The first was a retrospective case series analysis looking specifically at delayed puberty. A possible association between ADHD and delayed puberty mainly amongst males was noted. This was not associated with stimulant treatment. The authors were cautious about their findings as they felt that an association did not prove causality and that the population studied may have lent itself to falsely high positives.

The second was a study looking mainly at growth of 124 boys with ADHD. This concluded that there was no discernible link between ADHD and delayed puberty.

The final two articles were literature reviews which included the information of this second study. Due to this, they came to a similar conclusion but acknowledged the lack of concrete evidence looking at sexual maturation in children with ADHD.

There have also been animal studies showing a negative effect of stimulant medication on testes size in monkeys. However this effect was temporary.

Conclusion There is a lack of research looking specifically at ADHD and puberty and this has led to differing opinions. Further prospective studies would help to determine if there is a link between the underlying mechanism of ADHD and the factors that control the onset of puberty.

Association for Paediatric Palliative Medicine

G35 A REVIEW OF THE OUTCOME OF A COHORT OF INFANTS BORN WITH TRISOMY 18

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Trisomy 18 (T18), Edward's syndrome, is a rare condition with a prevalence of 0.1/1000 livebirths in the UK.[1] The majority of these infants do not survive the neonatal period with up to 10% surviving for a year [2]. Clinicians are faced with difficult discussions regarding outcome. This study stems from questions posed by parents of a baby girl who died at home aged 22 months.

The study was designed to address the parents' questions:

1.What is the likelihood of a baby being born with T18 with no identified antenatal risk factors?

2.What is the prognosis for a baby born with T18?

3.What support should families receive following a diagnosis of T18?

Method Retrospective study of all karyotype confirmed postnatal diagnoses of T18, born between 2000 and 2010 at hospitals within a perinatal network. Patients were identified from genetic databases. Information was extracted from paediatric case-notes to a pre-designed audit sheet.

Results Over 11years, 19 live born cases were identified. Information is available for 18. Nine cases (50%) were suspected antenatally but karyotyping declined until after birth. Nine cases (50%) were not suspected before birth. The median gestation was 38 weeks with range of associated anomalies; cardiac defects being the commonest. 4 babies died before discharge and all babies discharged from hospital had a named paediatric consultant. Survival was 94% at one week, 72% at one month, 39% at 3 months, 22% at 6 months and 11% at one year of age. Community nursing and hospice support was provided for 12 (66%) babies. Clinical genetics input was documented for 16 families; 6 before and 10 after discharge. Evidence of end-of-life -planning was poorly documented in the case notes.

Conclusions Half of the babies in this cohort were not suspected antenatally. Overall survival rate was 10% at one year consistent with previous studies but medium term survival was higher than other published studies. Better documentation of end of life care is required.

G36 PALLIATIVE CARE IN NEONATES WITH ANTENATALLY AND POSTNATALLY DIAGNOSED CONGENITAL HEART DISEASE

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Introduction The RCPCH[1] and BAPM[2] have issued guidance on palliative care for neonates with life limiting conditions. There is no reference to congenital heart disease (CHD).

Methods We reviewed 7 babies with CHD born between March 2010 and December 2012 who received palliative care.

Results Seven babies were identified with a median birthweight of 2690g (1740–3900g) and gestation 40 weeks (35+3–42+0). Five had antenatally detected complex CHD which was confirmed postnatally. In 3 cases palliative care plans were made antenatally and these babies did not receive any medical intervention. Two were discharged and died at home in the community at 3 days of age with support from their general practitioner and the hospice (True Colours Team). One died in hospital at 7 days in accordance with the parents' wishes.

For two babies there were antenatal discussions but no agreed postnatal plans made. One had an umbilical line for a prostaglandin infusion until the decision was made for palliative care at six days of age. She died at home at sixteen days with support. Another baby with antenatally diagnosed severe tetralogy of Fallot with absent pulmonary valve was admitted to NICU. On day three she collapsed and required ventilation and inotropes. After careful discussion intensive care was withdrawn on day 4 and she died in hospital later that day.

Two babies were diagnosed with CHD postnatally. One had a 6mm atrial septal defect as part of Smith-Lemli-Opitz (SLO) Syndrome. After confirmation of the diagnosis of complex SLO, palliative care was instigated. She was discharged home at 10 weeks and died at home at 14 weeks of age. A baby with a large VSD had trisomy 18 confirmed on day 8 and the decision for palliative care was made the following day. She died at home aged 21 months.

Conclusion This case series shows that the local end of life care pathway, introduced in 2011, is effective for complex CHD. Multiprofessional hospital and hospice teams have learnt important lessons, including: supply pain relieving medications at discharge, early involvement of the GP and the importance of an ongoing lead paediatric consultant overseeing care.

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G37 WITHDRAWN BY AUTHOR

G38 PARENTAL DECISION-MAKING AT THE END OF LIFE IN CHILDREN DYING OF CANCER

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Background When a child with cancer no longer has a realistic chance of cure, the parents are faced with a range of decisions regarding further treatment options, place of care and place of