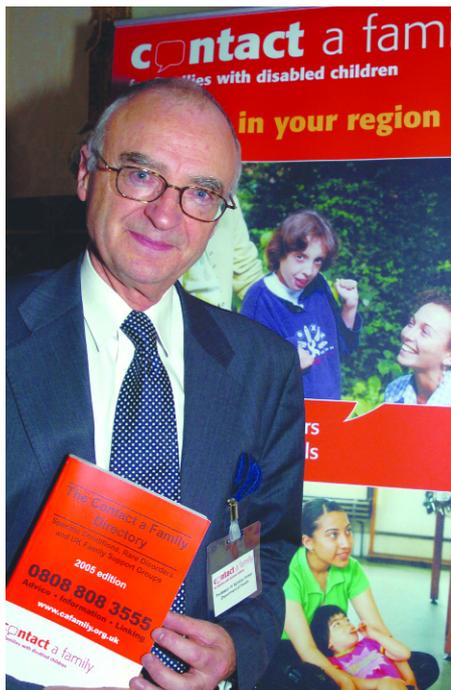


## National Clinical Director launches Directory of Rare Disorders

Announcing the publication of Contact a Family's Directory of Specific Conditions and Rare Disorders 2005, the Charity's new president and National Clinical Director for Children, Professor Al Aynsley-Green, described the publication as an essential resource for healthcare professionals and families.

Now in its fourteenth year, the Directory has been expanded to embrace recent medical developments. It includes 25 new entries on recently diagnosed rare conditions, a more detailed 'cancer' entry which highlights the malignancy risk associated with a range of conditions, and a section entitled 'Procedures and Management' which lists support groups to help people manage common symptoms and therapies. The Directory contains over 380 conditions and articles with all the relevant support groups.



All entries in the Directory, the only publication to collate information on a wide range of rare disorders, are written or checked by medical experts. A distinguished medical advisory panel provides guidance on editorial policy and direction.

Directories are available on 020 7608 8700 at £35 for the book; at £88.13 for a single-user CD-ROM which is updated quarterly; and at £29.38 for a single on-line user. To sample the 2005 directory, visit [www.cafamily.org.uk](http://www.cafamily.org.uk)

## Award winning neonatal transport team



Pictured from left are Claire Pettie, David Booth, Jenny Ashley, Luc Cornette, Claire Harness, Sophie Breheny, Collete Vicars and Lisa Auty.

In November 2004, the Yorkshire Neonatal Transport Team was voted one of the best public sector multidisciplinary teams in the country, during the annual Top Team Competition ceremony at Kensington Town Hall, London. The event is organised by the Public Services Management Network, and aims to find the best team in local government, public sector and partner organisations. There were nearly 50 submissions from England and Wales. The Yorkshire team came second out of seven finalists.

The team was highly commended for the service provided, their innovative team structure and the achieved outcomes.

### The service provided

In January 2002, the Yorkshire Region allocated sufficient financial resources to create a dedicated multidisciplinary Yorkshire Neonatal Transport Team, endeavouring to safely transport all newborn babies within Yorkshire. Its aims are:

- to keep newborns as close as possible to home
- to minimise trauma by demonstrating to parents that their critically ill newborn is in safe hands
- to establish a national example of clinical excellence within neonatal transport. Key components are:
  - up-to-date knowledge of safe neonatal transport principles;
  - professional excellence, i.e. communication between team members and parents
  - efficient service delivery, based on

collaborative working, motivation and good time management  
– strategic planning based on analysis of achievements versus ongoing needs

### Innovation and creativity

The team structure is unique, as it consists of 45 supernumerary nurses (+ medical lead), who are exclusively involved in neonatal transfers during each shift (24 hours service, 7/7 days).

Thought-provoking creativity was reflected in the team's "Stabilisation guidelines prior to neonatal transport" created by nurses and doctors from all hospitals within Yorkshire. The team has developed the first framework for clinical excellence within neonatal transport.

### Achieved outcomes

The team has achieved significant improvements in the overall outcome and survival for the sickest newborn infants within Yorkshire, by:

- increased speed of organising the neonatal transfer
- improved access to intensive care cots closer to home
- improved training and education of all staff within Yorkshire
- improved region-wide links within the neonatal service

The team has received many grateful comments from relatives and national recognition through media attention and presentations at meetings.

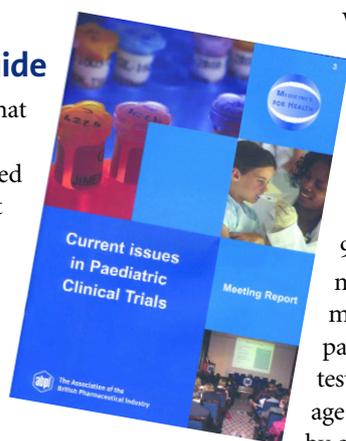
Dr Luc Cornette, Lead Clinician for the Yorkshire Neonatal Transport Service, commended the Transport Team for this achievement.

## ABPI publishes paediatric trials guide

Moves towards ensuring that children benefit from medicines especially tailored to their needs are spelt out in a new publication on paediatric clinical trials from the Association of British Pharmaceutical Industry (ABPI).

A clinical trial that involves children is one of the most difficult ethical, medical and regulatory issues for the pharmaceutical industry. The difficulty in conducting trials in young age groups is behind a current shortfall in the range of medicines specifically formulated for children.

The new book *Current Issues in Paediatric Clinical Trials*, which originated from a major meeting on the subject, examines the principle problems and offers some solutions. It features presentations from NHS R&D Director, Professor Sally Davies; Kedge Martin of patient group



Wellchild; Clinical Trial Ethicist, Dr Hugh Davies and Dr Julia Dunne of the Medicines and Healthcare products Regulation Agency (MHRA).

“Currently more than 90% of medicines used in newborns and 45% of medicines used in general paediatric care have never been tested or licensed for use in that age group and are used off-label by clinicians,” said Dr Richard Tiner, ABPI Director of Medicine.

“This situation needs to be changed but clinical trials in so many age groups are expensive, the market for companies is small and persuading parents to allow their children to participate is understandably difficult.”

***Current Issues in Paediatric Clinical Trials*, priced £10, is available from ABPI Publications. To order a copy, email: [publications@abpi.org.uk](mailto:publications@abpi.org.uk) or telephone: 020 7747 1446.**

## Analysis of vital signs set to improve outcome for premature babies

Fairy Non-Bio is supporting the work of BLISS by making a donation of £100,000. A large part of the funding will be invested in a ground-breaking research project, Vital Signs Monitoring, led by Professor Neil McIntosh from the University of Edinburgh.

Says Professor McIntosh: “The pilot project will help neonatal nurses and doctors diagnose deterioration in a baby’s vital signs more quickly and accurately. This will ensure that specialist treatment can be given as soon as possible, giving special care babies a better outcome.”

The project is a computer-based study to develop a patho-physiological pattern recognition software programme using algorithms based on data collected from over 2,000 premature babies. It will be able to spot downward trends in a baby’s vital signs more quickly and accurately and will enable clinicians/nurses to intervene before the situation could become acute.

Following successful completion, the system will be rolled out to hospitals across the UK. The research will take place over a three year period.

## UNICEF recognises breastfeeding progress at Royal Oldham

Newly-appointed UNICEF UK Ambassador Elle Macpherson presented the Royal Oldham Hospital with a Baby Friendly Award, in recognition of the hospital’s achievements in supporting mothers who want to breastfeed. Elle, who has been a long-term supporter of UNICEF, was shown around the hospital’s maternity unit and chatted with midwives and mothers.

“I’ve been so impressed by the commitment of the staff to the ideals of being baby friendly,” said Elle. “It is clear to me that it has made a difference to mothers who give birth here.”

Breastfeeding levels in the Royal Oldham Hospital were very low in 1994 before the Hospital started working towards the standards required to become Baby Friendly. Initiation rates were 29% but almost all mothers stopped breastfeeding within the first four weeks. By 2004, 64% of new mothers were



starting to breastfeed, and four weeks later 40% were still doing so.

Val Finigan, Infant Feeding Advisor for Oldham, who has led the hospital through the process of becoming Baby Friendly said: “I’m so proud of all the maternity staff here. It is not easy to keep standards up to the level required to become Baby Friendly, but they have managed it now for five years. “All the hard work pays off when you hear a new mum telling the midwife how wonderful she has found the experience of breastfeeding her baby, thanks to the help she received in hospital. It is only right that every mother should be offered that level of care.”