



**Andy Cole**

Chief Executive  
BLISS – the premature  
baby charity

## BLISS – Changing priorities to meet new challenges

Since BLISS was set up as a charity by a group of concerned parents 27 years ago, nearly £20million has been raised towards our work helping premature and sick babies. Although our work has undergone changes in focus and direction to adapt to the changing environment and needs of neonatal services, our overarching aim remains – ‘to ensure the best possible outcomes for premature and sick babies’ – and our work is as relevant now as it was three decades ago.

In the early days, BLISS’s primary aim was to raise funds to buy urgently needed neonatal equipment and much of this equipment is still in operation and helping babies in units across the country. The Blue Peter Appeal in 1999 resulted in £500,000 that was spent on two dedicated neonatal ambulances that are now being used to transport babies needing intensive care in North East England and West Scotland.

More recently, our priorities have changed to reflect the fact that a cot in a special care unit is worth very little if there is no nurse to staff it and provide the vital specialist care needed. Advances in technology and increased medical knowledge mean more babies now survive than ever before, but unless the shortage of resources for the service is urgently addressed, mothers and babies will continue to be transported hundreds of miles to find a staffed cot in a unit with the right facilities.

We know that all the equipment in the world won’t resolve this situation. We now work closely with government and other decision-making bodies to call for changes in policy that will see more resources dedicated to neonatal care so that premature and sick babies have the best possible outcomes. In the last two years, we have seen some tremendous successes. Our annual Baby Reports<sup>1,2</sup> have charted the state of neonatal care over the last three years, bringing the crisis into the limelight and championing recommendations of ways it can be improved. More recently, we have launched *Action for BLISS*, our campaign network that uses creative ways to get BLISS supporters directly involved in our campaigning activities, and with the policy-makers themselves.

But it is not only these decision-makers that can help us achieve our goals: close contact with medical professionals working in all areas of neonatal care has made us aware of the changes in practice and areas for development that would most benefit babies and their families. In the past twelve months alone, we have funded five major research projects including a three-year neonatal

nursing research fellowship in conjunction with the National Perinatal Epidemiology Unit; a three-year project to develop intelligent software to monitor vital signs of babies in a NICU; and the development of a simulation unit for training purposes. Our discussions with professionals have shown that, despite the progress that is being made in terms of technical advances and knowledge, the spread of new trends and changes in practice can be slow. We are helping to address this situation in a variety of ways, including training opportunities through study days to update knowledge and practice and a three year project to share the learning from the *Confidential Enquiry into Stillbirths and Deaths in Infancy* conclusions on best practice in units.

Developmental care is a particular area of interest for BLISS and many of our clinical colleagues have spoken to us about the importance of this new approach and its potential to improve outcomes for babies. There is evidence that consideration of the comfort, sensory, emotional and relationship needs of babies whilst receiving intensive care can have a dramatic impact on the developmental prognosis for babies born sick or premature. Despite this, our 2005 report *Special care for sick babies... choice or chance?* showed that only 24% of units in the UK had a member of staff trained or being trained in the approach and less than half of units said they had identified a lead person who would promote the approach. BLISS is developing a programme of work which includes reviewing current literature on developmental care, exploring and evaluating developmental care training (including the NIDCAP (Newborn Individualized Developmental Care and Assessment Program) approach to developmental care), and creation of a virtual support network for people interested in promoting developmental care.

Providing support and information for families has been a priority for BLISS from the very beginning and we are always actively seeking to reach more parents and particularly those from communities most at risk of premature birth. As well as information and advice available via our website, publications, local branches and family days, all parents who have a baby admitted to a neonatal intensive care unit should now receive a free copy of the BLISS Parent Information Guide. In addition we have just been awarded a substantial three-year grant from the Department of Health to translate the guide into other

### References

1. **Green, B.** Special care for sick babies... choice or chance? BLISS 2005.
2. **Robinson, E.** Weigh less, worth less? BLISS 2006.

languages. Another way we are reaching parents is through POPPY (Parents of Premature babies Project – Your needs). This is a three-year collaborative research project with the National Childbirth Trust, the Royal College of Nursing and the National Perinatal Epidemiology Unit, which aims to find effective ways of giving information and support to parents of premature babies, and in particular asking parents what they find most useful. We also provide invaluable confidential advice and support via our helpline and parent-to-parent support network, and we are indebted to a dedicated core of volunteers without whom none of this would be possible. All our services for families are free and we would encourage every neonatal unit to make use of them.

This is a very exciting time for BLISS. We are extremely proud of what we have achieved over the last 27 years, whilst being firmly focused on the future and the many challenges that lie ahead. Premature births are on the increase in the UK and there is still much for us to achieve. We have every intention of continuing our work for at least another 27 years, helping those babies born too small, too soon or too sick to cope on their own.

## STOP PRESS

On Tuesday 17 April, BLISS published *Special Delivery or Second Class: are we failing special care babies in the UK?*, which reports on the continuing issues of lack of capacity, nursing shortfalls, closures and transfers in neonatal services. The new report shows that the service is further than ever from achieving recommended staffing ratios, and that closures and inappropriate transfers are still happening on a regular basis. The research indicates that units are understaffed by an average of over a third, and that there is great pressure on capacity in intensive care units in particular. The 129 units that reported having to close once or more in a six month period were shut to new admissions for an average of 24 days and for anything up to 112 days, due to a lack of staffed cots. We are concerned that these shortages could mean that more babies needing intensive care are now being treated in units without the facilities to give it.

In the report, we make a number of recommendations, including the following:

- Instigate a ten year plan to build capacity in line with the projected growth in birth rates.
- Implement a Payment by Results tariff for all levels of neonatal care and a separate tariff for neonatal transport so that long term financial plans can be put in place to increase investment in both areas.
- Mandate the implementation of staffing standards as outlined by BAPM in 2001.
- Develop a long term strategy to increase the recruitment and retention of neonatal nurses.

To coincide with the launch, BLISS took a group of parents of premature babies to meet Professor Sir Al Aynsley-Green, Children's Commissioner for England, to talk about their own experiences of having a baby on a neonatal unit. Among the issues raised at the meeting were long-distance transfers and the trauma and upset they cause, the isolation and guilt felt by some mothers, and the financial hardship and strain on relationships that parents sometimes experience.



**UKAMB**  
United Kingdom Association  
for Milk Banking



### Renowned International and National Speakers Including:

Dr Lois Arnold (USA)  
Anne Hagen Grovslien (Norway)  
Frances Jones (Canada)  
Dr Camilla Kingdon (UK)  
Dr Alison Leaf (UK)  
Dr Peter McCormick (Child Advocacy International)  
Professor Guido Moro (Italy)  
Professor Guy Putet (France)

# International Human Milk Banking Conference

Thursday 20th and Friday 21st September 2007

Venue: The Racecourse Conference Centre In The Historic Roman City of Chester

In celebration of 10 years of  
**Making Every Drop Count**

[www.ukamb.org](http://www.ukamb.org)

Donor Milk and the Protection and Promotion  
of Breastfeeding

Human Milk Banking Regulation

New Technologies in Milk Banking

European and wider International Milk Banking Issues

Safety and Risk Management

Using Donor Milk on the NICU -  
When, Why and How



Further details available from Gillian Weaver: [info@ukamb.org](mailto:info@ukamb.org) | [www.ukamb.org](http://www.ukamb.org) | 020 8383 3559

Posters Welcomed