

Three decades and counting – Bliss' 30th birthday Baby Report

A look at Bliss' significant achievements and the progress of neonatal care over the last 30 years, as well as some insight into what needs to be done to ensure the best possible outcomes for babies born sick or premature in the future.

This month special care baby charity Bliss turns 30. To mark the occasion they are releasing a report on the changes in neonatal care over 30 years and the constant battle for more resources to ensure the best outcomes for babies, born sick and premature, and their families.

Each year around 80,000 babies are born in need of specialist neonatal care. This represents 11 per cent of all babies born in the UK. This means that, on average, one baby is admitted to neonatal care every six minutes. The birth rate is increasing, and more babies are being born prematurely and surviving than ever before. This puts additional strain on the already understaffed and over-stretched services that provide care to our most vulnerable babies.

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Bliss
for babies born too soon,
too small, too sick

From the beginning

In August 1979, when neonatal care was in its infancy, *The Daily Telegraph* published a story on the lack of resources for specialist baby units¹ (FIGURE 1). Dr Donald Bartrop told *The Daily Telegraph*:

"The premature baby may live but unless he receives adequate care, may suffer serious brain damage and multiple handicaps for life... To care for a severely handicapped individual for a 50 year life could cost at least £250,000. A sum like this would cover all annual revenue expenses for optimal perinatal care within a district."

The following week a letter appeared in *The Daily Telegraph* suggesting the setting up of a society to raise funds to buy life-saving equipment and to pay for the training of specialist staff. From this, Bliss was born². The aim of the charity was, and still is, to give every baby an equal start in life and to ensure that vital equipment and specialist care are available to every baby who needs it.

Within five years, Bliss had raised nearly £750,000 and 82 hospitals had received donations of specialist neonatal equipment (FIGURE 2). It was around this time that Bliss published the results of its first national survey of neonatal care³. It branded services as "inadequate and haphazard". It found that there was at least a 50 per cent shortfall in the provision of skilled nursing care in some units – based on the British Paediatric Association's recommendations.

In 1988, the Royal College of Physicians released a report entitled 'Medical Care of the Newborn in England and Wales'⁴. This recommended coordinating the care of babies regionally, in what would become known as managed clinical networks.

1990s

The 1990s heralded two of the most significant improvements in treatment for premature babies. These were the introduction



FIGURE 1 The Daily Telegraph article which acted as a catalyst for the formation of Bliss.



FIGURE 2 Very early neonatal incubator being donated by Bliss.



FIGURE 3 Baby being given light therapy for jaundice at UCLH in 2009.



FIGURE 4 Modern day incubator, baby being given routine checks by staff at UCLH.

of surfactant and antenatal steroids. These two advances led to many more premature babies surviving and going on to have better outcomes.

In 1993, the Audit Commission Report ‘Children First’ marked the beginning of a series of detailed local audits of hospital services for children in England and Wales⁵. The report argued that the service should monitor the outcomes for children who needed neonatal care, so that techniques could be improved and research carried out into better treatments. To coincide with this, Bliss published another survey of neonatal resources⁶. It found that two-thirds of neonatal equipment on units had been donated by charities and it highlighted a worrying shortage of neonatal nurses.

In 1996, the British Association of Perinatal Medicine (BAPM) published its ‘Standards for Hospitals Providing Neonatal Care’⁷. This was in answer to previous guidelines being criticised for a lack of evidence backing up their recommendations. These standards set out the reasons why a nurse caring for a very sick baby should not have to look after another baby at the same time.

2000s

In 2000, Bliss donated equipment worth over £2 million and spent several hundred thousands of pounds on nurse training, research and supporting families. However, Bliss could not keep up with the demand. During this year, Bliss donated ten essential incubators to one London hospital and ran a media campaign highlighting the extent to which units across the country were reliant on charity for their equipment. The story made the front page of the *Daily Express*, and resulted in an additional £6.5 million influx into neonatal care⁸. From this point, Bliss started to reduce the amount of money it spent on equipment, and instead focused on funding more professional training and long-term research into innovation projects. The charity also took the decision to put more resources into raising the profile of neonatal care and issues within the Government.

In 2001, BAPM revised its 1996 standards on how neonatal care

should be provided⁹. The new standards set out clearly that any baby needing intensive care should receive one to one nursing care as a minimum. These standards still apply today, yet due to staff shortages only around a third of all units in the UK are able to meet them.

In 2003, a comprehensive review of neonatal care was carried out by the Department of Health which Bliss was involved in¹⁰. The review came up with £72 million to assist with the introduction of dedicated networks. Following the review, Bliss decided to try and monitor how the £72 million was being invested, and started a programme of reports looking at how care services were improving.

In December 2007 however, the National Audit Office (NAO) released findings of an audit of the reconfiguration of neonatal services, which found that it wasn’t possible to account for all of the £72 million investment from 2003¹¹. It also found that staff shortages constrained the amount of care that services could provide. An accompanying study revealed that 78 per cent of neonatal units in the UK had to turn babies away in 2006; an eight per cent increase from 2005¹².

Following this, at a meeting of the Parliamentary Public Accounts Committee, the Chief Executive of the NHS was asked to respond to these criticisms. As a result, the NHS Neonatal Taskforce was assembled to address the various problems that had been highlighted by Bliss and the NAO.

Over the last 18 months the Taskforce has undertaken the most comprehensive review of neonatal care in Bliss’ lifetime, and is the best opportunity there has ever been to raise neonatal care services up to the standard that sick and premature babies and their families deserve (**FIGURES 3 and 4**).

The services that care for sick and premature babies have been the subject of many reports and reviews over the last 30 years¹³⁻¹⁹. These have often had common findings and recommendations which have never been fully implemented.

This year should be the last year that we have to argue that babies have the same right to high-quality care as everyone else. The NHS Neonatal Taskforce recommendations should be fully

implemented and the Government should act now and put the appropriate resources in place to ensure the best outcomes for our most vulnerable babies.

Bliss' vision for the future

Looking ahead Bliss will aim to ensure every baby is treated as an individual and with dignity, that care decisions are based on the baby's best interest with parents actively involved as partners in the baby's care, and that babies receive the nationally recommended level of specialist care in the unit nearest their family home. We will also aim for units to encourage parents to be involved in plans for continuous service improvements, ensure parents are informed guided and supported, that breast milk expression and breastfeeding are encouraged and that discharge planning is facilitated from admission to discharge home, to ensure baby and family have the appropriate care and resources.

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Don't miss this opportunity! We look forward to welcoming you to Durban, South Africa, and our warm friendly rainbow nation.

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