

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

H Lagercrantz. Astrid Lindgren Children's Hospital, Karolinska Institute, Stockholm, Sweden

10.1136/archdischild-2014-307384.45

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<sup>1</sup>). 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.<sup>2</sup> 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.<sup>3</sup>

#### REFERENCES

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

- Mahmoudzadeh M *et al*. Syllabic discrimination in premature human infants. *PNAS*. 2013;110:4846–4851
- Raichle M. The brain's dark energy. *Scientific American*. 2010;302:44–49

## Understanding Haemodynamic Transition at Birth: From Bench to Bedside

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

B Urlesberger. Division of Neonatology Department of Pediatrics, Medical University Graz, Graz, Austria

10.1136/archdischild-2014-307384.46

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 may 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 Vonderer *et al*, Arch Dis Child Fetal Neonatal Ed 2014) behaviour of stroke volume and cardiac output (van Vonderer *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

G Sefton. PICU, Alder Hey Children's Hospital, Liverpool, UK

10.1136/archdischild-2014-307384.47

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.