

# Exploring the current research agenda to reduce SIDS



The Lullaby Trust Annual Grantholders' Meeting, London, 22 September 2016

This year in the UK, we saw sudden infant death syndrome (SIDS) rates fall to an all-time low. While this is to be celebrated, babies and toddlers continue to die in their sleep without explanation, motivating research teams across the country to try and identify the causes of SIDS.

The Lullaby Trust was set up 45 years ago to investigate the causes of SIDS and how best to prevent babies dying. The charity has allocated nearly £12 million towards key research projects, which in turn has been translated into evidence-based advice for parents. In September, the charity held its Annual Grantholders' Meeting to showcase research currently being undertaken.

**Dr Andrew Boon**, Chair of The Lullaby Trust's Scientific Committee, opened the meeting by setting the scene. He highlighted a significantly higher SIDS rate in babies born to young mothers or those born prematurely or at low birth weight. He reiterated that more should be done to target specific groups with SIDS reduction

advice and that research was needed to understand the physiological mechanisms that take place leading to sudden death in infants.

Professor of Anthropology at Durham University **Dr Helen Ball** presented interim findings on a feasibility study on the use of infant sleep boxes entitled 'A new approach for improving infant sleep-sharing safety'. This study uses a shallow plastic box, similar to those successfully introduced in New Zealand, to provide a safer, more mobile place for babies to sleep close to their parents, potentially in the adult bed. The study is looking at whether parents will use the boxes and whether this has an impact on decision making in relation to co-sleeping. This study is important given the huge interest in so-called safer sleep enablers, such as baby boxes. The Lullaby Trust is currently counselling caution about the use of such products until evidence emerges that they are safe.

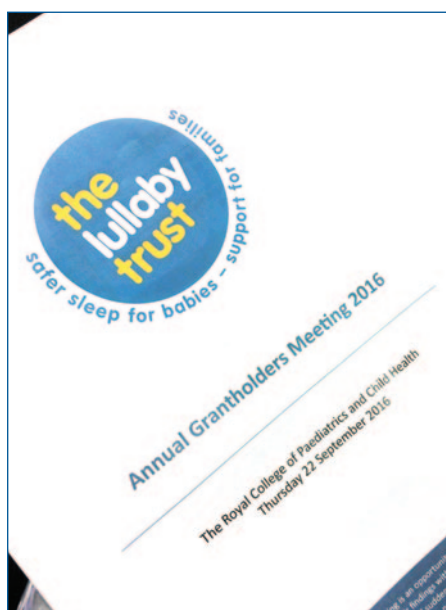
**Professor Peter Fleming** introduced an innovative study that has just begun in Bristol; the Oto Acoustic Signals Investigation Study (OASIS). The study looks at developmental brainstem physiology and epidemiology and the possibility that this provides potential clues to the risk of unexpected infant deaths. Almost all babies born since 2007 in England have newborn hearing screening, which includes recording the wave-form. The study will compare results between SIDS cases and controls, and use the results to assess the potential value of otoacoustic emissions (OAE) screening as part of a risk scoring system for sudden unexpected death of an infant (SUDI). The team is also investigating the relationship between maternal smoking and other known risk factors and OAE findings.

**Dr Anna Pease** reported on results from her PhD, focussing on how disrupted routines can influence decision making for infant care. Existing evidence shows an increased risk for infants that sleep in positions or environments that they are unaccustomed to and Dr Pease's research

looked at why the changes in routine took place. Dr Pease said disrupted routines happen for many reasons, and urged professionals to give advice that takes account of the need to plan for these scenarios to ensure safer sleeping.

**Dr Victoria Bryant** from Great Ormond Street Hospital has commenced work on a study looking at sudden unexpected death in childhood. This considers the characteristics and autopsy findings for children over the age of 12 months who died suddenly. The considerably smaller number of unexplained deaths in older children compared to SIDS means this group have not been the subject of much research. This study attempts to address this by using the extensive autopsy database held at Great Ormond Street. While in its early stages, the study is considering three emerging areas: hippocampal malformations, sudden cardiac death and possible hidden sepsis.

**Dr Robert Coombs** considered the prevalence of long QT syndrome gene variants in SIDS. This study has been



The Lullaby Trust Annual Grantholders' Meeting took place at The Royal College of Paediatrics and Child Health, London, on 22 September 2016.



Chief Executive of The Lullaby Trust Francine Bates.



Dr Robert Coombs.

recruiting families for several years and looking at identified gene variants and those that are potentially relevant for SIDS. The study is due to complete next year and findings are still to be analysed, however, it is clear that SIDS is not caused as a result of a single gene disorder.

Chief Executive of The Lullaby Trust **Francine Bates** presented the work of the Global Action and Prioritisation of Sudden Infant Death (GAPS) study led by The Lullaby Trust. The charity worked with other SIDS organisations across the world to identify future research priorities into SUDI. Two key themes emerged. Firstly, the

biological cause of SIDS is still not understood and work in this area must continue in order to solve the mystery of why some babies succumb to SIDS. Secondly, there is more to be done to reach out to high risk families who do not follow safer sleep advice. Findings of the study will be published later this year.

Finally, special guest speaker **Ruth Gilbert**, Professor of Clinical Epidemiology at University College London, Great Ormond Street Institute of Child Health, highlighted the importance of systematic review. Professor Gilbert demonstrated that long-standing published evidence of

the risk of SIDS to infants that slept in the prone position failed to emerge as quickly as it should have done across the world. This was because of the failure to use systematic review methodology.

## Jenny Ward

Director of Services, The Lullaby Trust

The next meeting of The Lullaby Trust Grantholders will be held in September 2017.

Contact The Lullaby Trust at [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)

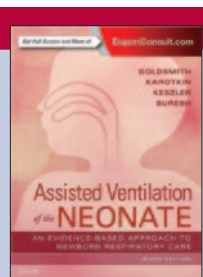
## Book review

### Assisted Ventilation of the Neonate: An Evidence-Based Approach to Newborn Respiratory Care, sixth edition

Jay P. Goldsmith, Edward Karotkin, Martin Keszler, Gautham Suresh Elsevier, November 2016

ISBN: 9780323390064

£64.99, hardcover



I set out to review this book with some trepidation. It is more than 500 pages long and the author list reads like a *Who's Who* of American neonatologists (with a couple of Canadians and Australians added for good measure). The first edition was published back in 1981 but neonatal care has come a long, long way since then. So do we need a book on ventilation, when avoiding ventilation seems to be our main goal these days?

The book is divided into five sections and the first thing that struck me was the breadth of relevant topics to the whole of neonatal respiratory medicine including quality improvement, ethics, physiology, cardiovascular assessment, oxygen, pharmacology, bronchopulmonary dysplasia, transport, extracorporeal membrane oxygenation, neurological effects, developmental outcomes, surgical management... and ventilation. Phew!

This book is a reference book, not a series of guidelines. Reading it will

definitely strengthen knowledge, regardless of experience, and nurses will find this as useful as doctors. However, inevitably, readers will sometimes find themselves at the mercy of the author. For example, I found a discussion on nasal high flow in chapter 27 (Respiratory Care of the Newborn) based on rather dated references (the latest being from 2008); the author is clearly not a fan. Yet in chapter 17 (Non-invasive Respiratory Support) two important studies on high flow from 2013 are mentioned. Many other chapters do have recent references and discuss hot topics, such as newer ways of delivering surfactant, and overall the balance is excellent and relevant for UK practice.

Key studies are reviewed well. I loved the chapters on blood gases and oxygen, and the depth and discussion is impressive in places. The book also tackles controversies, such as whether morphine should be routinely used in the ventilated baby; babies are routinely sedated for ventilation

in the UK, yet the book points out that there is limited evidence for this (best avoid ventilation if possible – saves making tricky decisions like this!) However, the book emphasises that there are many things neonatal health care professionals don't know, even if we think we do. I therefore really enjoyed the discussions in many chapters on the limitations of evidence.

The tables are generally excellent and there are useful diagrams, photographs, charts and references. The diagrams and photographs are a mix of colour and black and white although there could have been more colour photographs. There is also access to a complementary online version with references.

So do we need a book on neonatal ventilation in 2017? The answer is a resounding yes. Arguably even more so as our increasingly deskilled neonatal workforce (at all levels) needs updated knowledge to make good decisions on when and how to use ventilation correctly. This book covers the whole of neonatal respiratory medicine, not just ventilation, and despite its US-centric nature it is a valuable and comprehensive resource. Recommended!

**Peter Reynolds**

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