



CrossMark

# Highlights from this issue

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## DISABILITY AND ECONOMIC DISADVANTAGE

The association of socioeconomic disadvantage and the onset of chronic disabling conditions in childhood is well known although whether socioeconomic disadvantage is on the causal pathway to, or arises as a consequence of childhood chronic disabling conditions is less clear. Nick Spencer and Lyndall Strazdins report a longitudinal study comparing children who developed a chronic disabling condition between 6/7 and 10/11 years with children without a chronic disabling condition at either age. Chronic disabling conditions included physical conditions, learning difficulties, hearing and visual problems (all >6 months with functional restriction). If potential confounders were considered (maternal chronic disabling condition, lone parent) children in the lower income quintile had a two and half times greater odds of chronic disabling condition onset than those in the highest centile. Over the study period income increased across the whole sample although less in chronic disabling condition onset households than no chronic disabling condition onset households (165 AUD,  $p < 0.033$ ). In some respects the data is predictable—more chronic disabling conditions in children from poorer families and once there is a child with a chronic disabling condition in a family unit the families finances will deteriorate. The challenge is how to best deal with this and whether policies which alleviate social disadvantage could potentially impact. In an accompanying leading article Professor Maggie Atkinson, Children's commissioner for England discusses the wider issue—Disability and economic disadvantage—facing the facts. *See pages 317 and 305.*

## PREVALENCE AND MANAGEMENT OF GASTROINTESTINAL MANIFESTATIONS IN SILVER RUSSELL SYNDROME

Silver Russell syndrome is an imprinted disorder characterised by intrauterine growth retardation, relative microcephaly, failure to thrive, a typical facial phenotype and body asymmetry. Feeding difficulties are common. Marsaud and colleagues report the nutritional status and gastrointestinal manifestations in a cohort ( $n = 75$ , median age 24 months) prior to starting growth hormone. Nutritional impairment was common—70% had a weight/expected weight for height ratio of <80%. Gastro-oesophageal reflux

was frequently seen with severe vomiting in infancy in 50%, persistent after 12 months in 29%. Feeding difficulties were seen in 65% requiring nutritional support (49%) including the need for gastrostomy (22%). Constipation was a significant issue in 20%. The authors rightly advocate systematic exploration of nutritional status and gut manifestations in these children prior to starting growth hormone and emphasise that if the nutritional status is impaired even with growth hormone growth may not be optimised. *See page 353.*

## ADVANCE CARE PLANNING: PRACTICALITIES, LEGALITIES, COMPLEXITIES AND CONTROVERSIES

The prevalence of life limiting conditions has increased significantly over the last 10–20 years. The best delivery of health and social care to this group is complex with an increasing need to recognise when death and dying may be possibilities so that appropriate discussions can be had with families (Advance Care Plan). Karen Horridge describes the components of the paediatric Advance Care Plan and the evidence to support its use. In essence the Advance Care Plan provides a framework for paediatricians, families and their multidisciplinary teams to consider, reflect and record the outcome of their conversations about what might happen in the future in order to optimise the quality of clinical care and inform decision making including for situations where death is a possibility. The elements of the plan are discussed in detail including potentially difficult areas which may be controversial and difficult to address, for example the legal framework which will help with decision making. There is also a useful list of red flags that dying and death are significant possibilities, tips to consider when planning a conversation about the possibility of dying and death of a child or young person and a checklist for use if dying or death may be possible. In the complex medical world this is an essential read and will help ensure that the care to children with complex medical problems is considered and appropriate. *See page 380*

## ANTI TNF THERAPY FOR PAEDIATRIC IBD

Biological agents are increasingly used in paediatric onset IBD in the UK and worldwide. Cameron and colleagues report the

Scottish national experience using Infliximab and Adalimumab (132 children, <18 years, 2000–2010, 114 Crohn's disease, 16 ulcerative colitis, 2 IBD unclassified). This is therefore an important 'real life' data set and likely to reflect experience in other centres. 127 received Infliximab to induce remission—61 entered remission, 49 had a partial response and 17 no response. 72 were given maintenance of whom 23 required dose escalation. 18/127 had infusion reactions and 27 other adverse events 10 of which required hospitalisation (including gastroenteritis, peri-anal sepsis, lupus like reaction, rectal stricture). 29 had adalimumab (24 of whom had also had Infliximab); 10 entered remission, 12 had partial remission and 7 no response—all went on to maintenance therapy. 19 required dose escalation. Nine had adverse events of whom two required hospitalisation (perianal abscess, *C. difficile* infection). The data set reflects the complexity of treating IBD and the adds to data that informs the risk benefit discussion when treatment escalation to biological agents is required and highlights potential adverse events (some likely to reflect the use of biologicals, some reflecting the severity of disease) that need to be considered when patients on these therapies present unwell. Dan Turner highlights the international context of this real life data set in an accompanying editorial. *See pages 394 and 399.*

## IN E&P THE MONTH

In an excellent Pharmacy Update, Elder *et al* consider the important issue of hydrocortisone for adrenal insufficiency including the basic science and physiology, causes of adrenal insufficiency (particularly high dose/long term steroids), and replacement particularly during illness, hospitalisation and procedures. The value of the steroid card/alert bracelet is emphasised. There is a helpful summary at the end and a set of multiple choice questions to ensure you are updated on this important topic. In addition there are excellent articles from the 15 minute consultation series (herpes encephalitis, Eczema Herpeticum), Interpretations (how to use central venous line tip culture), a dermatophile, a review of the NICE guidance for head injury in children and young people and more articles from the equipped series on clinical audit and developing clinical guidelines. All fun to read and excellent CPD.