Repeat cot deaths: majority are due to natural causes

A team of researchers – Professor Robert Carpenter, Alison Waite, Dr Robert Coombs, Dr Charlotte Daman-Willems, Angela McKenzie, Professor J Huber and Professor JL Emery – has carried out the largest ever study of families who have had more than one baby die suddenly and unexpectedly. The study, published this month[1], was based on 6,373 babies enrolled on the Care of the Next Infant (CONI) programme. CONI is funded by the Foundation for the Study of Infant Deaths and the NHS to support families, who have already had a baby die, with their subsequent babies. Forty eight babies died unexpectedly whilst on the scheme and 83% of these subsequent deaths were judged to be due to natural causes.

Joyce Epstein, Director of FSID, said: "The study found that a second death is much more likely to be due to natural than unnatural causes. It shows that any form of automatic suspicion such as the so-called "Meadow's law" is unjustified. This unique research shows how important it is to examine each infant death thoroughly and fairly, and not leap to conclusions based on preconceived notions. FSID has long been calling for professionals to voluntarily follow a standard protocol when responding to sudden unexpected infant deaths. The Kennedy report published two months ago recommended such a protocol now be made compulsory. We call on the government to make such a protocol compulsory without delay."

FSID's campaign for a standard protocol has three key recommendations:

- A paediatrician, working in conjunction with the police, should visit each family within 24 hours of the death to take a complete medical history and offer initial support to the family
- All post mortem examinations should be carried out by a paediatric pathologist, a specialist in babies' disorders
- A case discussion should be held with all the professionals who were involved with the family or the baby to review all available information, learn as much as possible about why that baby died, and plan future support for the family.

Reference

1. **R.G. Carpenter, A. Waite, R.C. Coombs, C. Daman-Willems, A. McKenzie, J. Huber, J.L. Emery.** Repeat sudden unexpected and unexplained infant deaths: Natural or unnatural? *Lancet* 2005; **365** (i).

Viv Evans and her team from the NMU, St Mary's Hospital, Manchester, collect their award.

CBT Outstanding Bereavement Support Awards

To celebrate their 10th anniversary year, The Child Bereavement Trust decided to recognise outstanding bereavement support delivered by those working in the NHS in both hospitals and the community, with an awards ceremony held at the Queen Elizabeth Hall on the South Bank in November.

There were 80 nominations either for individuals or teams, submitted by professionals or families. The winners were:

- Jean Wilde, a Hospital Play Specialist at North Hampshire Hospital
- The Bereavement Support Team at the Regional Neonatal Medical Unit, St Mary's Hospital, Manchester
- Grovehurst Surgery, Sittingborne Kent
- Bernie Halford, a Health Visitor from the Vale of Aylesbury NHS Primary Care Trust

After presentation of the awards by the Chief Medical Officer, Professor Sir Liam Donaldson, the winners gave a brief insight into their work with bereaved families. The event proved to be both emotional and inspirational and illustrates what excellent work is being done in a difficult but essential area of care.

Lost your lust for life? Try trekking the Inca Trail

Ever wanted to travel further than the local shops? Ever had the desire to push yourself to the limit? Then take the Inca Trail Trek – and raise money for a worthy cause. There are eight million people in the UK with lung conditions including premature babies with RSV, children with asthma and adults with TB, lung cancer and COPD.

The British Lung Foundation (BLF), which works for people with all lung conditions, is looking for dynamic, adventurous types ready to take on a BLF place in its Inca Trail Trek to Machu Picchu from 22 September to 1 October 2005.

From the high remote mountain trails to the first sight of the legendary Lost City of the Incas, Machu Picchu, this is a challenging trek on steep trails climbing to 4200m in fantastic and diverse mountainous country. The trek will take you through lush forest, green valleys and high passes with breathtaking views of snow-capped Andean peaks.

Anyone who thinks they're up to the challenge can reserve a place for £250 and must then raise a minimum of £2,500 – in return you'll have a truly once in a life time experience.

If anyone would like to be part of Team BLF, please contact 020 7688 5581 or email events@blf-uk.org.

Ground-breaking email service scoops award

Contact a Family's new web-based linking service, www.makingcontact.org, scooped first place for best confidential email service at the Helpline Awards, run by the Telephone Helplines Association in conjunction with BT. Launched in July 2004, the website enables families with disabled children to get in touch with each other across the UK and, uniquely, across the world – important when just a handful of children have the same rare condition.

Parents can see at a glance if other families affected by the same condition are registered and can register their own details for free. Initially all details are confidential, with families choosing an alias, and emails are routed via the website. Eventually, families can elect to correspond directly, or not to continue. A token fee of £5 per annum is charged once families start to email each other, to deter nuisance users and to stop children registering, as discussions are not monitored. Adults wishing to discuss their own disability can also register.

Network of Neonatal Nurse Researchers

Neonatal nurses may be aware of an initiative aimed at facilitating the development of neonatal nursing research. BLISS, the premature baby charity, has generously funded the post of Neonatal Nurse Research Fellow and the post is based at the National Perinatal Epidemiology Unit (NPEU), University of Oxford. Merryl Harvey and Andy Leslie are first holders of this new post, and both are working in the role half-time.

One of the main objectives for the Research Fellow post is to raise the profile of neonatal nursing research by helping nurses to network. Consequently the Network of Neonatal Nurse Researchers (N3R) has been established and 25 delegates attended the first network meeting at the NPEU on 5th November 2004. Future plans for the network include setting up a website and further meetings, the next of which will be held in May 2005.

Participation in the N3R is open to neonatal nurses and those involved in neonatal nursing research. Merryl and Andy would be pleased to hear from anyone interested in joining the network. For further details please contact them at the NPEU. Tel: 01865 226628 or email: neonatal_nurse.research@perinat.ox.ac.uk

Paul Cornick pictured in front of the Dräger stand.

Dräger Medical Scholarship supports training of nitric oxide delivery in neonates

Paul Cornick has been awarded a Dräger scholarship to enable him to undertake a Delphi Survey aimed at producing a UK consensus about the most appropriate and effective way to train neonatal nurses to safely use nitric oxide. Mr Cornick works as an ECMO specialist at Glenfield hospital. He also works as a Neonatal Project and Development Nurse between the neonatal units at Leicester Royal and Leicester General hospitals where he has been the lead nurse setting up and running the nitric oxide training programme.

"The Dräger scholarship will enable me to travel to different neonatal units around the UK to explain the survey and recruit potential participants. Such face-to-face meetings are important when setting up a project in which the participants will not meet or know the identities of other participants" said Mr Cornick.

"This survey will hopefully give UK neonatal staff a solid base on which to develop and improve their individual nitric oxide training programmes" said Alan Montague, of Dräger Medical UK.

Alison Gibbs and Tina Pollard – two of the members of the expert panel – leading the discussion forum.

BLISS 25th Anniversary Conference

BLISS, the premature baby charity, celebrated 25 years of helping babies born too soon, too small or too sick to cope on their own, by organising a conference entitled 'Partners in Care', held at the Royal College of Obstetrics and Gynaecology in November.

The conference was very well attended and the audience was treated to some excellent presentations on current issues and developments in neonatal care from some of the country's leading specialists and practitioners. However what made this conference different was the involvement and participation of parents of premature babies. The afternoon session consisted of a discussion forum focusing on the future, the problems the expert panel could foresee and suggestions for what needed to change.

Comments from the parents highlighted the fact that although on the whole they are very satisfied with the care they receive in hospital, there is a lack of follow-up care after discharge leaving the parents feeling very vulnerable and struggling to cope. Also continuity of care between hospitals and between regions often doesn't happen and can lead to disruption in treatment. Other issues highlighted by the panel included the shortage of neonatal nurses and the ageing workforce, as well as the necessity of transferring babies from one side of the country to the other to find an available neonatal cot. So although neonatal care has made huge strides in the last 25 years, there is still a long way to go.