

haemorrhagic telangiectasia (HHT) has been performed for more than 30 years, in order to diagnose and/or treat pulmonary arteriovenous malformations (PAVMs). Childhood screening thoracic CT scans are currently recommended international practice [2]. Our aim was to explore if breast cancer rates differed in HHT patients compared to controls.

**Methods** To provide sufficient power to compare breast cancer rates in HHT patients and controls, we developed a questionnaire capturing data on multiple relatives per respondent, powered to detect differences in breast cancer rates. Blinded to cancer responses, reports of HHT-specific features allowed assignment of participants and relatives as HHT-subject, unknown, or control.

**Results** By data download on 30.6.2012, 1,307 participants (including 1,012 HHT-subjects, 142 controls) had completed the international questionnaire, with the majority of respondents residing in North America. Ages (medians 55/53 ys), gender (65/65% female) and general demographics were similar between the groups. Combining data of participants and relatives resulted in a control-arm of 2,817 (52% female), and HHT-arm of 2,166 (58% female). Median ages were 77ys [IQR 65–82] and 66ys [IQR 53–77] respectively. Rates of breast cancer in the control group matched the age standardised frequency reported by Globocan for the general population, with a ratio of observed/expected incidence of 1.22. As expected, cancer rates increased with age ( $p < 0.0001$ , all cancers). Following age-adjustment, breast cancer was reported significantly more frequently for the HHT group than controls (quadratic regression age-adjusted OR 1.52 (1.07, 2.14,  $p = 0.018$ ).

**Conclusions** Individuals with HHT may be more likely to develop breast cancer. Further study is required to validate, and to assess if any excess is related to radiation exposure, or other factors. Nevertheless, given the rationale for PAVM screening programmes relates to risk reductions in adult life, the data support the widespread view that PAVM screening CT scans should be postponed until after puberty.

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#### P84 HOW WAS IT FOR THEM? EXPERIENCES OF PARENTS OF CHILDREN UNDERGOING SURGICAL TREATMENT FOR EMPYEMA THORACIS

<sup>1</sup>C Simmister, <sup>2</sup>Rp Lee, <sup>1</sup>Mf Thomas, <sup>1</sup>Da Spencer; <sup>1</sup>Department of Respiratory Paediatrics, Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne, UK; <sup>2</sup>Institute of Health and Society, Newcastle University, Newcastle Upon Tyne, UK

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**Introduction** Opinion is divided regarding the management of empyema thoracis in children. There is wide regional variation in treatment, which is only partially related to variations in the availability of skills and resources. There is currently no published evidence of parent experience of treatment of empyema thoracis in children.

**Objective** To explore the experiences of parents of children who have undergone definitive surgical treatment for empyema thoracis.

**Methods** Qualitative, face-to-face, semi-structured interviews with parents of children who had undergone definitive surgical treatment for empyema thoracis. Methodology: interpretative phenomenological analysis. Participants were recruited from a

large UK teaching hospital between December 2012 and March 2013. They were interviewed in hospital just before discharge. Parents of 8 children aged 11 months to 6 years, 8 mothers and 2 fathers (2 sets of both parents).

**Results** The overarching theme revealed in all of the parents' accounts was trust. The parents' perceptions of development or undermining of trust was influenced by several factors. They include: communication and interactions with staff; information provision and methods used to provide explanations including use of visual aids; staff competence demonstrated by knowledge and experience; evidence of team-work and non-verbal actions such as smiling, eye contact and perceived attitude. The establishment of trust also differed through the stages from GP referral, admittance to secondary and tertiary hospitals, peri- and post-operative phases.

Additionally the accounts revealed that parents were relieved when surgery was undertaken. Most parents were pragmatic about the scars following surgery, but considered that *all* of the scars were significant, not just the thoracotomy scar.

**Conclusions** Verbal and non-verbal communication used by staff when talking to families can have a significant impact on the development or undermining of trust. This can affect parental perception of competence and care provided by practitioners.

#### P85 HOME AND SCHOOL DIRECTLY OBSERVED THERAPY IN A CHILD WITH DIFFICULT AND LIFE THREATENING ASTHMA

G Nyamugunduru, J Smith, V Moreton; University Hospital of North Durham, Durham, UK

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**Background and aim** We report the case of a child with difficult and life-threatening asthma whose control improved with directly observed therapy (DOT). School based DOT improves adherence<sup>1</sup> but to date there are no publications of combined home and school DOT.

**Case report** The child was commenced on Beclomethasone aged 4 years following repeat admissions with asthma. Clinic attendance was erratic. Occasionally she arrived in clinic with wheeze and saturations in the 80's. Health behaviour did not change despite warning parents about risk of death. A common assessment framework (CAF) was initiated.

Following a life threatening asthma episode (aged 6 years) maintenance therapy was increased to Seretide 250 mcg bd (spacer) and Montelukast 5mg od. IgE was 1556 and House Dust Mite RAST positive. Clinic attendance and asthma control temporarily improved. Following another two admissions with life threatening attacks SloPhylline 250mg am/125mg pm was added. Theophylline levels were found to be  $<2$  mg/l after a further serious admission. Maintenance oral prednisolone was commenced and she was referred to tertiary hospital for consideration of Omalizumab. She was concurrently referred to Social services.

At case conference she was put under a child protection plan for reasons of child neglect. DOT service at home and school was commenced. Non-attendance to clinics immediately ceased. There were no further hospital admissions. She was weaned off prednisolone. SloPhylline was reduced to 125mg bd. A lower dose of Seretide was attempted but unsuccessful.

DOT was funded by Social services. The cost was £24.24 per week term- time and £37.66 per week during school holidays.

**Discussion** Before starting regular oral prednisolone or Omalizumab in difficult paediatric asthma a trial of DOT could be worth considering. It is safer and cheaper.

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**P86 EXPLORING THE EMOTIONAL JOURNEY PATIENTS WITH ASTHMA EXPERIENCE AND THE DIFFERENCE BETWEEN CHILDHOOD AND ADULT DIAGNOSIS**

Y Ochiai, NF Mathieson, C Goode, A Mulgirigama; *Boehringer Ingelheim UK Ltd, Bracknell, UK*

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**Background** Asthma affects 5.4 million people in the UK. We wanted to explore the emotional journey patients with asthma experience during their management.

**Methods** Market research was conducted with an independent agency to investigate the emotional journey patients with asthma experience. Methodologies used to collect this data included patient immersion interviews with ethnographic elements, video diary and the Soulmate™ Duo interview technique. Soulmate™ is a technique where for a proportion of the interview, patients interview each other without a moderator, allowing deeper insight into their experiences to be obtained. A total of 21 patients were interviewed, including partners and families to fully understand the impact of asthma on the individual affected.

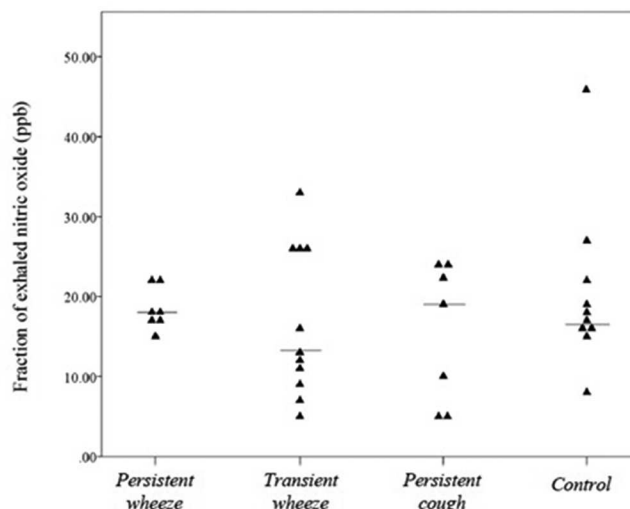
**Results** Experience of asthma varies considerably depending on whether symptoms first presented in early childhood or later in life. Patients diagnosed in childhood or infancy were found to normalise their symptoms more and may underestimate the severity of their condition, leading to lower adherence. Those diagnosed in adulthood were found to be more aware of the impact asthma was having upon their life. These patients tend to be regimented about taking medication and develop strategies to help them remember. Patients experience a range of emotional ups and downs throughout the treatment journey. The emotional dynamic was found to change with certain events, from diagnosis to their first asthma exacerbation. The key emotional themes identified with regards to asthma as a disease were feeling; 1) vulnerable and insecure of experiencing an asthma attack at any time, 2) restricted and constrained in terms of what they could do with their life, 3) tired and deflated over a battle that can never be won, 4) calm and relaxed when they did not experience symptoms. Impact on partners of patients with asthma was significant and often unrecognised.

**Conclusions** Patients diagnosed with asthma in childhood are at risk of under-estimating their symptoms and are potentially at greater risk of being mis-managed. These patients need a deeper exploration of their asthma symptoms to optimise their management.

**P87 IS FRACTION OF EXHALED NITRIC OXIDE (FENO) IN ASYMPTOMATIC OLDER TEENAGERS RELATED TO PRESCHOOL WHEEZE AND CHRONIC COUGH?**

<sup>1</sup>LR Marshall, <sup>1</sup>C Beardsmore, <sup>1</sup>W Monteiro, <sup>2</sup>A Pescatore, <sup>2</sup>C Kuehni, <sup>1</sup>E Gaillard; <sup>1</sup>University of Leicester, Leicester, United Kingdom; <sup>2</sup>Institute of Social and Preventive Medicine, University of Bern, Bern, Switzerland

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Horizontal lines represent median values.

**Abstract P 87 Figure 1. Fraction of nitric oxide in exhaled breath of persistent wheeze, transient wheeze, persistent cough, and control groups.**

**Background** Many children with preschool wheeze and chronic cough become asymptomatic in later childhood, only for asthma to be diagnosed in adulthood (1). A previous study found in individuals with apparently outgrown childhood asthma, fraction of exhaled nitric oxide (FeNO) was significantly increased (2). Whether teenagers with a history of preschool wheezing or chronic cough have elevated FeNO, and whether this differs between preschool wheeze phenotypes is unknown.

**Aims** We compared FeNO and induced sputum inflammatory cell counts in asymptomatic teenagers from the Leicestershire Respiratory Cohort, who had persistent ‘multiple trigger’ wheeze (PW), transient viral wheeze (TW), persistent cough (PC), or no respiratory symptoms (controls) during the preschool years.

**Methods** Thirty-six subjects (mean age: 16 years) participated: 7 with PW; 12 with TW; 7 with PC; and 10 controls. FeNO was measured using a portable electrochemical analyser (NIOX MINO® Asthma Inflammation Monitor, Aerocrine AB, Sweden). Sputum was induced with nebulised hypertonic saline and processed according to previously published protocol (3) with an adaptation for smaller samples.

**Results** There was no statistically significant difference in mean logFeNO between groups ( $p = 0.563$ ) (Figure 1). Median% sputum eosinophils for PW and TW groups were significantly higher than in controls. Sputum total cell counts were significantly greater in PW and PC groups than in controls.

**Conclusions** We did not find evidence that FeNO in asymptomatic adolescents is related to history of preschool wheeze and chronic cough. However, we found evidence that eosinophilic airway inflammation is increased in asymptomatic adolescents with preschool PW and TW. The relationship between FeNO and evidence of elevated inflammatory cell counts in sputum remains enigmatic. These findings have implications for the understanding of the natural history of preschool wheeze and chronic cough.

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