insufficiency, it is related to disturbances in various aspects of neurodevelopmental outcome. Risk factors for cerebral damage are either related to the patient's disease, ECMO treatment itself, or a combination of both.

It is of on-going importance to further understand pathophysiological mechanisms resulting in cerebral haemorrhage and ischemia due to ECMO and to develop neuroprotective strategies and approaches.

IS-042 NEONATAL EXTRACORPOREAL MEMBRANE OXYGENATION, NEUROIMAGING AND OUTCOME

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Abstract IS-042 Table 1 Neuroimaging score

Abnormal finding	Score
Ventricular Dilatation (rw = 1)	
Minimal	1.0
Moderate	2.0
Marked	3.0
Subarachnoid Space (rw = 1)	
Wide interhemsipheric fissure	0.5
Large subarchnoid space	1.0
Haemorrhage (rw = 2)	
Subependymal only	0.5
Single petechial	0.5
Scattered petechial	1.0
Intraventricular	1.0
Small parenchymal (<1 cm)	1.5
Large parenchymal	3.0
Extraaxial small	0.5
Extraaxial large	1.0
Parenchymal lesions (rw = 3)	
Focal PVL or hypodensity	0.5
Focal atrophy	0.5
Patchy PVOL of hypodensity	2.0
Diffuse PVL or hypodensity	3.0
Mild generalised atrophy	2.0
Moderate generalised atrophy	3.0
Mass lesion/infaction	3.0

rw = relative weight.

ECMO in neonates: neuroimaging findings and outcome Extracorporeal 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.

IS-044 APPRAISAL OF DISABILITY IN RARE DISEASES WITH THE ICF-CY: THE ORPHANET DISABILITY PROJECT

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Aim Very little information is available about the disabilities encountered by rare disease (RD) patients, of whom more than half are children. The Orphanet (www.orpha.net) Disability Project aims to improve the knowledge and visibility of disabilities associated with RDs.

Method We are indexing the functional consequences of each RD with the Orphanet Functioning Thesaurus, an adaptation from the "Activities and participation" and "Environmental

factors" domains of the International Classification of Functioning, Disability and Health-Children and Youth version (ICF-CY, WHO, Geneva, 2007) which includes additional terms for cognitive abilities, sleep, temperament and behaviour. Through a questionnaire sent to medical experts, disability specialists and patient organisations, we collect, for each RD, the activity limitations and participation restrictions (113 terms), their temporality during the course of the disease (permanent or transient difficulty, delay, loss of abilities), their severity and respective frequency in the patient population, and some environmental factors influencing disease course. Data is analysed and standardised to constitute the Orphanet Functioning Database. This project is funded by the French *Caisse Nationale de Solidarité pour l'Autonomie*.

Results More than 900 RDs are already indexed and 650 more in progress, with the contribution of hundreds of people and organisations from 46 countries. These RD disability core sets will be freely available in 7 languages.

Conclusion It increases knowledge and aids in evaluating and managing the daily difficulties and needs experienced by RD patients. It can also help social agencies in distributing appropriate disability compensation measures and decision makers in assessing the social burden of RDs.

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

IS-045 CONSCIOUSNESS AT THE BASIS OF DEVELOPMENTAL CARE

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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 about 25 weeks cortical responses in the somatosensory area have been recorded by near-infrared spectroscopy (NIRS) and facial expressions similar to adults sustaining pain have been observed in preterm infants after 25 weeks The preterm infant is aware of its body, itself and to some extent of the outside world. It recognises faces, vowels and smells it has been exposed to. Recent NIRS studies have shown that the preterm brain reacts differently to female versus male voices.[2] It expresses emotions like joy. By functional MR it has been demonstrated that there is a spontaneous resting activity encompassing the somatosensory, auditory and visual cortex, although there is less activity in association area and the prefrontal cortex as compared with adults. There is an incomplete default mode network which is assumed to be related to consciousness.[3]

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Understanding Haemodynamic Transition at Birth: From Bench to Bedside

IS-046 STUDYING HAEMODYNAMIC CHANGES IN THE DELIVERY ROOM. FIRST EXPERIENCES FROM HUMAN STUDIES

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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 inmay have significant impact on 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.

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.

Nursing Education

IS-047 MAKING HOSPITALS SAFER FOR CHILDREN: EARLY WARNING SCORES AND SAFE SYSTEMS

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There is increasing evidence highlighting that missed deterioration in hospitalised children is a significant problem with increased risk of mortality and morbidity (Odetola *et al* 2007). Currently Paediatric Early Warning scoring systems (PEWs) are advocated by (CEMACH 2008, DOH 2012) for use as a safety measure to assist in the identification of seriously ill or deteriorating children, in hospital, so that targeted care can be delivered to prevent serious adverse events. However there is a paucity of evidence to inform the development of such scores, with ad hoc score development based on local consensus opinion or inadequately validated scores.

This session will explore the challenges of studying this complex intervention, review evolving evidence, identify gaps in the literature, and make recommendations for future research.