Conclusion Management of early onset scoliosis in patients with PWS using MAGEC rods is challenging and can be associated with a high complication rate. Limited spinal growth was observed amongst this cohort.

66 INCREASING RECRUITMENT TO GOSH SAMPLE BANK

Katie Payne, Natasha Carroll, Katherine Miles. *Great Ormond Street Hospital*

10.1136/archdischild-2020-gosh.66

Background GOSH Sample Bank is a key Research Hospital initiative, enabling patients' leftover samples to be stored and potentially used for child health research. It was launched to staff, patients and families in 2019, following extensive piloting to determine acceptability, feasibility and resource requirements. Initial recruitment was slow, with 83 patients recruited between September 2017 and April 2020. As all patients should have the opportunity to participate, we investigated different methods to reach more patients and increase recruitment.

Aim To increase inpatient recruitment to Sample Bank, raise awareness of the initiative amongst ward staff, deliver training to staff and develop a model for sustainability to help achieve the Research Hospital vision for this initiative.

Method To drive engagement, especially at an extremely busy time clinically, Research and Innovation (R&I) staff worked with nursing staff to identify wards to visit to seek consent. The training needs of R&I staff, who are familiar with seeking research consent and are GCP compliant, were determined and a training plan was implemented to ensure familiarity with the initiative and competency in obtaining informed consent.

Results Over a 5 month period from April 2020, 308 patients were consented to Sample Bank, across 4 wards (Sky, Koala, Pelican and Panther). Of all patients identified or approached, 65% consented, 13% declined, 6% were ineligible, 13% were discharged before consent could be taken and 3% were eligible but not approached. In total, 24 clinical and 18 non-clinical staff were trained to obtain consent.

Conclusion Although resource intensive, this method of obtaining consent proved highly effective at increasing recruitment. We will now investigate opportunities for embedding obtaining consent for Sample Bank into routine clinical practice, including providing training for clinical staff and amending the clinical consent process, providing all GOSH patients with the opportunity to participate.

67 ADVANCED NURSE PRACTITIONERS IN CLINICAL RESEARCH: AN INNOVATIVE ROLE AT GREAT ORMOND STREET HOSPITAL

Helen Ashton. *GOSH*

10.1136/archdischild-2020-gosh.67

Advance Nurse Practitioner (ANP) roles in clinical research provide significant scope to utilise research resources more efficiently while offering a high level of specialised holistic care. However, within Clinical Research Facilities (CRF) throughout the United Kingdom (UK), there are very few ANP roles.

Great Ormond Street Hospital (GOSH) now have two ANP roles and one trainee ANP role within the Research and Innovation department. This is a role currently only present in three other trusts across the UK with the first such role commencing in Manchester in 2012. The first paediatric position was established in Birmingham in 2015, and the first trainee position at GOSH in 2017. Since 2019 there have been two fully qualified ANPs in research at GOSH with another trainee post developed in 2019.

A national forum for ANPs in research was formed in 2018. This has been pertinent in tackling the historic and evolving challenges collectively, collaborating on initiatives to raise the awareness of these unique roles within the NHS and across key stakeholders, as well as supporting clinical research teams who are keen to establish the roles within their departments.

There are many challenges involved in any new role and there have been common challenges recognised across the national forum. These vary from local issues of recognition of the role within the trust to wider issues related to Good Clinical Practice guidelines. Many of these challenges have been overcome and there have already been many successes within this role.

It is hoped in the future these roles will grow into a pivotal part of clinical research networks with the profile being raised nationally and internationally.

68 PREVALENCE AND TREATMENT OF VITAMIN K DEFICIENCY IN PAEDIATRIC PATIENTS WITH RECESSIVE DYSTROPHIC EPIDERMOLYSIS BULLOSA- SEVERE SUBTYPE (RDEB-S)

¹Natalie Yerlett, ²Gabriela Petrof, ¹Katie Holsgrove, ¹Anna Martinez. ¹Great; ²Great Ormond Street Hospital

10.1136/archdischild-2020-gosh.68

Introduction Patients with RDEB-S are at risk of vitamin K deficiency, potentially causing abnormal clotting, excessive bleeding, poor bone metabolism and abnormal vascular calcification.

This study quantifies vitamin K deficiency prevalence in this cohort and identifies potential risk-factors to prevent deficiency.

Methods RDEB-S patients who attended the EB service between 2014–2020 were included. Serum vitamin K and PIV-KAII were measured within the nutritional blood screen. Dietetic and medical notes were reviewed to establish: antibiotic use, enteral feed intake and micronutrient supplementation.

Results 16/25 64% (10/16 female), 22–180 months, had serum Vitamin K and PIVKAII analysed. 6/16 (37.5%) patients had vitamin K deficiency requiring supplementation.

2/6 (33.3%) normalised serum vitamin K after 12 weeks supplementation with oral Menadiol Diphosphate. 4/6 (66.6%) await re-testing following supplementation.

6/6 (100%) patients with vitamin K deficiency were not consuming a gastrostomy/sip feed. 9/10 (90%) patients with sufficient vitamin K levels were consuming either; minimum 200 mls prescribed sip feed or 400–800 mls gastrostomy feed daily (containing 5.9µg–11µg/100 mls vitamin K). One patient with normal vitamin K and no enteral feeds had raised PIVKAII.

16/16 (100%) received antibiotics (range 1–4 courses/year). Patients with the most frequent antibiotics (n=4) had normal