



The Lullaby Trust Strategy 2015-2020

Introduction

This document sets out our updated strategy for The Lullaby Trust following a mid-term review by the Board of Trustees in October 2016.

This strategy comes at a critical time as emphasis is rightly placed on improving public health, combined with a renewed drive to address health inequality and calls from the child health community to tackle preventable infant and child mortality rates in the UK.

Who we are and our proud track record

The Lullaby Trust was founded in 1971 as The Foundation for the Study of Infant Deaths to fund research into the causes of sudden infant death at a time when there were over 2,000 infants dying suddenly and unexpectedly each year in England and Wales. Now the figure for England and Wales has reduced to approximately 500 deaths. Of these deaths over half remain unexplained after post mortem/ referral to the coroner and are registered as Sudden Infant Death Syndrome (SIDS) or Unascertained. Sadly SIDS, also known as Cot Death, is still the most common cause of death in babies between the ages of one month and one year.

Over the years, the charity has spent £12 million on scientific research. We have made a significant contribution to understanding the possible reasons for why some babies die and have been pivotal in reducing the rate of SIDS by 85% since the 1990s. We launched a national “Reduce the Risk” campaign alongside the government’s own Back to Sleep campaign and transformed safe baby care practices in the UK. This has saved an estimated 19,000 babies lives.

Our previous Strategy 2012-2015

In 2012, the Board of Trustees developed an ambitious strategy for the charity setting out our four key objectives. These were:

- To maintain research funding into the causes of unexpected infant death
- To provide universal and evidence based information to all parents and key professionals on how to reduce the risk of Sudden Infant Death Syndrome (SIDS)
- To raise awareness of the continuing numbers of unexpected infant deaths and SIDS in particular
- To provide specialist support to bereaved families who experience the unexpected death of a baby whether the cause is known or unknown

Believing we could do much more to reduce SIDS, we set ourselves the goal of reducing the number of babies dying in the UK, from over 300 to below 150 by 2020.

We have made significant progress. Figures released in August 2016 showed the number of infant deaths registered SIDS or Unascertained was 230 across the UK. A further 17 babies between the age of one and two died with no cause.

To support our goal, we took the momentous decision to change our name from the Foundation for the Study of Infant Deaths, to appeal more directly to the wider community of parents. After full consultation with our supporters over the period of a year, we became The Lullaby Trust in April 2013.

Our strategy going forward to 2020

While SIDS rates continue to fall, the wider infant mortality rate in the UK remains a significant cause for concern. The UK has one of the highest infant mortality rates in the developed world and there are stark inequalities in the survival chances between rich and poor children in the UK. We believe that The Lullaby Trust should be leading the debate and working with others to tackle the tragedy of all infant deaths, as well as continue to drive down SIDS still further.

In a landmark report, *Why Children Die, Death in infants and children and young people in the UK* published in May 2014, Dr Ingrid Wolf and her colleagues set out the challenge. In 2012 over 3,000 babies died before their first birthday. This is in part driven by the fact that nearly two thirds of these babies were born pre-term and/or of low birth weight. The UK also has the highest stillbirth rate of 12 high-income countries; the UK rate is 3.8 stillbirths per 1,000 births, contrasted with 2.2 per 1,000 in Norway.

Low birth weight rates are higher amongst disadvantaged families and are particularly linked to issues such as poor prenatal care, substance abuse, poor nutrition during pregnancy and smoking. For example, smoking in pregnancy is associated with a 20- 30% higher likelihood of stillbirth, a 40% higher rate of infant mortality and a 200% higher incidence of SIDS.

More research and increased public health interventions are urgently needed to tackle and prevent the tragedy of infant mortality. The Lullaby Trust wants to share our knowledge and expertise to ensure that we maximise the life chances of every baby and young child

In order to do this, we will actively seek out opportunities to work with pregnancy and baby loss charities to maximise our collective expertise to drive down infant mortality rates and support bereaved parents. Areas for potential collaboration will include policy development, awareness raising and jointly developing new services.

Our Vision

The Lullaby Trust wants to stop all unexpected deaths of babies and young children

Mission Statement

Our purpose is

- To reduce the incidence of SIDS in England, Wales and Northern Ireland
- To reduce and prevent where possible the unexpected deaths of babies and young children.
- To continue to fund and instigate research into both the causes and prevention of SIDS and unexpected deaths of babies and young children
- To provide evidence based advice to parents to maximise the life chances and health of their babies and young children
- To provide evidence based knowledge to professionals, policy makers and the media to reduce the rate of unexpected deaths of babies and young children and promote child health
- To offer emotional support and advice to all bereaved parents, family members and professionals affected by the unexpected death of a baby or young child and a safe space for people to remember and talk about their child, whether the bereavement was recent or many years ago.

Our Values

The Lullaby Trust has four core values at the heart of everything we do:

- Our work is driven by the needs of bereaved parents and what they tell us. This helps us to care for and support families devastated by the death of a baby or young child
- Our advice to parents and professionals is based on peer-reviewed international evidence. This has helped us identify why, when and where babies may be at risk
- We believe that all families, whatever their circumstances, have an equal right to access high quality advice and support to help them care safely for their babies and young children
- We are committed to working in partnership with professionals, parents, statutory, voluntary and corporate sectors to achieve our objectives

The Lullaby Trust Strategic Objectives for 2015-2020

To reduce the numbers of babies who die from SIDS to below 150 across the UK by 2020 by promoting our Safer Sleep message

To support and fund research into the causes and prevention of unexpected deaths of babies and young children

To provide support to bereaved families affected by the unexpected death of a baby or young child

To work across the infant and child health community to reduce infant mortality in the UK

What will we do operationally to achieve these objectives?

To reduce the numbers of babies who die from SIDS in the UK to below 150 by 2020, by promoting our Safer Sleep message

- Ensure that all new parents in England, Wales and Northern Ireland are aware of, and have access to, free Lullaby Trust resources on safer sleep, both antenatally and after the birth of their baby
- Expand our reach by providing training and information annually to at least 3,500 healthcare and community professionals on the latest safer sleep advice including NICE guidance on Co-Sleeping (2014) through our team of Regional Development Officers
- Develop new Safer Sleep training for professionals that can be undertaken digitally
- Develop and relaunch the Lullaby Trust Website to reach out to parents and professionals
- Hold a national Safer Sleep Awareness Week every March to reach more families with our safer sleep advice
Develop our messaging on risk of smoking in pregnancy and exposure of babies to second hand smoke in collaboration with the public health community and other baby and parenting charities
- Continue to provide specifically tailored, targeted support for vulnerable groups, in particular young parents.

- Continue to provide advice and support to higher risk families through our Care of Next Infant programme delivered in partnership with the health visiting services

To support and fund research into the causes and prevention of unexpected deaths in babies and young children

- Publish a 10 year research strategy based on the key research priorities identified by bereaved parents and researchers through the Global Action and Prioritisation on Sudden Infant Deaths project (GAPS)
- As part of the research strategy actively seek applications from junior/ early career researchers who wish to pursue a career in sudden infant death research and unexpected deaths in childhood
- Identify strategic partnerships with other bodies and institutions to jointly fund and broker research, which will further our knowledge on preventing unexpected infant and child deaths
- Publish and regularly update our evidence base as a key document, referencing the research behind the advice on reducing the risk of SIDS
- Widely disseminate new research findings through meetings, conferences, the media and our website and ensure that any new research findings are translated into practice
- Maintain our global reputation by taking an active role in the International Society for Prevention of Perinatal and Infant Death (ISPID) as an organisational member of the Executive Board and through attendance at the next International conference in 2018

To provide support to bereaved families affected by the unexpected death of a baby or young child

- Provide a free 365 day bereavement telephone support line to anyone affected by the sudden and unexpected death of a baby or young child staffed by professionals and trained volunteers
- To provide specialist support and information to families affected by the sudden and unexpected loss of a baby or young child
- Offer every bereaved family the opportunity of a family day out each year
- Offer specialist and continuing support to bereaved families after their initial contact with us, including peer-to-peer support through trained Befrienders and online support
- Develop an interactive forum on the website for bereaved families

- Ensure the Care of Next Infant (CONI) Programme continues to be commissioned and provide training and advice to support local coordinators
- Train professionals, statutory agencies and other relevant bodies to ensure that their response to bereaved parents is appropriate and supportive
- Work with wider pregnancy and baby loss charities to explore the possibility of developing a joint bereavement service for families
- Work with charities and opinion formers, notably the All Party Parliamentary Group on Baby Loss to increase awareness and press for consistent standards of bereavement care across the UK

To work across the infant and child health community to reduce infant and child mortality in UK

- Take a leading role in building a consensus amongst all agencies working across the early years and child health community to set a shared goal for reducing the number of preventable infant and child deaths by 2020
- Work with other pregnancy, infant and child bereavement charities to raise awareness of baby loss and the issues surrounding it through Baby Loss Awareness Week held annually in October
- Secure commitment from national policy makers to reduce infant and child mortality across England, Wales and Northern Ireland, tackling regional variations and addressing inequalities that exist in disadvantaged communities
- Work in partnership with the Scottish Cot Death Trust to support their objective to reduce SIDS in Scotland
- Continue to collaborate with Ash, Public Health England and the UK Centre for Tobacco and Alcohol Studies to support the ambition to reduce the numbers of women who smoke in pregnancy to 6% by 2025.
- Work in partnership with local government and public health professionals to develop effective interventions to help parents maximise the life chances of their babies
- Promote the public health commissioning of the CONI Plus programme to support parents with high risk families