

Bliss Baby Charter Conference

Driving innovations in
family-centred care

12 March 2018

Park Inn by Radisson Manchester



Bliss
for babies born
premature or sick

About Bliss

Bliss is the leading UK charity for babies born premature or sick. We were founded in 1979 and we exist to give babies the best chance of survival and quality of life by:



Supporting parents to be as involved as possible in care and decision-making for their babies when they are in neonatal care.



Supporting neonatal professionals to deliver high quality care and involve parents actively in their babies' care.



Placing premature and sick babies' voices at the heart of decision-making to ensure their best interests are always put first.



Enabling research that can tangibly improve care for babies born premature or sick.



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Welcome



I am delighted to welcome you to the Bliss Baby Charter Conference, a national event designed to bring together health professionals from across the UK to showcase excellence in neonatal care and provide opportunities to learn how best to increase parental involvement in their babies' care.

Bliss has a long history of putting parents at the heart of their babies' neonatal care, and it is enormously encouraging to have seen such rapid progress, over recent years, in a new national and local focus on ensuring that parents can truly be parents on the neonatal unit. Indeed, having launched the original Bliss Baby Charter in 2005, it is with great pride that we are now supporting the majority of neonatal units across the country to work through the audit toolkit to achieve the Bliss Baby Charter standards.

Today's event forms a core part of our strategic objective to support neonatal professionals to deliver high quality family-centred care and to involve parents actively in their babies' care. I hope you enjoy the day and that you take away some key insights to inform your practice back at your unit; and also that you learn more about how Bliss can continue to support you and your colleagues in our shared vision: that every baby born premature or sick in the UK has the best chance of survival and quality of life.

Caroline Lee-Davey
Chief Executive



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bliss.org.uk

The Bliss Baby Charter – driving change in neonatal care

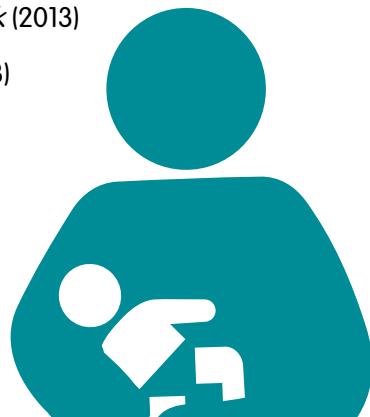
The Charter's role

The Bliss Baby Charter was designed to standardise high quality family-centred care across the UK. It is a practical framework for neonatal units to assess their practice against a set of seven core principles and develop meaningful improvements that benefit babies and their families.

The Charter's reach

The Bliss Baby Charter is a nationally recognised and endorsed tool to drive improvements in family-centred care. It is an integral part of the current Neonatal Critical Care Transformational Review and referenced in:

- BAPM, *A Framework for Neonatal Transitional Care* (2017)
- BAPM, *Neonatal Service Quality Indicators* (2017)
- NHS England Quality Surveillance Neonatal Peer Review (2017)
- Neonatal Care in Scotland, *A Quality Framework* (2013)
- *All Wales Neonatal Standards*, 2nd edition (2013)



As of January 2018, over 160 neonatal units are working towards Bliss Baby Charter accreditation.

80% of units currently engaged

The Charter's impact

Three neonatal units are currently Bliss Baby Charter accredited:

- **Frimley Park Hospital, Frimley (July 2017)**
- **Queen Alexandra Hospital, Portsmouth (October 2016)**
- **The Princess Anne Hospital, Southampton (May 2016)**

The Charter continues to drive changes in units across the UK:

- West Middlesex University Hospital, London, gave free parking to parents.
- The Jessop Wing, Sheffield, are using funds raised by The Sheffield Hospitals Charity to invest in updating their family room.
- Frimley Park Hospital, Frimley, trained staff members to provide dedicated emotional support to families.
- St Richard's Hospital, Chichester, have developed teaching boards on pain management and understanding behavioural cues.

View more examples and share your own at bliss.org.uk/baby-charter

The Charter's future

The Baby Charter will evolve in response to emerging needs and research, and we're committed to keeping it on the national political agenda. The quality of support available to units will continue to develop with greater opportunities for sharing excellence. With your engagement and determination, we can create a neonatal model of care where the family are consistently and expertly involved.

Morning

09.00 Registration

Welcome refreshments and exhibition

09.30 Welcome

Caroline Lee-Davey Bliss Chief Executive
Zoë Chivers Bliss Head of Services

10.00 Family-centred neuroprotective care – why is it taking so long?

Inga Warren Senior NIDCAP Trainer, Author and Co-Director of FINE

10.45 Getting the best for babies from our neonatal services

Prof. Neil Marlow Professor of Neonatal Medicine

11.30 Refreshments, exhibition and networking

11.50 Bliss Baby Charter – where does organ donation fit in?

Dr Joe Brierley Consultant Critical Care and Director of Paediatric Bioethics at Great Ormond Street Hospital (GOSH)

12.35 Parent speaker

Jenny Vaidya

13.00 Lunch, exhibition and networking

Afternoon

14.00 Workshop sessions

Co-creating a neonatal communication tool with parents

Susanna Sakonidou MBBS, MRCPCH NIHR Clinical Research Fellow and Paediatric/Neonatal sub-speciality trainee doctor

“I thought I was going mad”: Perinatal mental health, parents and the NICU experience

Sasha Barber Fellow of the Institute of Health Visiting, Mental Health and Bereavement Lead, Women and Children’s Health Southmead Hospital

Family and Infant Neurodevelopmental Education (FINE): Will it work for you?

Inga Warren Senior NIDCAP Trainer, Author and Co-Director of FINE

Making it happen: Involving families and engaging staff

Neil Patel Consultant Neonatologist at the Royal Hospital for Children Glasgow

Palliative care – getting it right for babies and families

Alex Mancini Pan London Lead Nurse for Neonatal Palliative Care Chelsea and Westminster Foundation Trust and the True Colours Trust

15.25 Refreshments, exhibition and networking

15.45 Getting to accreditation

Panel discussion

16.15 Neonatal Excellence Awards

16.45 Reflection and close

Lectures

Chairs' welcome and opening remarks



Caroline Lee-Davey is Chief Executive at Bliss. She sits on the Executive Committee of the British Association of Perinatal Medicine (BAPM) and is a member of the Independent Advisory Group for the Maternal, Newborn and Infant Clinical Outcome Review Programme. Caroline is also a trustee of Crisis, the national charity for homeless people.



Zoë Chivers is Head of Services at Bliss. She oversees our research, information and support, and the training and development work we do with health professionals through the Bliss Baby Charter. Zoë also represents parents' views on NHS groups such as the Neonatal Critical Care Clinical Reference Group.

Family-centred neuroprotective care – why is it taking so long?

- Describe core themes of successful family and infant centred developmental care (FICDC)
- Identify the core skills needed to translate FICDC theory into good practice
- Recognise barriers that make it difficult to deliver FICDC and potential solutions



Inga Warren is a Senior Trainer with the UCLH NIDCAP Centre. She has many years' experience as a Paediatric Occupational Therapist and a Neonatal Developmental Specialist and has international experience as a lecturer, trainer and researcher. She is co-author of *Caring for your Baby in the Neonatal Unit; a Parents' Handbook* and she works with Bliss to deliver the Family and Infant Neurodevelopmental Education (FINE)

programme in the UK and around the world. She has a few more projects in the pipeline, including photography projects and a new book for parents at home with their baby.

Getting the best for babies from our neonatal services

- Understand current neonatal service pressures
- Learn where the review is up to
- Consider options available to improve the service



Neil Marlow is Professor of Neonatal Medicine at University College London and Chair of the NHS England Neonatal Critical Care Clinical Reference Group and NHS England Neonatal Transformation Review. Before UCL, Neil spent 11 years as Professor of Neonatal Medicine at Nottingham University and 7 years as Senior Lecturer in Bristol. He is an Honorary Consultant in the University College Hospital

Neonatal Service and provided advice to the Department of Health on the Toolkit for High Quality Neonatal Services. Neil's major academic interests are in long-term outcomes following prematurity and he is the Director of the MRC-funded EPICure studies (epicure.ac.uk).

Bliss Baby Charter – where does organ donation fit in?

- Learn how organ donation should be considered as a usual part of end-of-life care planning at all ages
- Understand the different modes of death certification and organ donation, and the ethical and legal aspects of this
- Know the history of organ donation from babies in the UK, hear the voices of parents and understand cultural and spiritual issues in donation



Joe Brierley provides critical care for neonates and children at Great Ormond Street Hospital. Joe is the lead on bioethics for the RCPCH's Ethics and Law Special Interest Group and Child Health Ethics and Law Special Interest Group (CHELSIG). These groups seek to explore ethical and legal issues affecting children's healthcare. Joe was previously President of the European Society of Paediatric and Neonatal Intensive Care

(ESPNIC) and lead for the speciality EPIC Diploma (European Paediatric/Neonatal Intensive Care diploma).

Workshops

Workshop 1

Co-creating a neonatal communication tool with parents

- Parent engagement and the role of social media
- How quality improvement methods can support parent co-design
- Stakeholder engagement - do I have the right people?

Led by: Susanna Sakonidou

Workshop 2

"I thought I was going mad": Perinatal mental health, parents and the NICU experience

- Understand the role of the health visitor in supporting families with babies in NICU
- Identify risk factors for becoming mentally unwell in the perinatal period and clinical signs and symptoms of the most common perinatal mental illnesses
- Learn about psychosocial interventions that can help prevent mental illness and support and promote good mental health

Led by: Sasha Barber

Workshop 3

Family and Infant Neurodevelopmental Education (FINE): Will it work for you?

- Recognise gaps in knowledge and skills, across all disciplines, that hamper FICDC
- Identify areas of your own practice that you would like to develop
- Describe how the FINE pathway meets diverse educational needs

Led by: Inga Warren



Workshop 4

Making it happen: Involving families and engaging staff

- Develop practical ideas to achieve change and implement the Baby Charter
- Appreciate the importance of empowering families and staff
- Identify and share real-life examples of innovative practice in family-centred care

Led by: Neil Patel

Workshop 5

Palliative care – getting it right for babies and families

- An understanding of a multi-disciplinary approach to neonatal palliative care
- Develop plans for your unit to deliver equity of care for babies and families
- Identify gaps in unit practice in line with the Bliss Baby Charter

Led by: Alex Mancini

Bliss' Neonatal Excellence Awards

Bliss' Neonatal Excellence Awards will recognise and celebrate outstanding individuals, teams and projects that make a difference to babies born premature or sick through delivering high quality family-centred care as part of the Bliss Baby Charter.

The award categories are:

- ★ Parents' Choice sponsored by Mothercare
- ★ Project of the Year sponsored by Chiesi
- ★ Team of the Year sponsored by Pampers

Sponsors and exhibitors



Pampers

Platinum sponsor

Last year, Pampers launched the smallest ever nappy, the Pampers Preemie Protection Size P3, and have so far donated 100,000 to neonatal units across the UK and Ireland. Available in sizes P1, P2 and P3 the nappies are the result of an in-depth study, where neonatal nurses told Pampers existing nappies did not fit the smallest babies, so often had to be cut and folded to size. The new nappies offer a customized fit and have been designed for babies who weigh from 1.8-5lbs. Email pampers.preemie@sykes.com to get a free supply for your hospital. pampers.co.uk

mothercare

Mothercare

Gold sponsor

Mothercare produce a premature baby clothing range (available from 3lb) which is available in selected stores and online with free home delivery. Mothercare have a long standing relationship with Bliss, which was strengthened this year with Bliss being voted as their Charity of the Year. mothercare.com



Chiesi Limited

Silver sponsor

Chiesi Limited is part of the Chiesi group, an international family-owned company with more than 80 years of experience focussing on research, development, production and marketing of innovative prescription medicines in the field of respiratory, neonatology, transplant medicine and rare diseases. Chiesi is committed to improving patient outcomes and quality of life.

Chiesi has provided sponsorship to cover the provision of exhibition space and Project of the Year Award. chiesigroup.com



Central Medical Supplies

Bronze sponsor

Central Medical Supplies Ltd (CMS) are the exclusive distributor for Ameda® breastpumps and breast feeding equipment.

Ameda® offer a range of breastpumps suitable for both hospital and personal use. The Ameda® pumpsets contain a unique silicone diaphragm that creates a barrier protecting the pump and collected breastmilk from potential viruses and bacteria.

Ameda® are launching the new Finesse™ Double Electric Breastpump – a sleek, reliable pump inspired by Ameda's® hospital technology. ameda.com

Solus

Bronze sponsor

Solus Medical Ltd is an award winning business selling, distributing and servicing medical products and equipment to hospitals and homecare communities across the UK. They supply a wide range of specialist neonatal and paediatric products, including one of the leading High Flow Therapy systems. They also have expertise in pioneering drug delivery systems, home care respiratory solutions and fluid/patient warming for Neonatal, Paediatric and Adult Critical Care.

Solus Medical Ltd are committed to offering fantastic service from initial queries and product expertise to servicing support and training. solusmedical.com

Child Bereavement UK supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement. They provide a range of training, consultancy, support services, publications and resources. childbereavementuk.org/training

The Lullaby Trust provides emotional support for bereaved families, promotes expert advice on safer baby sleep and raises awareness of sudden infant death.

Working with the NHS they run a national health-visitor service for bereaved parents, which supports families before and after the birth of their baby. lullabytrust.org.uk

Sands, the UK's stillbirth and neonatal death charity, supports anyone affected by the death of a baby, works in partnership with health professionals to ensure bereaved parents receive the best possible care, and promotes and funds research to reduce the loss of babies' lives. sands.org.uk

Tamba (Twins and Multiple Births Association) is a UK charity supporting and campaigning for multiple birth families. Multiples make up 1.5% of pregnancies and 3% of births but account for 7% of stillbirths and 14% of neonatal deaths.

Tamba provides information and support to both families and health professionals, including bereavement support. tamba.org.uk

NNA (Neonatal Nurses Association) is a national organisation representing neonatal nurses in the UK and abroad. They help to shape government policies and services for neonatal nurses and also the care structure for neonatal families and carers. nna.org.uk



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Developmental Care



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