The Surrey, Sussex & Kent Regional Paediatric & Neonatal Research Network

Third Annual Research Day

Wednesday 16th September 2009

Audrey Emerton Education Centre,

Eastern Road,

Brighton BN2 5BE

Lecture Hall – Level 2

Scientific Committee:

PD Dr Heike Rabe, BSUH NHS Trust

Prof. Somnath Mukhopadhyay, Brighton and Sussex Medical School

Dr Paul Seddon, BSUH NHS Trust

Dr Phil Amess, BSUH NHS Trust

Mr Scott Harfield, BSUH NHS Trust

Dr Terry Pountney, Chailey Heritage Clinical Services

Programme		
08:30	Registration & Coffee	
09:25	Introduction & Welcome	PD Dr Heike Rabe
Session I Chair: Prof. Somnath Mukhopadhyay & Dr Ian Male		
09:30	Childhood obesity: Monitoring and Management in both Clinical and School settings.	Dr Julia Potter
10:00	The effects of Calogen supplementation in children with chronic non-specific diarrhoea.	Miss Charlie Dey
10:15	Can a low amine diet help relieve the symptoms associated with CVS in children?	Dr Penny Barnard
10:30	**Coffee Break**	
Session II Chair: Dr Paul Seddon & Dr Sarath Ranganathan		
11:00	"CPAP for Preterm babies: when & how?"	Dr Samir Gupta
11:30	To ascertain the smoking status of adolescents with diabetes as compared to non-diabetics.	Ms Louise Elliott
11.45	Experiences of diagnosis and subsequent support for children with an Autistic Spectrum Condition; parents' views of a local community service.	Ms Jenny Clarke
12.00	How should we present information to parents of children with Hemiplegic Cerebral Palsy? An exploratory study.	Miss Beth Goundry/ Dan Wattley
12.15	An evaluation of an online training resource for parents of children with an autistic spectrum condition.	Andrew Lindner
12:45	**Lunch**	
Session III Chair: Dr Shankar Kanumakala & Dr Terry Pountney		
14:00	Treatment with cooling for perinatal asphyxia: Evidence from Randomised Controlled Trials and current UK practice.	Dr Denis Azzopardi
14:30	Relationship between microcirculatory changes in children with severe meningococcal disease and cell adhesion molecules.	Dr Fauzia Paize
14:45	High rates of adrenal suppression with inhaled steroids – review of current studies and results to date.	Dr Dan Hawcutt
15:00	Monitoring of clinical research in Royal Alexandra Children's Hospital, Brighton.	Dr Shrabani Chakraborty
15:15	Caring for children and families receiving palliative care: a phenomenological study.	Mrs Kathryn Summers
15:30	**Tea Break**	
Session IV Chair Dr Philip Amess & Dr Neil Aiton		
16:00	Fetal Alcohol Spectrum Disorders, neurodevelopmental outcomes.	Dr Raja Mukherjee
16.30	Thanks and Close	PD Dr Heike Rabe

The Surrey, Sussex & Kent Regional Paediatric & Neonatal

Research Network

Paediatricians attending this event may claim up to 4.5 CPD points in accordance with the current RCPCH CPD Guidelines

We value your feedback. Please place your feedback questionnaire in the box at the exit of the lecture hall at the end of the day.

We hope you enjoy the day,

yours sincerely

Miss Denise Stilton on behalf of the regional network

Delegate Speakers

Session I

(09:30 – 10:00)

Childhood obesity: Monitoring and Management in both Clinical and School settings.

Dr Julia Potter – Senior Lecturer, University of Chichester

Session II

(11:00 - 11:30)

"CPAP for preterm babies: when and how?"

Dr Samir Gupta- Consultant Neonatologist, University Hospital of North Tees

Session III

(14.00 – 14.30)

Treatment with cooling for perinatal asphyxia: Evidence from Randomised Controlled Trials and current UK practice.

Dr Denis Azzopardi – Senior Lecturer in Neonatology, Imperial College

Session IV

(16.00 – 16.30)

Fetal Alcohol Spectrum Disorders, neurodevelopmental outcomes.

Dr Raja Mukherjee – Consultant Psychiatrist for people with LD, Surrey and Borders Partnership NHS Foundation Trust

DELEGATE SPEAKER ABSTRACTS

Childhood obesity: Monitoring and Management in both Clinical and School settings.

Dr Julia Potter – Senior Lecturer, University of Chichester, Bishop Otter Campus, College Lane,

Chichester, West Sussex PO19 6PE

This presentation a brief summary of lessons learnt from the New LEAF (Lifestyle, Eating, Activity, and Fitness) project. The New LEAF project is a collaborative project between the University of Chichester and St Richard's Hospital aimed at intervening on childhood obesity. This project has been carried out at a secondary care level and in local secondary schools since 2001.

The presentation aims to consider some of the concepts behind childhood obesity measurement, monitoring and intervention.

"CPAP for preterm babies: when and how?"

Dr Samir Gupta- Consultant Neonatologist, University Hospital of North Tees, Stockton-on-Tees TS19

8PE

Continuous positive airway pressure (CPAP) is a non-invasive form of respiratory support. It is increasingly used at birth in spontaneously breathing premature babies, and is a standard form of providing respiratory support in babies after extubation. The efficacy of CPAP post extubation has been limited to babies ventilated for less than 2 weeks.

The stimulus to use CPAP at birth as a mode of support for very low birth weight infants comes from an observation by Avery et al, subsequently confirmed by Van Marter. This unit (Columbia University) used markedly less surfactant (10% versus 45%), and yet was able to maintain a low rate of chronic lung disease (CLD) compared to the other regional centres. These practices, however, preceded the "surfactant era," when use of antenatal corticosteroids was also low. The recent experience from Columbia has been presented in more depth by Ammari et al, who reviewed the courses of 261 infants <1250 g and reported their outcomes at 72 hours of age based on the initial respiratory support modality. They observed that infants who succeeded on CPAP were about three weeks more mature and weighed about 300 g more than those who failed ($p < 0.001$). Babies ventilated from birth were about 30 times more likely to have received positive pressure via bag and mask at delivery than infants who were started on CPAP (91% versus 24%; OR = 29.9, 95% CI (8.8, 102)).

So far, most of the information on the early use of CPAP has come from retrospective cohort studies, but results of randomised controlled trials have started to appear. These should provide a better level of

evidence. One such study, recently been published is the COIN trial. Among 610 babies 25-28 week gestation they reported that CPAP group had fewer deaths or need for supplemental oxygen (OR 0.63, 95% CI, 0.46 to 0.86, p = 0.006) at 28 days postnatal age. This advantage was, however lost at 36 weeks' PMA. The intubation rate in the first five days for the CPAP group was 46% (55% for 25-26 weeks and 40% for 27-28 weeks). There were no significant difference in the duration of respiratory support or the incidence of complications related to prematurity, but there was a significant increase in the rate of pneumothorax in the CPAP group (9% versus 3%). This trial could not assess the advantages of surfactant and CPAP and the results of two other trials SUPPORT (completed recruitment) and NICHD network trial are awaited who have compared 3 groups including surfactant + CPAP group.

How to provide CPAP? There is a variety of CPAP devices available and based on the flow characteristics, they can be broadly grouped into "variable" flow and "continuous" flow devices. Infant flow driver® CPAP (IFD CPAP) & Benveniste® gas jet valve CPAP are prototypes of "variable" flow device, and Ventilator CPAP and Bubble® CPAP are continuous flow device. Apart from the flow characteristics other factors can also influence the delivery of nasal CPAP. This includes type of nasal interface, level of nasal CPAP and position of mouth.

IFD CPAP utilizes a dedicated flow driver and generator with a unique fluidic flip mechanism to adjust the gas flow throughout the respiratory cycle. The fluidic flip action of the IFD assists spontaneous breathing and provides more stable pressure delivery and functional residual capacity. It is also reported to cause less thoraco-abdominal asynchrony and is associated with reduced work of breathing. On the contrary, Ventilator CPAP & Bubble CPAP utilise a fixed flow of gas. In ventilator CPAP pressure is increased or decreased, in general, by varying the ventilator's expiratory orifice size. The exhalation valve works in conjunction with flow and pressure transducers, to maintain the CPAP at the desired level. Bubble CPAP delivers pressure through the distal end of the expiratory tubing immersed underwater and the CPAP pressure generated is equal to the level of the CPAP probe under water. Varying the depth of the underwater expiratory tube can vary the CPAP pressure. It has also been proposed that chest vibrations produced with Bubble CPAP may contribute to gas exchange. Bubble CPAP thus appears to be an effective and inexpensive option for providing respiratory support to premature infants.

A large study by Stefanescu et al compared Infant flow driver CPAP and Ventilator CPAP after extubation and did not show any difference in extubation failure rate between the two CPAP groups. Lee et al reported improved gas exchange with Bubble CPAP when compared to Ventilator CPAP. This was attributed to effects of bubbling and improvement in gas exchange. Animal studies by Pillow et al suggested Bubble CPAP promotes airway patency and may offer protection against lung injury.

The earlier published studies failed to show any difference between IFD CPAP (variable flow) and ventilator CPAP (continuous flow). Among the continuous flow devices, Bubble CPAP was suggested to have

advantages over ventilator CPAP. The study by Gupta et al compared the IFD CPAP a prototype of variable flow device, and Bubble CPAP a continuous flow device but with the advantages of bubbling. The results of this study suggested significant reduction in extubation failure on Bubble CPAP in babies ventilated for less than 2 weeks, the subgroup previously reported to have benefits of CPAP after extubation. Babies on Bubble CPAP also required significantly shorter duration of CPAP support.

The comparison of CPAP devices after extubation has provided evidence on short term outcomes. Further trials comparing long term outcomes and evaluation of CPAP devices at birth is now warranted.

Further reading:

- Sinha SK, Gupta S, Donn SM. Immediate respiratory management of preterm infant. Seminars in Fetal & Neonatal Medicine 2008;13(1):24-30
- Morley CJ, Davis PG, Doyle LW et al. Nasal CPAP or intubation at birth for very preterm babies. N Engl J Med 2008;358:700-8.
- Davis PG, Henderson-Smart DJ. Nasal continuous positive airway pressure immediately after extubation for preventing morbidity in preterm infants. *Cochrane Database of Systematic Reviews* 2003, Issue 2. Art. No.: CD000143. DOI: 10.1002/14651858.CD000143
- Liptsen E, Aghai ZH, Pyon KH, et al. Work of breathing during nasal continuous positive airway pressure in preterm infants: a comparison of bubble vs variable-flow devices. J Perinatol 2005;25:453-8
- Stefanescu BM, Murphy WP, Hansell BJ, et al. A randomized trial comparing two different continuous positive airway pressure systems for the successful extubation of extremely low birth weight infants. Pediatrics 2003;112:1031-8
- Gupta S, Sinha SK, Tin W, Donn, SM. A randomized controlled trial of post-extubation bubble continuous positive airway pressure versus Infant Flow Driver continuous positive airway pressure in preterm infants with respiratory distress syndrome. J Pediatr 2009;154:645-50

Treatment with cooling for perinatal asphyxia: Evidence from Randomised Controlled Trials and current UK practice.

Dr Denis Azzopardi – Senior Lecturer in Neonatology, 5th Floor, Ham House, Imperial College, Hammersmith Campus, Du Cane Road, London W12 ONN

Clinical trials of neuroprotection following birth asphyxia

Despite extensive experimental studies of neuroprotection following asphyxia, relatively few clinical studies have been carried out. Initial studies used pharmacological intervention to reduce free radical or excitotoxic mediated brain injury, but were mostly unsuccessful partly because of logistical problems in

enrolling sufficient numbers of subjects very soon after birth or because of adverse effects. Recently results from randomised trials of hypothermia started with 6 hours and maintained for 72 hours confirm that cooling to 33.5C reduces mortality and improves neurological outcomes in survivors. However several questions concerning therapeutic hypothermia such as whether cooling is effective beyond 6 hours after birth or whether it is modified by the severity of encephalopathy cannot be addressed with the current data, but further studies addressing these issues are on going. Despite these concerns, hypothermia is now rapidly becoming the standard of care in developed countries but its safety and feasibility in resource poor countries has not yet been confirmed. Following these studies focus has moved towards reducing the progressive phase of brain injury that occurs over several days following asphyxia and is thought to be primarily involving apoptosis. Clinical trials targeting these mechanisms such as with erythropoietin and xenon gas are underway and preliminary results are very promising. Therefore there is now conclusive evidence from clinical trials that intervention following perinatal asphyxia is feasible and effective. The emphasis in future studies will be to determine modifying clinical factors, identifying synergistic therapeutic interventions and exploring these therapies in other patient groups, including preterm infants.

Fetal Alcohol Spectrum Disorders, neurodevelopmental outcomes.

Dr Raja Mukherjee – Consultant Psychiatrist for people with LD, Surrey and Borders Partnership NHS Foundation Trust, Bracketts Resource Centre, 116-118 Station Road East, Oxted, Surrey RH8 OQA

Fetal Alcohol syndrome is the most common cause of Learning Disability in the worlds with estimated prevalence rates of 10 per 1000 for the overall spectrum of presentation. Despite this it often goes unrecognised. Partly through complicated diagnostic methods and uncertainty about the interrelationship with other conditions such as ADHD and ASD it is not always labelled. The presentation will cover how to diagnose the condition, as well as its relationship to other neurodevelopmental disorders. Current research data will be presented as well as brief suggestions for clinical management being provided.

Presented Abstracts

Session I

(10:00 – 10:15)

The effects of Calogen Supplementation in Children with Chronic Non-Specific Diarrhoea.

Miss Charlie Dey- Dietician, Dietetics, St Georges Hospital, Blackshaw Road, London SW17 OQT

INTRODUCTION: Chronic Non-Specific Diarrhoea (CNSD) is one of the most frequently seen forms of chronic diarrhoea in children in the western world. Diagnosis criteria from Boyne et al (1985) include the following:

- Three or more loose, watery stools a day
- No associated malabsorbtion
- Normal growth and development
- Persistent diarrhoea

Current evidence concerning this condition is limited. Several studies have shown the importance of fat in the diets of these children (Cohen et al (1979, Boyne et al (1985), Kneepkens & Hoekstra (1996) & Hoekstra et al (1998). The aim of this study was to audit the effectiveness of supplementation with Calogen (Nutricia ®) for the management of CNSD.

METHODS: In a retrospective case note review patients attending our paediatric gastroenterology clinic between 2005 -2008 who were referred to the dietitian with CNSD & supplemented with Calogen were included in the audit. Calogen is a fat emulsion consisting of long chain triglycerides (LCT). Data was collected for weight & height and stool frequency and stool consistency using the Heaton Scale (Lewis & Heaton, 1997) pre- and post-treatment. A four day food record chart or diet recall was used to calculate carbohydrate, fat and protein intake prior to Calogen supplementation.

RESULTS: Patients had a mean dietary intake of 27% of energy from fat, which is below the recommended DRV of 35% (Great Ormond Street 2000). A pre-treatment modal stool consistency of 7 and stool frequency of 3 were identified on the Heaton Scale. Sixty seven percent of the children had improvements in CNSD symptoms after treatment with Calogen. There was a statistically significant decrease in stool consistency ($P<0.002$) and stool frequency ($P<0.001$). Stool consistency reduced to a mode of 4 and stool frequency reduced to 1-2 times a day in the responsive group. These symptom scores resulted in patients no longer meeting the diagnostic criteria for CNSD.

CONCLUSION: The audit suggests that this patient group are consuming less than the recommended intake of fat per day, providing support for the hypothesis that low fat intakes are a potential cause of CNSD. Increasing the fat content of the patients' diets has a role in improving CNSD symptoms. However, the profiles of the non-responders have suggested that other dietary factors including a high intake of

fluid, fibre and fruit juice may also contribute to this condition. Further investigation through randomised controlled trials is required to confirm these findings. This could then contribute to the development of management guidelines for CNSD which are currently lacking.

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Boyne LJ. Kerzner B. McClung J (1985) Chronic Non-specific diarrhoea; The value of a Preliminary Observation Period to Assess Diet Therapy. *Paediatrics*. **76**(4) 557-561

Cohen SA. Hendricks KM. Mathis RK. Laramee S. Walker WA (1979). Chronic non-specific diarrhoea; dietary relationships. *Paediatrics*. **64**(4), 402-7

Great Ormond Street Hospital for Children NHS Trust (2000) Nutritional Requirements for children in Health and Disease. Third Edition, revised by Angela Cocks. Cambridge, UK.

Hoekstra JH (1998) Toddler diarrhoea; more a nutritional disorder than a disease. *Archives of Disease in Childhood.* **73**(2), 126-30

Kneepkens CM. Hoekstra JH. (1996) Chronic non-specific diarrhea of childrhood; pathophysiology and management, *Pediatric Clinics of North America,* **43**(2), 375-90

Lewis SJ. Heaton KW (1997) Stool from scale as a useful guide to intestinal transit time. *Scandinavian Journal of Gastroenterology.* **32**(9), 920-4.

(10:15 – 10:30)

Can a low amine diet help relieve the symptoms associated with CBS in Children?

Dr Penny Barnard- Specialist Dietician Paediatrics, Dietetics, Western Sussex Hospitals NHS Trust, St Richards Hospital, Chichester, PO19 6SE

INTRODUCTION: Cyclical Vomiting Syndrome (CVS) consists of stereotypical acute episodes of vomiting & or abdominal pain. CVS is frequently compared with migraine and has been included as a new headache type in the revised International Classification of Headache Disorders (2004). Migraine related mechanisms could play a role in CVS[1].Patients often have a family history of migraines. A low amine diet has been used to treat migraine for many years[2]. The aim of this audit was to see if a low amine diet could reduce the symptoms of patients with CVS.

METHODS: In a retrospective case note review patients attending our paediatric gastroenterology clinic between 2002 -2007 who fulfilled the Rome III criteria for CVS & who were treated with a low amine diet were included in the audit. Rome III criteria include 1. Two or more periods of intense nausea and unremitting vomiting or retching lasting hours to days. 2. Return to usual state of health lasting weeks to months. Foods rich in amines were eliminated from the diet. Foods rich in amines would typically be cheese, chocolate, pork & pork products, citrus fruits & their juices, caffeine & yeast extracts. All patients were

seen by a paediatric dietitian & high amine foods replaced with suitable alternatives. Dietary exclusion varied depending on the length of time between attacks. After the agreed time of dietary exclusion if symptoms had improved food reintroduction were overseen by the dietitian. If no improvement was seen the children returned to their original diet.

RESULTS: The case note review identified 20 patients with CVS and 20 (9 girls & 11 boys) who were commenced on a low amine diet. Sixteen patients (80%) reported an improvement in their symptoms when following the diet. Of those, 10 children (aged 3 –15 years) showed relief of their CVS symptoms after 3 months and 6 showed an improvement in some of their symptoms. Three (aged 8-10 years) did not respond to the diet. One patient failed to return for follow up.

CONCLUSION: We found a low amine diet can be very useful in treating the symptoms of most children with CVS. A controlled trial of dietary management of CVS appears warranted.

REFERENCES:

1. Li BU, Misiewicz L: Cyclic Vomiting Syndrome: a brain-gut disorder. Gastroenterol Clin N Am 2003; 32: 997-1019
2. HanningtonE: Migraine. In *Clinical reaction to food* Lessof M. H. (Ed)1983 pp155-80 John Wiley & Sons, Chichester

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Session II

(11:30 – 11:45)

To ascertain the smoking status of adolescents with diabetes As compared to non-diabetics.

Ms Louise Elliott- Medical Student, Brighton and Sussex Medical School, BSMS Teaching Building, University of Sussex, Brighton, East Sussex BN1 9PX

Background: Thirteen people every hour die in the UK as a result of smoking, and this is equivalent to over 120,000 deaths per year. Another factor that significantly affects a person's risk of cardiovascular disease is the presence of Diabetes Mellitus, with similar pathophysiology seen to affect diabetic patients as those who smoke. Therefore, it is even more dangerous for a diabetic patient to smoke than a non-diabetic. Due to the young age that Type 1 Diabetes is often diagnosed it is important for the anti-smoking message to be well communicated to the young adolescents, as this is the time that the majority of smokers take up the habit. We aimed to find out the proportion of young diabetics that are smokers, and whether this varies from the normal population.

Methods: 55 patients (24 diabetics and 31 non-diabetics) attending the Royal Alexandra Children's Hospital or Royal Sussex County Hospital, were approached and asked to fill in a lifestyle questionnaire and provide a urine sample. The participants were between 11 and 25 years old.

All the urine samples provided were then analysed using Liquid Chromatography Mass Spectrometry, detecting the presence of cotinine, the major metabolite of nicotine. The self-reported smoking status and "true" smoking status were then compared for the diabetic and non-diabetic groups.

Results: 55 questionnaires were completed and 49 urine samples were provided. 84 patients were initially approached, giving a 65% response rate. The average age of the participants was 14.8, 47.3% (26) were female and 52.7% (29) were male. 43.6% (24) participants were diabetic.

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	Cotinine Positive	Cotinine Negative
Admitted to smoking in past 2 weeks	5	1
Not admitted to smoking in past 2 weeks	2	41

Using the urinary cotinine analysis as the gold standard test, the sensitivity was calculated to be 0.71 and the specificity 0.98.

	Cotinine Positive		Cotinine Negative	
Diabetic	4	17.4%	19	82.6%
Non-diabetic	3	11.5%	23	88.5%

The overall smoking prevalence was seen to be 14.3%, with 17.4% of diabetics true smokers and 11.5% of non-diabetics..

Discussion: Smoking seems to be more prevalent in young diabetic populations than in non-diabetic populations, although a much larger study would need to be conducted in order to draw significance from the statistics. This may suggest that there are further issues such as diabetics having an increase in risk-taking behaviour, although this has not been explored in literature to any depth, so would be another area of possible research. We may also need to re-evaluate the anti-smoking message that is given by the hospital, in order to reduce these figures.

(11.45 – 12.00)

Experiences of diagnosis and subsequent support for children with an Autistic Spectrum Condition; parents' views of a local community service.

Ms Jenny Clarke – Medical Student, Brighton and Sussex Medical School, BSMS Teaching Building, University of Sussex, Brighton, East Sussex BN1 9PX

Introduction: Autistic spectrum conditions (ASC) have become increasingly recognised in recent years, requests for assessment of possible ASC representing a third of referrals to our child development team. Whilst a diagnosis may help in understanding a child better, families often need ongoing support for example in managing their child's behaviour or in enabling their child to cope at school. This study set out to evaluate diagnostic services in a local child development team and subsequent experiences of children receiving a diagnosis, including availability of subsequent support and outcomes.

Method:

1) Questionnaires were sent to parents of 133 children still under the care of the child development team, who had received a diagnosis of ASC between 2003 and 2008.

2) Notes of children receiving a multidisciplinary diagnostic assessment (MDA) in 2007 were audited against the National Autism Plan (NAP, 2003)

Results:

50/133 (38%) parents completed the questionnaire. Average age at diagnosis was 6 years, and at time of questionnaire was 10 years. 58% rated the diagnostic process as good or excellent, 27% as weak, this being influenced by later age of referral ($p<0.001$) and diagnosis ($p<0.001$). Qualitative responses suggested that length of time awaiting a diagnosis (notes audit showed mean wait from referral to MDA was 44 weeks- outside 30 week standard in NAP) and lack of early follow up support were significant issues. 38 (76%) had started in mainstream school, with 35 (70%) remaining so. 12 (24%) were in specialist schools. 10 (20%) had been excluded, and 10 (20%) on part time curriculum. 24 (48%) reported their child had been bullied.

Conclusions:

Whilst the majority of parents had a positive experience of diagnosis, this could be improved by better post diagnosis support, for example through a keyworker. The majority of children with ASC attend mainstream school, suggesting this is no longer a condition exclusive to children with learning difficulties, although a significant proportion struggle in this setting.

(12.00 – 12.15)

How should we present information to parents of children with Hemiplegic Cerebral Palsy? An exploratory study.

Miss Beth Goundry (Dan Wattley) – Medical Student, Brighton and Sussex Medical School, BSMS Teaching Building, University of Sussex, Brighton, East Sussex BN1 9PX

Introduction: For parents, discovering their child has "cerebral palsy" conjures images of a child in a wheelchair, with learning difficulties. Yet most children with hemiplegic cerebral palsy will walk and attend mainstream school. The growth of information technology offers the opportunity to improve access to information available for parents following such a diagnosis.

This study aimed to explore parents views of how and what information they would like to receive following the diagnosis of hemiplegic cerebral palsy in their child.

Method: Questionnaires focussing on sources and quality of information already received, and on views about different methods of presenting information such as leaflet or internet, were sent to 17 local families with a child with known hemiplegic cerebral palsy. Parents were then invited to attend a focus group, where they were presented with the same information on hemiplegic cerebral palsy presented as a written information sheet, a leaflet with added pictures, a video and a multimedia powerpoint presentation.

Results: 9 parents completed the questionnaire, whilst 6 attended 1 of the 2 focus groups (3 at each). 5/9 (56%) felt information received was adequate. 7/9 wanted to receive information at the time of diagnosis, focus groups suggesting this should be basic, with more information, for example on epilepsy or school issues, to be given over time. Parents also found the term "cerebral palsy" very worrying and would prefer to be told their child had "hemiplegia". Choice of information resource varied, direct contact with a health professional being highly valued. Mothers preferred written information they could carry around with them, whilst fathers preferred computer based information, which all felt would also be popular with siblings.

Conclusions: Access to multimedia information technology has opened up new ways of presenting information particularly to those with more visual learning styles. However information still needs to be available in more traditional formats, and early on direct contact with health professionals explaining the diagnosis remains critical. The impact of diagnostic labels such as "cerebral palsy" needs to be considered

(12.15 – 12.30)

An evaluation of an online training resource for parents of children with an autistic spectrum condition.

Andrew Lindner – Medical Student, Brighton and Sussex Medical School, BSMS Teaching Building, University of Sussex, Brighton, East Sussex BN1 9PX

Introduction: Parents of children with an autistic spectrum condition often need support in understanding and managing this. Whilst professional advice seen as very helpful, access to this can be limited. Alternative sources of information such as the OnlineInset Training, designed to teach teachers about ASC, may therefore have a useful role.

This study evaluated the use of an online multimedia training resource (OnlineInset Training) in supporting parents of children with ASC.

Method: Parents of 15 children with ASC were invited to participate on the OnlineInset Training course, which was expected to take 6 hours over 8 weeks to complete. As part of this there was access to an online forum and "tutor". Pre and post course questionnaires around knowledge and confidence in managing ASC were completed.

Results: 17 parents completed the pre course questionnaire. Only 6 of 17 completed the course. 8/10 completing the post course questionnaire were very positive about the course, its quality of presentation, information contained and access to the online forum. However, it was felt there was too much text, and that predictably the information was geared towards school settings. There was a small increase in scoring of confidence levels managing ASC, although with small numbers this was not statistically significant.

Conclusions: Online training, utilising multimedia information technology, can provide an alternative information resource for parents of children with ASC. For those parents with similar tendencies, access to information outside social settings, and with online discussion may be of particular interest. The current course is to be reviewed with parents from this study to produce a more parent friendly format.

Session III

(14.30 – 14.45)

Relationship between microcirculatory changes in children with severe meningococcal disease and cell adhesion molecules.

Dr Fauzia Paize – Paediatric Specialist Registrar, Neonatal Unit, Liverpool Women's Hospital, Crown Street, Liverpool L8 7SS

Aims: Sidestream Darkfield Imaging (SDF) is a non-invasive method of visualising the microcirculation (capillary blood flow) in real time. Studies using SDF in adults with severe sepsis have shown abnormalities in capillary blood flow but no studies have used this technique in children. Disturbances in the microcirculation result from endothelial dysfunction mediated through adhesion molecules. We aimed to ascertain whether the microcirculatory disturbances seen in adults with severe sepsis are present in children with meningococcal disease (MCD) and whether these disturbances correlate with adhesion molecules.

Methods: Twenty children admitted to the paediatric intensive care unit intensive care with MCD were recruited. The sublingual microcirculation was visualised using SDF at admission and at timed intervals until extubation. All SDF images were obtained by the same investigator. Images were analysed by two blinded investigators, by assessment of the Microvascular Flow Index (MFI), Capillary Density (CD), Proportion of Perfused Vessels (PPV) and Perfused Vessel Density (PVD. Plasma ICAM-1, VCAM-1, E-selectin and P-Selectin were measured

Results: A significant reduction of CD, MFI, PPV and PVD were found in children with severe MCD when compared to controls at admission ($p<0.005$). These differences were no longer significant pre-extubation. There were significant correlations between MFI and PPV and ICAM-1, VCAM-1, and E-selectin. MFI: $r= -0.88$, $p<0.01$, $r= -0.88$, $p<0.01$, $r=-0.87$, $p<0.01$ respectively. PPV: $r= -0.59$, $p<0.01$, $r= -0.52$, $p<0.01$, $r=-0.63$, $p<0.01$ respectively. There was no correlation between any of the microvascular variables and P-Selectin. All children survived.

Conclusion: These results confirm microcirculatory dysfunction in children with severe MCD and microcirculatory recovery alongside clinical recovery. Microcirculatory variables correlate with markers of endothelial activation, and could be a useful adjunct in guiding resuscitation in severe sepsis in children.

(14.45 -15.00)

High rates of adrenal suppression with inhaled steroids – review of current studies and results to date.

Dr Dan Hawcutt – Lecturer (Clinical) Paediatric Pharmacology, Child Health, University of Liverpool, Alder Hey Children's Hospital, Eaton Road, Liverpool L12 2AP

Introduction: Inhaled corticosteroids (ICS) are recommended for asthma management, and there is good evidence of their efficacy. Adrenal suppression is a recognised systemic side effect of corticosteroid therapy (including ICS) and can cause hypoglycaemic seizures, coma and death.

Methods: There are currently 2 complementary studies actively recruiting children with asthma on inhaled and systemic steroids in the NIHR Medicines for Children Research Network – Early Morning Salivary Cortisol (EMSC) study (validating the use of early morning salivary cortisol as a screening tool) and Pharmacogenetics of Adrenal Suppression with inhaled Steroids (PASS) study (looking for genetic causes for adrenal suppression in well characterised asthmatics). Both require a low dose short synacthen test (LDSST), although a participant may be part of both studies with a single LDSST. Results of the LDSST are defined as follows:

Normal: peak > 550nmol/l and increase of >200nmol/ml

Impaired: peak ≤ 550nmol/l **OR** increase of <200nmol/ml

Flat: peak ≤ 550nmol/l with increment < 200nmol/l OR baseline cortisol <100nmol/ml

Results: 48 children (age 5-17) have been recruited to date (results of the LDSSTs shown in table 1). Abnormal LDSST were noted in children taking a range of different products and different doses, including children maintained on licensed doses of inhaled steroids only.

Steroids prescribed	Recruited children	Normal LDSST (%)	Abnormal (impaired or flat) LDSST (%)	Flat LDSST (%)
Licensed dose inhaled steroids only	22	10 (45.5)	12 (54.5)	5 (22.7)
Above licensed dose inhaled steroids only	17	7 (41.2)	10 (58.5)	1(5.9)
Regular additional steroids (e.g. flixonase or oral prednisolone)	9	1 (11.1)	8 (88.8)	5 (55.5)
Total	**48**	**18 (37.5)**	**30 (62.5)**	**11 (22.9)**

Table 1. Low Dose Short Synacthen Test results for children recruited into the Early morning salivary cortisol study (EMSC) and Pharmacogenetics of adrenal suppression with inhaled corticosteroids study (PASS) to date. High rates are seen at all doses of inhaled corticosteroids prescribed.

Conclusion: While clinical concern about adrenal suppression and the invasive test used as part of the

studies may have skewed the population recruited, children taking both unlicensed and licensed doses of ICS are at risk of adrenal suppression. The reasons for individual susceptibility are unclear and are being evaluated as part of the studies.

(15.00 – 15.15)

Monitoring Of Clinical Research In Royal Alexandra Children's Hospital, Brighton.

Dr Shrabani Chakraborty – Clinical Fellow, Royal Alexandra Children's Hospital, Eastern Road, Brighton BN2 OBE

Background: During World War II, medical professionals carried out unethical research experiments on persons with physical and/or mental disability without consent, which were investigated and publicised during the Nuremberg Trials and the Doctors' Trial. This led to the development of the first ethical code of practice, The Nuremberg Code, with informed consent being the primary tenet.

The declaration of Helsinki states the ethical principles developed by the World Medical Association to 'provide guidance to physicians and other participants in medical research involving human subjects'. This includes principles on safeguarding research participants, obtaining informed consent, minimising risk and adhering to an approved research plan/protocol for identifiable human material or data.

Compliance with Good Clinical Practice (GCP), the international ethical and scientific quality standard for designing, conducting, recording and reporting trials involving participation of human subjects, provides public assurance that the rights, safety and well-being of research participants are protected and consistent with the principles of the Declaration of Helsinki, and that the clinical trial data are credible.

The International Conference on Harmonisation (ICH) GCP guideline was developed with consideration of the current good clinical practices of the European Union, Japan, United States, Australia, Canada, the Nordic countries and the World Health Organization (WHO), to provide a unified standard to facilitate the mutual acceptance of clinical data by the regulatory authorities in these jurisdictions.

We have previously adopted these principles to develop a tool to monitor randomised controlled trials in children. However, no such guidance is available for clinical research, not involving any medicinal products.

Objectives: To develop a standard protocol for monitoring the overall quality of clinical research involving children, not involving any medicinal products in Royal Alexandra Children's Hospital, Brighton.

Methods: We have developed a simple checklist for trial master file contents for three ongoing paediatric studies in the Department of Respiratory Paediatrics at Royal Alexandra Children's Hospital in Brighton. A monitoring visit was performed to check all the documents in the master file and a visit report was prepared.

We have observed that the documents, filing and format of documentation were appropriate and in accordance to the guideline. However, the logs of delegation of responsibilities and staff signature, sponsorship letters and indemnity cover needed inclusion in the folders. The amendment logs, correspondence logs and meeting notes needed further updating.

Conclusions: We have developed a tool to monitor the quality of documentation for the research projects involving children, in Royal Alexandra Children's Hospital. By creating a monitoring committee within the research team in conjunction with the NHS R&D, we aim to provide assurance, that the data and reported results are credible, accurate and the rights, integrity and confidentiality of research participants are protected.

In future, we wish to develop a policy to standardise the design, conduct, performance, monitoring, auditing, recording, analysis and reporting of non medicinal clinical research as per the ICH/GCP guidelines which may have an impact on the safety and well-being of the research participants.

(15.15 – 15.30)

Caring for children and families receiving palliative care: a phenomenological study.

Mrs Kathryn Summers – Senior Lecturer in Child Nursing, Canterbury Christ Church University, North Holmes Road, Canterbury, Kent CT1 1 QU

Introduction: Children's palliative care is an evolving specialty. The special case for palliative care for children and young people is unlike the adult model, which tends to focus on the terminal stages of the disease in that it aims to accompany the whole family from the child's diagnosis right through to end of life care and bereavement. There is, at present, an absence of an evidence research base of nurses' experiences of providing palliative care in paediatrics, which has impeded progress in furthering quality care delivered to children and their families.

Aim of the study: To describe the experience of children's nurses caring for children and families receiving palliative care.

Methodology: A descriptive phenomenological approach following the works of Colaizzi (1978) and Moustakas (1994) was utilized.

Method: In-depth focused one to one interviews were conducted with a purposeful sample of six children's nurses who were working in a community based Children's palliative care team.

Results: Four themes emerged from the data: Coping of parents and nurses, Physical symptom relief, Psycho-social care for child and family and Effective Partnership with children and families.

Conclusion: To be an excellent palliative care nurse for children and families, one has to have experiences in clinical practice under facilitative supervision - one cannot excel in this field from reading a book!

Poster Display

Poster No	Title of poster presentation	Authors
1	ACUTE PAINFUL NEUROPATHY (INSULIN NEURITIS)A CASE REPORT.	[1]L Heva Hendige, [1]P Desilva & [2]D Lipscomb
2	COMPARISON OF CLINICAL CHARACTERISITCS OF CHILDREN WITH ASTHMA BETWEEN SCOTLAND AND SUSSEX	Kaninika Basu, Shrabani Chakraborty, Jason Cunningham, Paul Seddon, Somnath Mukhopadhyay
3	The Paediatric Asthma Gene Environment Study (PAGES) Establishing a cross sectional UK database for the investigation of gene environment interaction in children 08-09.	J Cunningham[1], S Mukhopadhyay[1,2], CNA Palmer[3], JG Ayres[4], TV Macfarlane[5], A Mehta[2], G Mehta[2], D Cochran[6], S Cunningham[7], T Adams[8], K Anniruddin[9], D Corrigan[10], A Duncan[11], G Hunt[12], R Leece[13], U MacFadyen[14], J McCormick[2],S McLeish[13], A Mitra[15], D Miller[7], L Waxman[6], A Webb[16], S Wojcik[17], K Basu[1,2], S Chakraborty[1], SW Turner[13,]
4	GO-GHILD Study: Influence of Genetic and Environmental factors on Childhood Diseases	Ali Abd[1-2], Maureen Quin[2], Rebecca Ramsay[2],Konnie Basu[1], Shrabani Chakraborty[1], Heike Rabe[1], Sarath Ranganathan[1-2], Katy Fidler[1], Imogen Rogers[3], Paul Seddon[1], Somnath Mukhopadhyay[1-,2]
5	Supplement Snack-Bar: a new approach to improve compliance with oral supplements in children with CF.	Mr Chris Smith Nutrition and Dietetics, Royal Alexandra Children's Hospital
6	Monitoring progress in Prader Willi Syndrome– All is not always what it seems.	Mr Chris Smith Nutrition and Dietetics, Royal Alexandra Children's Hospital
7	Factors Affecting Child Coping Behaviour During Outpatient Venepuncture	Dr Liam Mahoney
8	Paediatric Head Injuries Brighton a study of the current practice with a view to improving the treatment pathway in line with the 2007 NICE guidance and Children and Young People (CYP) Emergency and Urgent Care Programme.	Michael Harrison
9	Research Studies in Paediatric Respiratory Care	Paul Seddon[1], Heike Rabe[1], Liz Symes[1], Cathy Olden[1], Denise Stilton[1], Suzanne Paginton[1] and David Wertheim[2].
10	Respiratory data from pulse oximeter plethysmogram traces in infants with chronic lung disease	Cathy Olden[1], David Wertheim[2], Liz Symes[1] and Paul Seddon[1]
11	The Impact of Gastrostomy Tube Feeding – A Young Person's Perspective	Alison Eccles
12	Studies in Neonatology	Denise Stilton, Heike Rabe

Poster 1- Room 6

ACUTE PAINFUL NEUROPATHY (INSULIN NEURITIS)

A CASE REPORT.

[1]L Heva Hendige, [1]P Desilva & [2]D Lipscomb

[1]Eastbourne District General Hospital, Department of Paediatrics, Eastbourne, UK
[2]Eastbourne District Hospital, Diabetic Centre,Eastbourne, UK

Insulin Neuritis is a self limiting iatrogenic complication described mainly in adult diabetic patients following initiation of insulin therapy and associated rapid improvement in metabolic glycaemic control. Very few case reports describe this condition in paediatric patients with Type 1 diabetes mellitus.

We report a 15 year old girl with Insulin Neuritis who had long standing poor glycaemic control and then developed neuritis when her HbA1c dropped from 16 to 10 over a three month period. In addition she also developed an acute massive fatty liver (confirmed on biopsy), insulin oedema and proteinuria. Her previous glycaemic control had been poor over a period of two to three years with her HbA1c over 16, and five emergency admissions for Diabetic Ketoacidosis. The poor control had been attributed to previous variable adherence with health care professionals and insulin therapy compounded by serious psycho-social issues.

She complained of disabling paresthesiae described as burning and shooting pain mainly affecting both lower limbs and sometimes associated with prickles and tingles in her feet causing severe distress. Neurological examination revealed normal reflexes with no objective sensory or motor loss. She declined nerve conduction studies. Various modalities of pain relief were tried without much success. Increasing doses of Pregabalin had no effect

Poster 2- Room 6

COMPARISON OF CLINICAL CHARACTERISITCS OF CHILDREN WITH ASTHMA BETWEEN SCOTLAND AND SUSSEX

Kaninika Basu, Shrabani Chakraborty, Jason Cunningham, Paul Seddon, Somnath Mukhopadhyay

Royal Alexandra Children's Hospital, Brighton

Background: Gene-environmental interactions contributing to the development of asthma and its subsequent severity has been the focus of public health interventions, improving adherence to asthma guidelines during recent years. We have established a large database (BREATHE) of asthmatic children across the UK to investigate the genetic markers of asthma susceptibility, severity, exacerbations and response to treatment. Initially BREATHE commenced in Scotland and later extended to Sussex to investigate the effects of ethnic, cultural and environmental diversity in exploration of a wide range of

associations in asthma phenotypic variation and specific genotypes.

Objectives: Compare the clinical phenotype and outcomes of asthma including exacerbations, between the two cohorts of similar dataset.

Methods: A cross-sectional survey was undertaken using electronic records and direct interviews, of asthmatic children in Brighton (n=140) and Dundee (n=155) aged 3-22 years attending secondary care asthma clinics. Both the cohorts were recruited during October to May. A detailed personal and family history was obtained including information on school absences, usage of oral steroids and hospital admissions over the previous 6 months. The asthma prescribing level was determined according to the British Thoracic Society (BTS) guidelines. From this data a global index of asthma severity was derived through construction of a composite variable.

School absences, oral steroid intake and admission to the hospital due to asthma exacerbations were grouped as present (minimum once over the previous 6 months) or absent. The total asthma exacerbation response was calculated as any of these measures and grouped as present or absent.

Pulmonary function was measured in participants not suffering from asthma exacerbations or other acute illnesses during measurement. Saliva was collected for genotyping and archiving.

The study was approved by the Tayside Committee on Medical Research and Ethics. All statistical analyses were performed by using SPSS for Windows version 16 (SPSS Inc, Chicago, Ill).

Results: In the Brighton cohort, mean patient age was 7.8years; 59% were boys. In the Dundee Cohort, mean patient age was 9.9years; 62% were boys. The proportion of children on higher step of asthma management as per BTS guidelines was greater in the Dundee cohort (Brighton: 1=14%, 2=41%, 3=30%; Dundee: 1=8%, 2=45%, 3=47%). On paired sample t-test comparing the Brighton cohort to the Dundee cohort, a significant increase in oral steroid intake ($p<0.005$), school absences($p<0.005$), hospital admissions($p<0.005$) due to asthma exacerbations and total exacerbations over previous 6months($p<0.005$) was observed in the Brighton cohort.

Conclusion: We have characterised and compared two similar populations of children with asthma in terms of relevant history, medication use and exacerbations. A significantly increased proportion of exacerbations in asthma were observed in the asthmatics from Brighton compared to Dundee. There is a need to explore the differences in genetic mechanisms in relation to clinical outcomes in asthma and management policies between the two areas. We predict that this study will help to explain underlying mechanisms for asthma, identify at-risk populations for susceptibility, severity and major life-events, define drug choice, provide uniformity of care, thereby contributing overall to significantly improved management strategies in the UK for asthma in the future.

Poster 3- Room 6

The **P**aediatric **A**sthma **G**ene **E**nvironment **S**tudy (PAGES)
Establishing a cross sectional UK database for the investigation of gene environment interaction in children 08-09.

J Cunningham[1], S Mukhopadhyay[1,2], CNA Palmer[3], JG Ayres[4], TV Macfarlane[5], A Mehta[2], G Mehta[2], D Cochran[6], S Cunningham[7], T Adams[8], K Anniruddin[9], D Corrigan[10], A Duncan[11], G Hunt[12], R Leece[13], U MacFadyen[14], J McCormick[2],S McLeish[13], A Mitra[15], D Miller[7], L Waxman[6], A Webb[16], S Wojcik[17], K Basu[1,2], S Chakraborty[1], SW Turner[13]

[1]Acadamic Department of Paediatrics, Brighton and Sussex Medical School, [2]Maternal and Child Health Services, University of Dundee, [3]Population Pharmacogenetics Group, Biomedical Research Institute, University of Dundee, [4]Institute of Occupational and Environmental Medicine, University of Birmingham, [5]Institute of Applied Medicine, University of Aberdeen, [6]Department of Respiratory Medicine, Yorkhill Hospital Glasgow, [7]Department of Respiratory, Sleep and General Medicine, Royal Hospital for Sick Children Edinburgh, [8]Department of Paediatrics, Cross House Hospital, Kilmarnock, [9]Department of Paediatrics, Victoria Hospital, Kirkcaldy, [10]Department of Paediatrics, Wishaw General Hospital, Wishaw, [11]Department of Paediatrics, Borders General Hospital, Melrose, [12]Department of Paediatrics, Royal Alexandra Hospital, Paisley, [13]Academic Child Health, University of Aberdeen, [14]Department of Paediatrics, Stirling Royal Infirmary, Stirling, [15]Department of Paediatrics, Dumfries Galloway Royal Infirmary, Dumfries, [16]Department of Paediatrics, Raigmore Hospital, Inverness, [17]Department of Paediatrics, Dr Grey's Hospital, Elgin

Background: Asthma is a common and heterogeneous condition which places a major financial burden on health care services internationally and can have dramatic impact on a child's quality of life. It has been hypothesised that a range of gene-environment interactions may explain some of the disease heterogeneity in childhood asthma. Here we illustrate the progress and challenges faced in establishing the PAGES database for childhood asthma, one year on.

Methods: PAGES is a cross sectional observational study with recruitment in 15 hospitals in Scotland and Sussex. Children aged 2-16 yrs, with a diagnosis of asthma and under the care of a respiratory paediatrician are being recruited between 2008 and 2010.

Phenotype will be collected through asthma questionnaire, spirometry, bronchodilator response, skin prick reactivity and exhaled nitric oxide. Environmental exposure will be ascertained using questionnaires (including food frequency questionnaire) and salivary cotinine assay. Genotype is established through salivary DNA extraction. The data will be entered into a purpose built database. From this database the interactions between candidate genetic polymorphisms, e.g. GSTM1, and plausible environmental exposures, e.g. exposure to tobacco smoke will be explored in order to study their influence on the heterogeneity, e.g. severity, of asthma in children.

Results: To date 698 children have been invited to participate and 267 (38%) asthma questionnaires have been returned, mean age 9.1 years, 60% male. Saliva has been collected in 235 children. Spirometry has been obtained in 125 children, mean % predicted (SD) FEV_1 93% (14) and median (IQR) BDR was 4% (2, 10). The median (IQR) FE_{NO} was 22 parts per billion (13, 56), n=129. Seventy nine of the 95 tested were

skin prick positive. Two % of participants were at British Thoracic Society treatment step 1, 14% step2, 58% step 3, 24% step 4 and 2% on step 5.

Conclusion: It is feasible to establish a national database to study gene-environment interactions within a population of children with asthma. PAGES is anticipated to extend current understanding of asthma heterogeneity and will enable us to develop novel approaches for managing asthma, allergy and other associated diseases in childhood.

Acknowledgements to Prof Helen Smith, Dr Booker, Dr Coutts, Dr Davies, Dr Devenney, Dr Gibson, Dr Marshall, Dr Paton, Dr Seddon and Professor Helms.

Poster 4- Room 6

GO-GHILD Study: Influence of Genetic and Environmental factors on Childhood Diseases

Ali Abd[1], Maureen Quin[2], Rebecca Ramsay[2], **Konnie Basu[1], Shrabani Chakraborty[1], Heike Rabe[1], Sarath Ranganathan[1-2], Katy Fidler[1], Imogen Rogers[3], Paul Seddon[1], Somnath Mukhopadhyay[1-,2]** Paul Seddon[2], Somnath Mukhopadhyay[1,2]

[1]Brighton and Sussex Medical School, [2]Brighton and Sussex University Hospitals NHS Trust

Asthma and allergy represent a major burden for public health in society. As a complex disease, both asthma and atopy have hereditary and environmental causes. We have recently identified a role for the interactions between gene and environment that influence allergy and asthma in children. In studies conducted in children and young adults aged 4-22 years, we have shown that the polymorphic variation in genes regulating the process of allergic inflammation strongly associates with clinical outcomes in asthma, eczema and allergy. Thus, if we are to understand the natural history of such diseases we need to be able study gene environment interactions longitudinally, on a prospective basis, over childhood.

We are aiming to establish data-base containing information about genotype, environment and health and disease outcomes, also to maintain this database indefinitely in order to explore gene-environment interactions relevant to asthma and allergy and other childhood diseases.

The study is designed as a prospective cohort study. The study will be conducted in three sites – Sussex, Fife and Tayside.

The purpose of the project is to study the relationships between variations in genes, environmental factors and disease phenotypes in infants and children by establishing a robust genotype-phenotype database. The database will allow us to understand the effect of gene-environment interactions that influence disease in childhood, thus allowing progress to future work, eventually enabling us to develop novel approaches for managing asthma, allergy among other diseases in childhood.

The study has been approved by the Tayside Committee on Medical Research Ethics (Ref: A 08/S1401/130), Brighton and Sussex Medical Research Ethics and also by NHS R&D Departments. We are aiming to recruit around 1600 babies between the three sites; this estimate is based on the birth rate at these areas taking in consideration the practicality of the recruitment process and possible pitfalls that we could face in sample collections and follow-up process.

Poster 5- Room 6

Supplement Snack-Bar: a new approach to improve compliance with oral supplements in children with CF.

Mr Chris Smith

Nutrition and Dietetics, Royal Alexandra Children's Hospital

Abstract Body:

Achieving optimal nutrition during childhood in CF is associated with improved survival. However, studies of interventions with oral nutritional supplements have shown conflicting results. The Cochrane Database Syst Rev. 2007 concluded that oral supplements do not confer any additional benefit and should not be seen as essential. It has been suggested however that the issue of compliance may have a strong role to play in the results of many studies. Compliance with medicines in chronic diseases has been estimated by the World Health Organisation to be around 50% in adults and further reviews specific to paediatrics have suggested a similar figure, Contributing factors to poor compliance are prescribing of untried supplements and poor understanding of varieties available: Children's tastes are individual and unpredictable. To address these issues and improve compliance, we introduced a novel "Supplement Snack-Bar", into our paediatric CF clinic for an experimental 9 month period, and assessed parents' and children's responses by anonymised questionnaires. At each clinic we invited manufacturers to present full-range tasting sessions of their products. Any child felt clinically to require oral supplements was allowed to try the available range before prescribing. Each child over 7 years of age was given one questionnaire to complete and one questionnaire for the accompanying parent. Eleven child/parents pairs of questionnaires were distributed; 11 child and 9 parent questionnaires were returned.

Results:

55% of parents and 36% of children found the sessions "very helpful", while a further 44% of parents and 55% of children found them "fairly helpful". When asked if there had been any effect on subsequent compliance with supplements, 11% of parents and 45% of children felt it had mad a "big difference", while a further 89% of parents and 36% of children felt it had made "some difference" – no parents or children rated "no difference". Our results suggest this type of intervention is popular which may have the potential to improve compliance with nutritional supplements, but a further study using more objective measures of compliance is needed.

Poster 6- Room 6

Monitoring progress in Prader Willi Syndrome– All is not always what it seems.

Mr Chris Smith

Nutrition and Dietetics, Royal Alexandra Children's Hospital

Prader Willi syndrome (PWS) is a rare genetic disorder. Characteristics include hypotonia, short statue and varying degrees of poor social and emotional development. PWS children have an inherent issue with satiety and excessive appetite (hyperphagia). This can lead to excessive weight gain and morbid obesity in untreated and unmonitored individuals. This patient group are faced with an inevitable struggle to control weight velocity and the families undergo much stress in attempting to manage dietary intake during childhood.

The combination of behavioural and nutritional problems requires a multidisciplinary team approach (MDT). There are, however, limited specialist PWS clinics in the UK and monitoring of these children is generally limited to reviews of their growth patterns on standard UK 90 growth charts in general clinics. Our unique approach in Brighton is establishing a consistent and learned behaviour to food portions adopted by all family members from a very early age. More recently we have introduced several new aspects of monitoring which have proved useful both for us and for the parents.

In this case study we have shown how 3 additional elements of monitoring (use of specific reference PWS growth charts, 3 day intake analysis and bio electrical impedence (BIA) measurements) has painted a different picture to that of standard monitoring alone

German and American specific PWS growth charts exist and describe the specific average growth velocity and patterns in this group.. In our case study the PWS specific charts show a far more acceptable pattern of growth. In the American case a near proportional centile position is seen compared to the 4-5 centile deviation discrepancy on UK90 charts.

3 day diaries of intakes provide useful insight as to the types of foods the child is having. Using analysis programmes we can get a more accurate idea of total calorie intake and where these calories are derived. This allows us to tailor advice far more specifically. The analysis results for our case study showed good control of calorie intake.

In BIA a weak electrical current is passed between 2 electrodes and resistance is measured. The system then uses algorithms to calculate total body water TBW and then % fat free mass (FFM) and fat mass.(%FM). For our case study it has shown how the weight gained between November 08 and March 09 was that of lean tissue (decrease in % fat)

In conclusion Standard UK 90 charts alone may mask the subtle positive aspects with children in this area. In isolation they may fail to encourage the family that they are managing well. These additional measures are quick, repeatable and cheap. Referral to a specialist clinic is preferable where children can

be seen as part of an MDT for full comprehensive assessment using a variety of tools. This provides essential support and reassurance to maintain the strict control that is fundamental for caring for the PWS child.

Further studies are needed in this area in particular for UK specific PWS growth charts and specific calibration of BIA in PWS.

Poster 7- Room 8

Factors Affecting Child Coping Behaviour During Outpatient Venepuncture

Dr Liam Mahoney

Brighton and Sussex University Hospitals NHS Trust

Background- Needle distress is a common problem in paediatric medicine. The anxiety, distress and pain that are associated with needle related procedures can produce profoundly negative physiological and psychological effects on children (Jay *et al* 1987). Whilst there is an increasing body of research relating to paediatric needle distress, much of the research focuses on particular populations (e.g. children with leukaemia) or procedures (e.g. immunisations). This study therefore aimed to investigate:

(i) Verbal interaction between children, carers, and health professionals and its relationship to child behaviour during venepuncture;

(ii) Procedural and situational variables such as child age, previous needle procedural experience and pre-procedural anxiety, and the relationship with child behaviour during venepuncture.

Method- 51 children aged between 7-16 years accompanied by their carer were video taped whilst having venepuncture performed. Child, parent and staff behaviours were coded according to the Child-Adult Medical Procedure Interaction Scale-Revised (Blount *et al.,* 1997). Prior to the procedure parents completed a sociodemographic questionnaire. In addition, the level of anxiety felt by the child was assessed with a numeric scale of anxiety. Basic medical information was obtained from patients and medical notes.

Results-

Observation and Correlation Analysis-

12.8% of children did not receive analgesia prior to the procedure. Staff coping promoting behaviour was negatively correlated to child age. The degree of anxiety felt by the child before outpatient venepuncture was significantly negatively correlated with the number of previous needle procedures a child experienced in the past year and the age of the child. The degree of anxiety felt by the child before outpatient venepuncture was significantly positively correlated to child distress and parent and staffs distress promoting behaviours

Hierarchical regression analysis-

Neither child age or trait anxiety of the child made independent contributions to the rate of child coping

or distress behaviours. Both parental and staff coping and distress promoting behaviours, were significantly related to child coping and distress behaviours. The regression analysis showed that, respectively, parental and staff distress promoting behaviours accounted for 64% and 4% of the variance seen in child distress behaviour, indicating that parental distress promoting behaviours have more of an influence on child distress during venepuncture. In addition, the regression analysis showed that staff coping promoting behaviours accounted for 37% and parental coping promoting behaviours accounted for 15% of the variance seen in child coping behaviour, signifying that staff coping promoting behaviours have more of an influence on child coping during venepuncture.

Conclusion- This research demonstrates that both parents and staff both have important influences on child coping and distress behaviour during venepuncture. It extends on previous research by implying that the behaviour of health care professionals has more of an important role with regards to child coping behaviours when compared to parents. It also reiterates the importance of the use of child coping promoting strategies during needle procedures, such as effective analgesia and techniques such as distraction despite a child's age.

Poster 8- Room 8

Paediatric Head Injuries Brighton a study of the current practice with a view to improving the treatment pathway in line with the 2007 NICE guidance and Children and Young People (CYP) Emergency and Urgent Care Programme

Michael Harrison

Brighton and Sussex Medical School

Background

Head injuries account for 8.5% of the paediatric A&E attendances in Brighton. More than 90% of these are minor, requiring no treatment beyond reassurance. Early identification of patients who may have an underlying brain injury is vital to preventing poor outcomes.

Details

Brighton is participating in the CYP emergency and urgent care improvement programme, developing an updated pathway for paediatric head injuries from entrance to A&E to effective discharge.

This audit compares practice in Brighton with NICE guidance and provides a baseline to assess the consequences of the proposed changes in the head injuries pathway. Details of all paediatric patients presenting to A&E in 2008 were analysed.

Methods

Details of all paediatric patients presenting to A&E in 2008, obtained from A&E's 'Symphony' system; were analysed for age, sex, head injury, admission, CT scan and transfer to tertiary centres. Patients presenting with a head injury and either admitted or given a CT scan, were identified. Their notes were

analysed against the NICE guidance for CT criteria, admission criteria and discharge information. We tracked the school nursing records for 45 of these patients; looking for hospital discharge information 'paragons'.

Discussion

Males are more likely than females to present with a head injury ($p < 0.01$), are more likely to undergo CT scan ($p < 0.01$), but are equally likely to be admitted ($p < 0.01$). 93% of patients given a CT scan fulfilled the NICE criteria. 49% of patients admitted but not CT scanned also fulfilled the criteria for CT scan.
After CT scan most (60%) patients were admitted (100% of patients <1 year). 68% of patients who were admitted fulfilled only the criteria 'clinical suspicion'.
Only 25% of the hosptial notes contained evidence that discharge advice was given. 53 % of child health records contained paragons.

Conclusion

From the results, it seems that there is room for improvement in following the NICE criteria for CT imaging. However, the clinical history and increased risks of radiation in young children need to be considered. If a child is being admitted, the risk of CT imaging should be weighed against the likelihood that the results will change their management. The discharge information given to patients, families and health professionals is being improved and a method of ensuring that this is retained in child health records needs to be developed.

Poster 9- Room 8

Research Studies in Paediatric Respiratory Care

Paul Seddon[1], Heike Rabe[1], Liz Symes[1], Cathy Olden[1], Denise Stilton[1], Suzanne Paginton[1] and David Wertheim[2].

[1]Respiratory Care, Royal Alexandra Children's Hospital, Brighton, UK and [2]Faculty of Computing, Information Systems and Mathematics, Kingston University, Surrey, UK

A study of non-invasive measurements of respiratory function.

Can a signal processing technique extract clinically useful information from pulse oximetry waveforms about respiratory status in infants and young children? Studying 3 groups:

1) Newborn – complete
2) Preterm babies having respiratory difficulties
3) Acutely wheezy children 18/12 to 5 years

Point of Contact: catherine.olden@bsuh.nhs.uk

Which is the most effective method of providing non-invasive respiratory support (NIRS) to preterm neonates with lung disease?

This study hopes to find out which of the 4 widely-used methods of Non-Invasive Respiratory Support is

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most effective in pre-term infants.

Recruiting 30 babies <34 weeks with lung disease from TMBU.

Point of contact: suzanne.paginton@bsuh.nhs.uk or catherine.olden@bsuh.nhs.uk

Developing a caregiver quality of life score for wheezy preschool children

Developing a questionnaire to assess the possible effects wheezing in the preschool years may have on the quality of life of both the child affected and his/her family.3 stages. First stage completed. Currently working on Second stage - questionnaire to 100 parents of wheezy preschool children and answers will be given impact score. Third stage will be validation

Point of contact: catherine.olden@bsuh.nhs.uk

Evaluation of bronchodilator response by interrupter technique as a way of improving the management of wheezy preschool children

The aim of this study is to determine whether a positive bronchodilator response (BDR), as measured by a significant fall in interrupter resistance (Rint), is predictive of a clinical response to asthma therapy in wheezy preschool children referred for assessment. The study is currently underway with a target recruitment of 160 children aged between 2 and 6 years with a history of wheeze.

Point of contact: liz.symes@bsuh.nhs.uk

Poster 10- Room 8

Respiratory data from pulse oximeter plethysmogram traces in infants with chronic lung disease

Cathy Olden[1], David Wertheim[2], Liz Symes[1] and Paul Seddon[1].

[1]Respiratory Care, Royal Alexandra Children's Hospital, Brighton, UK and [2]Faculty of Computing, Information Systems and Mathematics, Kingston University, Surrey, UK

We have previously reported that respiratory data can be derived from the pulse oximeter plethysmogram (pleth) trace in healthy newborn infants (Wertheim D et al, Arch Dis Child. Fetal Neonatal Ed. 2009;94;F301-F303;). The aim of this study was to examine if respiratory data can be obtained from the pleth trace in spontaneously breathing infants with chronic lung disease (CLD). Pleth data was collected with a Nonin 4100 Digital Pulse Oximeter (Nonin Medical Inc, USA) connected via Bluetooth to a notebook computer. Flow data was recorded using an EcoMedics Exhalyzer D infant pulmonary function system (EcoMedics AG, Switzerland). Two sections of pleth with little or no artefact and simultaneous flow data were recorded from each of five babies with CLD. Both pleth and flow traces were analysed using software we previously developed with MATLAB (The MathWorks Inc., USA) to assess the main frequencies present in the two signals. The median (range) post-conceptional age of the babies was 36 (31-39) weeks.

In 9 of the 10 recordings frequency analysis of the pleth signal showed a peak at a similar frequency to the respiratory rate obtained from frequency analysis of the flow waveform. These results suggest that

respiratory data can be obtained from the pleth waveform in infants with CLD in the same way as for healthy term infants, despite their higher respiratory rate. Further study is needed to establish whether this data may be clinically useful to non-invasively assess and monitor respiratory disease.

Poster 11- Room 8

The Impact of Gastrostomy Tube Feeding – A Young Person's Perspective

Alison Eccles

Chailey Heritage Clinical Services

Background

The researcher has experience of working with children and young people with eating and drinking difficulties and gastrostomy tubes and is aware of the difficulties faced by families and children when making the decision about whether to accept a gastrostomy or not. Young people have strong opinions about their lives including their eating and drinking difficulties and gastrostomy tubes and the researcher believes that it is possible to include young people with communication difficulties in research and that their contributions should be recognised and valued. Their perspectives should be used to inform professional practice and family decisions, and in turn to improve the service provided for the young people.

In addition, the Department of Health's, National Service Framework for Children, Young people and Maternity Services (2004) establishes clear standards for ensuring that the views of individuals are sought and responded to.

Aims

To investigate the impact of gastrostomy tube feeding and oral intake in young people with a physical disability from the young person's perspective.

Objectives

- To explore the young person's experience of having a gastrostomy tube.
- To support the idea that it is possible to include people with communication impairments in research.

Method

The research uses a series of semi structured interviews with young people with a gastrostomy tube.

Results

A number of themes were identified through data analysis. These were: the impact of a gastrostomy, before the gastrostomy, after the gastrostomy, choices, being involved and included and other people.

Within each of these themes, the participants expressed a range of views, opinions and experiences. All the young people thought that life was better with a gastrostomy tube. The individuality of the experience was highlighted.

All the young people had communication impairments and were able to participate in the research interviews. All the participants had something to say about their experience of gastrostomy and eating and drinking difficulties.

Conclusion

The young people's views on their experience of gastrostomy tube feeding were valid and varied, and could be very informing professional practice.

Poster 12- Room 8

Studies in Neonatology

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Neurodevelopmental follow-up of pre-term infants

Babies born before 29 weeks gestation with a birth weight less than 1000 grams are reviewed at 1 and 2 years of age for developmental assessment.

Parents Perception Research Trials

Parents are asked to participate in an interview to ascertain their opinions and thoughts on being asked to participate in research.

ADEPT Study

A multi-centre trial looking at two different ways of introducing milk feeds in babies less than 35 weeks with abnormal Doppler studies.

Slight delay in Clamping the Cord versus Milking of the Cord

This study looks into whether gently squeezing the blood from the cord into the babies less than 33 weeks would achieve the same amount of blood transfer into the baby as delayed clamping.

Non-invasive Lung Function Measurement in Babies

In this study the way babies are breathing and oxygen levels are measured with a view to finding a new way of monitoring baby's breathing.

Non-invasive Lung Function Measurements in Babies on CPAP

We hope to be able to find out which CPAP device would be best for an individual baby in the future.

Many thanks to our chair persons, speakers, presenters and guests,

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