

much blood volume is shared between the twins) would affect the volume of distribution and hypoalbuminaemia was likely to increase the apparent volume of distribution. Based on this, ceftriaxone dosing was advised on the combined weight of the twins and given at 50 mg/Kg to M only. Ceftriaxone is excreted mainly unchanged in the urine and bile with little renal clearance or hepatic metabolism so this was not a concern. After 2 days, Ds CRP had reduced and the twins were switched to oral amoxicillin. Dosing was based on the combined weight of the twins and each was given half the dose. As each twin has a separate stomach, it was assumed relatively individual enteral absorption occurs. Ds CRP continued to drop and the twins were discharged home on day 4 with a further 3 days of oral amoxicillin. Paracetamol dosing was advised at 15 mg/kg based on the combined weight and half given to each twin. As required use was agreed, as there was uncertainty over the amount of hepatic metabolism that would occur by the twins shared liver.

Lessons learnt Conjoined twins are a complex yet interesting challenge in terms of medication dosage and administration. There is a lack of evidence and dosing has been based on pharmacokinetic principles and adjusted according to clinical response.

REFERENCES

1. Owolobi AT, Oseni SB, Sowande OA, *et al.* Dicephalus dibrachius dipus conjoined twins in a triplet pregnancy. *Tropical Journal of Obstetrics and Gynaecology* 2005;22:87–88.
2. Electronic Medicines Compendium: Rocephin 1g powder for solution for injection or infusion - Summary of Product Characteristics. <http://www.emc.org.uk/> (Accessed 12 Jun 2018)

P020

VITAMIN SUPPLEMENTATION SURVEY: AN AUDIT OF THE USAGE OF VITAMIN D SUPPLEMENTATION IN PAEDIATRIC PATIENTS, PREGNANT WOMEN AND BREASTFEEDING MOTHERS

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Background A lack of vitamin D can lead to skeletal deformities and disturbances in growth.¹ The Scientific Advisory Committee on Nutrition (SACN) published a report in July 2016 making new recommendations for vitamin D supplementation. Subsequently, our local guidelines were updated on the supplementation of vitamin D in the paediatric population, pregnant women, and breastfeeding mothers.

Aim It is currently unknown whether these guidelines are being adhered to and as such, this audit was designed to assess the vitamin D supplementation status of these populations.

Objectives Establish current level of understanding around the routine use of vitamin supplements; Consider what advice is currently provided and who provides this advice; Determine the current use of vitamin D supplementation in children as well as the levels of vitamin D supplementation in breastfeeding mothers and pregnant women; Assess whether these groups are consuming appropriate quantities of vitamin D supplementation and identify reasons why they may not be.

Methods Data collection was undertaken by pharmacists across two hospitals. Standards were based on the new guidelines published by SACN and local guidelines and were agreed by the clinical lead paediatric pharmacist. Data capture tools were designed in alignment with the standards and piloted.

Modifications were made, exclusion criteria established and a total of 164 forms were distributed. All data collected was inputted to a database and analysed accordingly. Ethical approval was not required.

Results Of the 164 questionnaires distributed, 93 were returned (57% response rate). Less than 30% of the parents surveyed stated they had received advice on childhood vitamin supplementation (n=16 of total n=54) and only 24.5% of children (n=25 of total n=102) were receiving a form of vitamin supplementation. A significantly higher percentage of pregnant/breastfeeding mothers 77% (n=30 of total n=39) stated they had received advice regarding vitamin supplementation. In these cases, midwives and health visitors most commonly provided the advice. Despite this, only 54% (n=21) confirmed that they were taking vitamin supplements.

Conclusion With such low rates of vitamin supplementation, the overall outcome shows poor adherence to current guidance. The results suggest a great need to improve public understanding and education of the risks associated with lack of vitamin D. Standardising practice, enhancing services and the advice provided to patients are ways to encourage compliance to guidelines and ultimately improve the health of those populations who are at risk.

REFERENCE

1. Scientific Advisory Committee on Nutrition (SACN). *Vitamin D and health*. London: TSO; 2016.

P021

DO ADOLESCENTS WANT SEPARATE INFORMATION LEAFLETS?

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Aim Medicines for Children (MFC) is a collaboration between RCPCH, NPPG and Wellchild, a parent charity. It provides web-based, reliable information for parents about medications they give their children. There are leaflets on around 300 medicines. Currently the leaflets are primarily targeted at adults, (with 11–12 reading age), but due to the possible differing needs of adolescents, MFC are considering developing separate leaflets for adolescents. The aim was to explore the contrasting understanding and opinions of adolescents and adults on these leaflets thus informing Medicines for Children about the need for a separate leaflet. We used the Midazolam leaflet as an example to test this on.

Methods It was performed face to face using laptop Google form surveys in the paediatric outpatient department. Participants (parents, and adolescents aged 12–18) read the Midazolam leaflet and answered these 10 questions: Where do you go for information on medicines (for you or your children)? Have you heard of 'Medicines for Children'? How old are you/your children? Was the leaflet written in a way you could understand? Do you like the layout of this leaflet? At what time should someone call an ambulance if you/your child is having a seizure? Where should the Midazolam be given? What may be a common side effect of Midazolam that was mentioned in the leaflet? Is there any more information you would have liked from the leaflet? Do you think there should be a separate leaflet for adolescents? (Only asked to adolescents)

Results Overall 214 surveys were collected; 177 adults and 37 adolescents. Only 11 adults and 0 adolescents had heard of

'Medicines for Children' before. The majority of adults visit their GP or the NHS choices website (53 counts for both), and adolescents ask friends and family (22) for medication information. Overall participants were happy with the leaflet, with 71.2% of adults and 54% of adolescents wanting no changes. Most adolescents (75.7%) said no to separate leaflets, and were happy reading adult leaflets. A Chi-squared analysis was applied to the recall questions to determine if the correct responses between the two groups were significant for: Ambulance call time: 55.1% adults answered correctly vs 51.4% adolescents ($p=0.7016$). Where to give the Midazolam: 92.1% adults answered correctly vs 91.9% adolescents ($p=0.8797$). Common side effects: 69.9% adults answered correctly vs 75.7% adolescents ($p=0.8797$). These P values show there was no significant difference between adults and adolescents in the information ascertained by the reader.

Conclusion The awareness of MFC was low with many other sources being used for information. Recall of information was good in both groups, showing it's efficacy (perhaps due to the leaflet's 11/12 reading age). Most users, whether adult or adolescent, were content with the leaflet. Adolescents do not want their own leaflets. Medicines for Children's resources would be better spent further promoting public awareness of their existing leaflets rather than developing new teenage adolescent ones.

P022 ANAKINRA FOR USE IN NON- JUVENILE IDIOPATHIC ARTHRITIS (JIA) RELATED HAEMOPHAGOCYTIC LYMPHOHISTIOCYTOSIS (HLH): EVIDENCE BASE AND FUNDING

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Background Non JIA related HLH is a life-threatening complication that is increasingly recognised in paediatric patients, particularly in those who are unwell in the paediatric intensive care unit (PICU). Untreated or insufficiently treated HLH has a significant mortality rate (up to 53%).¹

Aim To review the evidence base for the use of anakinra in paediatric patients with non-JIA HLH refractory to systemic corticosteroids in patients who are not fit for treatment as per HLH 2004 protocol.

Methods A PubMed search with words 'anakinra' and 'hemophagocytic lymphohistiocytosis' was carried out on July 2018 to find out the evidence base with regards to the use of anakinra in non-JIA related HLH. Any published peer reviewed clinical studies or trials (including but not limited to retrospective or prospective controlled trials, comparative studies and observational/cohort studies) were considered. Case reports and series were considered if better evidence studies were not available. A recent case study from a tertiary paediatric centre will be used to illustrate the pathway followed to diagnose non-JIA related HLH and funding options.

Results Although a protocol exists for primary HLH treatment (HLH 2004), including chemotherapy and stem cell transplantation,² there is no consensus on how to treat secondary HLH. The literature mainly showed case reports and small case series,³ describing the use of anakinra collectively for 35 patients (median age 14 to 48 years) who met the HLH 2004 diagnostic criteria with an overall survival rate of up to 88% at time of discharge from the PICU3. Anakinra was used at

standard doses always in combination with corticosteroids. Some patients also received intravenous immunoglobulin (IVIG) and ciclosporin at the discretion of the medical teams.

Conclusion The evidence for use of anakinra in non JIA secondary HLH is limited to retrospective observational studies and mostly restricted to adult populations. Despite this caveat, these studies have demonstrated that anakinra therapy alongside other non-etoposide immunomodulatory therapies is associated with an improvement in short term survival. In patients with multi-organ dysfunction, who are too unstable to receive the existing etoposide based HLH-2004 treatment regimen due to concerns regarding significant treatment toxicity, personalised non-etoposide therapies including dexamethasone, IVIG, ciclosporin and anakinra may be better tolerated and provide a bridge to future more standardised treatment. Evidence to date shows that relapse of secondary HLH is possible with ciclosporin therapy. In JIA related HLH, anakinra was considered better than ciclosporin at inducing remission and having a lower incidence of adverse effects,⁴ and NHS England granted funding for the treatment based on these findings. The available evidence did not show any serious adverse events related to anakinra.

Recommendations This tertiary centre approved the use of anakinra for this patient and future patients with this indication despite lack of reimbursement from NHS England for the drug. An urgent interim policy review will be put together by a team of the British Society of Paediatric and Adolescent Rheumatology (BSPAR) and presented to the NHS England commissioners to seek funding for anakinra for paediatric patients with this indication

REFERENCES

1. Miettinen, *et al.* Successful treatment of severe paediatric rheumatic disease-associated macrophage activation syndrome with interleukin-1 inhibition following conventional immunosuppressive therapy: case series with 12 patients. *Rheumatology (Oxford)* 2011;**50**:417–9
2. Henter JL, Horne A, Arico M, Egeler RM, Filipovich AH, Imashuku S, *et al.* HLH-2004: Diagnostic and therapeutic guidelines for hemophagocytic lymphohistiocytosis. *Pediatr Blood Cancer* 2007;**48**:124–31.
3. Kumar B, Aleem S, Saleh H, Petts J, Ballas ZK. A Personalized Diagnostic and Treatment Approach for Macrophage Activation Syndrome and Secondary Hemophagocytic Lymphohistiocytosis in Adults. *J Clin Immunol* 2017;**37**:638–643
4. Boom V, *et al.* Evidence-based diagnosis and treatment of macrophage activation syndrome in systemic juvenile idiopathic arthritis. *Pediatr Rheumatol Online J* 2015;**13**:55.

P023 IMPROVING PARENTERAL NUTRITION PRESCRIBING

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Background Inpatient parenteral nutrition (PN) is historically administered by nurses against a fluid prescription with flow rates for aqueous and lipid phases. The prescription used to order PN from the aseptic unit is held with clinical pharmacists and not kept on the ward. On call doctors who are not familiar with the patient are asked to write the fluid prescription using an insert sheet accompanying the product. This process is fraught with delays and creates extra work for nurses and doctors. Nurses can't plan the optimal time to start PN in relation to other patient care, PN often starts late and often coincides with the end of shift or handover. Setting up PN at busy times is recognised within the hospital as a potential contributor towards errors. An audit on the