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