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

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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

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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)

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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 Menodiol 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

vitamin K and PIVKAI levels if they consumed a minimum of 200 mls prescribed sip feed or 400–800 mls gastrostomy feed daily.

16/16 (100%) patients took a multivitamin/mineral supplement; none contained vitamin K.

Summary The prevalence of vitamin K deficiency is 37.5% in this cohort. Patients whom were not consuming gastrostomy/sip feeds of at least 200 mls daily were at greatest risk of vitamin K deficiency. Patients on a micronutrient supplement remain at risk of vitamin K deficiency, as most contain no vitamin K. Prescribing a vitamin/mineral supplement that contains vitamin K is prudent.

12-week supplementation of oral vitamin K (5 mg/day for 1–10 years and 10 mg/day for 12–17 years) adequately improved stores.

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'THE IMPORTANCE OF PEER-SUPPORT FOR CLINICAL ACADEMICS AT GREAT ORMOND STREET CHILDREN'S HOSPITAL'

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Over the last four years, ORCHID (the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability) at GOSH has had great success in supporting nurses, allied health professionals (AHPs) and a junior doctor to apply for clinical academic funding from a range of highly competitive schemes, including the National Institute of Health Research (NIHR). This support has included the running of an internship programme funded by the GOSH NIHR BRC, regular teaching, and knowledgeable and supportive academic supervisors. This has enabled each clinician to lead on research and make valuable contributions to patient care in their specialist fields.

The process for individuals undertaking a PhD can be a challenging, and often lonely experience. The transition from expert clinician to novice researcher can be a shock. An important way to alleviate some of these challenges is to surround oneself with people who are enabling and supportive.

Peer-support has proved to be an invaluable source of support for this growing group of multi-disciplinary researchers. This diverse group, made up of a dietician, family therapist, junior doctor, nurses, physiotherapists, radiographer, speech and language specialist, occupational therapist and an orthoptist, has created a WhatsApp group, held virtual and in-person, social evenings and discussion forums to allow the sharing of positive and negative experiences, dissemination of practical tips and provision of moral support. The group has created a non-threatening, respectful, safe environment and welcomes all clinical academics embarking on a PhD.

This network of engaged, expert and motivated professionals is key to delivering world-leading patient outcomes and developing the GOSH research leaders of the future. Ensuring

their success, using the peer support described, will help support the Trust's aim of establishing a formal clinical academic career pathway for nurses and AHPs, as part of it becoming a research hospital.

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ANAESTHETIC MANAGEMENT OF PATIENTS UNDERGOING AORTOPEXY: A 4 YEAR REVIEW

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Objectives Aortopexies are part of GOSH's specialist tracheal services offered to children with severe tracheobronchomalacia, with an average of 10 cases performed per year. We wanted to identify safe and effective aspects of the anaesthetic care within this complex group of patients undergoing the procedure.

Methods We looked at patient characteristics and anaesthetic management of 26 aortopexies over 4 years with a view to creating some guidance for future practice.

Findings 26 patients (weight range 2.6 – 40 kg, from corrected gestational age of 38 weeks to 15 years of age) underwent aortopexies via the median sternotomy (n=15), thoracotomy (n=2) and thoracoscopic (n=9) approaches. These patients had complex medical backgrounds, including vascular compression of the trachea and trachea-oesophageal fistulae. The anaesthetic approach was tailored to the surgical approach, with median sternotomy (MS) and thoracotomies (To) requiring more analgesia, blood transfusions, invasive monitoring and use of longer-acting muscle relaxants to facilitate safe transfer to Intensive Care (ICU), compared to the thoracoscopic (Tc) approaches. All but one of the patients required postoperative ICU care. The median time to extubation was 2 days and the median stay in ICU was 5 days. The intraoperative course seemed safe overall with no documented intraoperative cardiac arrests and/or deaths. The MS and To cases were carried out in cardiothoracic theatres whereas the Tc cases were performed in general theatres. All the patients were fully paralysed and intubated for the procedure, with no noted trend of difficult intubations. 3 cases required blood transfusions of 10–20 ml/kg and no further blood component.

Conclusions We have been able to highlight areas contributing to safe care of this heterogeneous group of patients, including availability of ICU beds and appropriate location of surgery. Doing a prospective study in future will address some of the limitations of comparing these groups retrospectively.

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IT'S LIKE THE FUTURE! ART IN THE ZAYED CENTRE FOR RESEARCH

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The award-winning art strategy for the Zayed Centre for Research into Rare Disease in Children has delivered a programme of art commissions that create an inspiring, playful and welcoming environment for patients, their families, staff and other visitors. The art programme responds to the design of the building and integrated art installations aim to support