



# Target SUDI Together

Research Priorities in Sudden Unexpected Death in Infancy

July 2017



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

Working with the NHS we run a national health-visitor led service for bereaved parents, Care of Next Infant (CONI) programme, which supports families before and after the birth of their new baby.

We are committed to supporting research to understand why so many babies a year die suddenly and unexpectedly in the UK and to find out more about how to prevent these tragic deaths.

The Lullaby Trust operates nationwide across England, Wales and Northern Ireland. We run an information line for parents and professionals (0808 802 6869) and a dedicated line for bereaved families (0808 802 6868). Both are free to call from landlines and mobiles.

We campaign tirelessly, lobbying government to keep sudden infant death on the public health agenda. Since we formed as The Foundation for the Study of Sudden Infant Deaths in 1971 we have been pivotal in reducing Sudden Infant Death Syndrome by over 85%.

The GAPS project was carried out with the support of organisations in the UK, US and Australia:



**The Lullaby Trust** provides specialist support for bereaved families, promotes expert advice on safer baby sleep and raises awareness of Sudden Infant Death Syndrome (SIDS).

We are committed to supporting research to understand why babies die suddenly and unexpectedly and to find out more about how to reduce the risk of these tragic deaths.



**The American SIDS Institute**, a national nonprofit health care organization, is dedicated to the prevention of sudden infant death and the promotion of infant health through an aggressive, comprehensive nationwide program



**Red Nose** is dedicated to saving the lives of babies and children during pregnancy, infancy and childhood and supporting bereaved families.



**The International Society for the Study and Prevention of Perinatal and Infant Death (ISPID)** is a not-for-profit organization that is leading the world in discovering evidence-based preventive measures for stillbirth and sudden infant death. ISPID also works to promote improved quality, standardization of care for bereaved parents, and networking families, professionals, and scientists through resource sharing.



**Teddy's Wish** was founded by Edward's parents, Jen and Chris Reid, to raise funding to support grieving families and further research into SIDS, stillbirth and neonatal death. Teddy's Wish raises funds for potentially life saving research into SIDS, neonatal death and stillbirth and supports grieving families.

# FOREWORD

**Although great strides have been made in sudden infant death research, leading to safe sleep interventions that saved many babies' lives throughout the world, the previous dramatic decline in numbers of deaths has plateaued in recent years and the cause(s) of these deaths remains elusive. Ultimately, infants are still dying. In 2015, rates of sudden unexpected deaths in infancy (SUDI) were 0.255/1000 live births in England and Wales<sup>i</sup>; 0.4/1000 live births in Australia<sup>ii</sup> and 0.926/1000 live births in the US<sup>iii,iv</sup>.**

At The Lullaby Trust, we provide support to over 500 bereaved families each year and know just how important research is to find the causes of SUDI and ways to prevent it from occurring.

Whilst good SUDI research has been taking place around the world for many years, progress has slowed and often only small projects are being funded. This partly reflects the decline in the number of deaths across the world and a perception that SUDI is 'solved'. Researchers are still interested in this field but are spread far and wide and there has been a lack of focus. As such, we knew we had to find a way to bring the research community together, along with bereaved families, to identify those areas of research that are likely to have the most impact in the next 10 years. This is particularly important given the SUDI rate is still relatively high in the US, compared to other countries, and is prevalent amongst indigenous populations in Australia and New Zealand. Sadly, all countries show a higher rate of SUDI amongst groups experiencing significant health and social inequalities<sup>v</sup>. We needed to get people thinking in the same direction, to pool expertise and resources and to encourage a renewed effort to drive down SUDI rates. We also wanted to use this exercise to inform the future research strategy of The Lullaby Trust to ensure we were playing our part in targeting research funding most effectively.

Working with the International Society for the Prevention of Perinatal and Infant Death (ISPID), Red Nose (formerly SIDS and Kids) in Australia, and the American SIDS Institute, we launched a project ('GAPS') to achieve consensus by the international research community and bereaved families on the top 10 SUDI research priorities. This project has provided a new international, focused direction for SUDI research and also resulted in individual research priority lists for the UK, US and Australia. These lists are very similar to the international top 10 but allow for slight differences in cultural preferences.

While many shared priorities emerged between the three countries, a notable difference in the UK was that death scene investigation and systematic collection of data was viewed as a less strong priority in the UK. This reflects the fact that the investigation of SUDI and SIDS deaths and collection of data in UK is more standardised than other parts of the world and subject to long standing multi-agency protocols. While the UK priority list informed the development of The Lullaby Trust's Research Strategy for 2017-2027, we are keen to promote the international top 10 priorities also. The Lullaby Trust is committed to supporting our sister organisations in driving down the rate of SUDI. The international research priorities provide us all with a route map to spearhead one last push to reduce infant deaths across the world.

The Lullaby Trust has hugely benefited from undertaking the GAPS project and I would recommend the process to any medical research charity seeking to develop a research strategy over a long term period, particularly those that are addressing rare conditions and syndromes. Through this process, we heard views from around the world and brought experts and bereaved families to the same table. The result was fantastic and so important for future SUDI research.

Identifying the research priorities was just the first step and we now need to act upon them. But we can't do it alone and need funding to set research in motion. This is why we're calling for funds to support the research priorities and promote active engagement amongst researchers and policy makers in delivering change. We urge you to join us and help to Target SUDI Together. We can and will make the difference.

Francine Bates  
Chief Executive



# EXECUTIVE SUMMARY

The rate of decline in sudden infant death in most developed countries has slowed in the last decade, since a dramatic fall in deaths following the 'Back to Sleep' campaigns in the 1990s. If sudden unexpected deaths in infancy (SUDI) rates are to be significantly further reduced, strategic action is needed now. However, the SUDI research community is relatively small and spread thinly across the globe and available funding is very limited. Furthermore, there is an erroneous perception that the SUDI rate is now so low that the issue has, effectively, been solved. This is not the case.

The Lullaby Trust identified a critical need to bring this international community together, along with bereaved families, to agree where research efforts should be focused in order to most effectively make progress on reducing SUDI cases. In 2015, the GAPS project was established to identify SUDI research priorities and to help inform The Lullaby Trust's future allocation of charitable research funding to those projects with the most potential to reduce infant deaths.

Ten international research priorities were agreed and these fall into three broad themes:

- A)** Better understanding of mechanisms underlying SUID
- B)** Ensuring best practice data collection, management and sharing
- C)** Better understanding of target populations and more effective communication of risk

These research priorities represent the first significant attempt to set a research agenda in the area of sudden infant death that draws on the views of bereaved families as well as researchers and professionals. We believe that it is also the first time that the priority-setting partnership process has been successfully applied on an international scale.

The Lullaby Trust is delighted with the success of the project and now has a clear focus for its own future research strategy. Energy and resources will be strategically targeted where they are likely to have the most impact. However, to truly have a big impact on driving down SUDI cases, researchers, clinicians, funders, policy makers and parents now need to commit to, and take action on, the research priorities. To gain momentum on this, The Lullaby Trust is launching a research appeal as part of the Big Give Christmas Challenge 2017, to secure funding for research and will also be working hard to encourage collaboration in reducing sudden infant deaths.

## 1. THE SAD REALITY OF SUDI

### ▶ 1.1 What Is Sudden Infant Death?

Sudden infant death is the sudden and unexpected death of a baby that is initially unexplained. While rare, it still happens and there are some steps parents can take to help reduce the chance of this tragedy occurring. The usual medical terms referred to are: Sudden Unexpected Death in Infancy (SUDI), also known as Sudden Unexpected Infant Death (SUID) in other countries, or Sudden Unexpected Death in Childhood (SUDC) if the baby was over 12 months old.

A thorough post-mortem examination will reveal a specific cause of death in less than half of all sudden infant deaths. Causes may include accidents, infection, congenital abnormality or metabolic disorder. Deaths that remain unexplained after the post mortem are usually registered as 'sudden infant death syndrome' (SIDS) or 'Unascertained'. For these deaths, researchers think there are likely to be undiscovered causes. For many it is likely that a combination of factors affects a baby at a vulnerable stage of development.

The death of any baby is a tragedy for a family. That tragedy is compounded when a baby dies suddenly and unexpectedly and no cause is found. Many thousands of families have been profoundly affected by the unexplained death of a baby, not just in the UK but in many other countries.

## ▶ 1.2 Why Is Action On Sudden Infant Death Urgently Needed?

Sudden infant death syndrome (SIDS) remains one of the leading causes of death during the post-neonatal period in many developed countries and too many families are still experiencing this terrible loss. In the UK alone, around 250 babies and toddlers are lost every year to sudden unexpected death<sup>vi</sup> and thousands more families around the world are affected. Much research is still required to identify why some infants die in this way and what can be done to prevent such deaths.

Despite the pressing need, further research into SUDI is relatively slow to make progress as it is poorly funded and the international SUDI research community is small. There is a perception that SUDI is solved and resources are no longer required. In addition, there are differences of opinion on key risk factors and how to classify sudden deaths, and formal investigation procedures also vary widely between and within countries. This can mean that large-scale research is limited, and that there are huge challenges in designing and implementing effective public health campaigns to ultimately prevent deaths.

## 2. ADVANCING RESEARCH IN SUDI: THE GAPS PROJECT

The Lullaby Trust recognised that with only limited resources available to researchers and the possibility of small research teams spread across the world working in silos, it was vital to identify how the SUDI research community could come together to best direct its efforts. To address this, we initiated the Global Action and Prioritization of Sudden infant death (GAPS) project. GAPS aimed to establish international consensus on which areas of research should be prioritised to reduce the number of SUDI deaths globally, by investigating the concerns of both SUDI experts and bereaved family members from around the world. To enable this global research collaboration, we worked in partnership with the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID), Red Nose (formerly SIDS and Kids), and the American SIDS Institute.

### ▶ 2.1 How The GAPS Project Worked

The GAPS project was the first of its kind to bring together the expertise of both professionals and the lay community to identify SUDI research priorities. People from a wide range of countries, backgrounds and expertise participated in the project, including: bereaved family members; medical examiners; clinicians and researchers in paediatrics, neonatology, pathology, general practice, public health, epidemiology and statistics; nurses; health visitors; midwives; social workers; and others working in bereavement support, childcare, lactation support, education and voluntary organisations.

In essence, ideas for research priorities and their subsequent refinement into a final top ten list were generated via two online surveys and three workshops. The method was based on the priority-setting partnership model of the James Lind Alliance but extended across multiple countries and settings.

The first survey captured initial research suggestions from members of ISPID as well as other parents and professionals affiliated with the organisation. Potential research topics were reviewed and grouped into research areas, and a list of those considered to have the greatest potential to impact SUDI prevention, based on current evidence, were taken forward to a second survey. In the second survey, participants were asked to rate the series of

research areas based on how important they thought they were for reducing the rate of SUDI in the next 10 years. This survey was emailed to professionals and bereaved parents and publicised by the participating charities. The 30 research areas that scored most highly were then discussed at three workshops.

Workshops were held in the UK, US and Australia to discuss the 30 research statements and achieve consensus on a top ten. Participants were invited based on their high level of expertise in their field, or capacity to share their personal experience of SUDI. To identify a final international list of research priorities, an aggregate scoring system was applied to the priority lists produced by the three workshops.

Further details about the GAPS project methods and findings can be found in [Research Priorities in Sudden Unexpected Infant Death: An International Consensus](#), published in *The Journal of Pediatrics*.<sup>vii</sup>

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**I was thrilled to be invited to the research priorities workshop at The Lullaby Trust. My son died 14 years ago and, whilst it is great to do fundraising and raise awareness into SIDS, it is really important to me, personally, that research goes on to establish the cause of these tragic deaths in babies and infants. The workshop was a really good mixture of healthcare professionals, researchers and bereaved parents and it is good to know that this has led to a new research strategy for the charity.**

[Louise Barrett, bereaved parent]

## ▶ 2.2 International SUDI Research Priorities

The top 10 SUDI research priorities that were agreed by the international stakeholders (listed below) are intended to represent areas that were considered to have the most potential to reduce the rate of SUDI. They set out themes and avenues of research, rather than form specific narrow questions, to enable room for interpretation and allow researchers from multiple disciplines to approach them from different perspectives.

The priorities fall into three broad themes (indicated by the ticks in the table) (N.B. As the priorities were developed by, and for, the international research community, the term SUID was used, rather than SUDI):

- A)** Better understanding of mechanisms underlying SUID
- B)** Ensuring best practice data collection, management and sharing
- C)** Better understanding of target populations and more effective communication of risk.



TOP 10 PRIORITIES	A. Better understanding of mechanisms underlying SUID	B. Ensuring best practice data collection, management and sharing	C. Better understanding of target populations and more effective communication of risk
1: Studying mechanisms leading to death and how they interact with environmental risk factors.	✓		
2: Enabling best practice processes and systematic data collection for accurate classification of SUID deaths to inform research and prevention.		✓	
3: Developing and evaluating new ways to make safe sleep campaigns more effective.			✓
4: Understanding to what extent social and cultural factors affect parental choice in sleep practices and responses to risk reduction campaigns.			✓
5: Identifying specific biomarkers to assist pathologists in determining the cause of death.	✓		
6: Understanding the role of genetic factors in SUID risk.	✓		
7: Understanding what mechanisms underlie SUID risk at different ages.	✓		
8: Conducting further research on the role of abnormal or immature brain anatomy and physiology.	✓		
9: Better understanding of the practice of sharing any sleep surface with an infant, notably how it interacts with other factors to make it more or less risky.			✓
10: Identifying what factors are associated with SUID where all aspects of recommended risk reduction have been followed.	✓		



SUDI knows no boundaries. It is a global problem and the global SUDI community now has a list of shared research priorities to inform a unified and strategic approach in ultimately helping protect more infants from sudden unexpected death. These priorities offer a unique opportunity for global action: to pool limited resources and capitalise upon the expertise of a multidisciplinary community of professionals from many countries. Collaboration is key if we are to effectively build a statistically significant and compelling body of evidence, share best practice and monitor progress.

## GAPS PROJECT IN NUMBERS

### **GAPS**

 Global Action and Prioritisation  
 of Sudden infant death

GAPS project was the first to build consensus on the future of SUDI research as a whole



**4x**

International SIDS charities and research organisations working in collaboration

**#1**

GAPS was the first of its kind to bring together professionals and bereaved family members to identify research priorities in SUDI



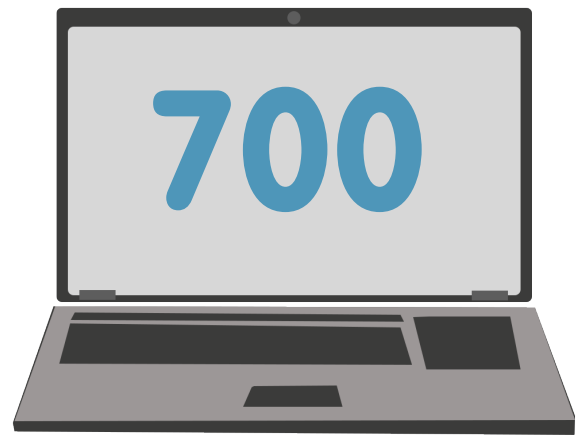
**25**

In total, people from 25 different countries took part, from every continent except Antarctica



17

Professionals from at least 17 different disciplines contributed, as well as bereaved family members

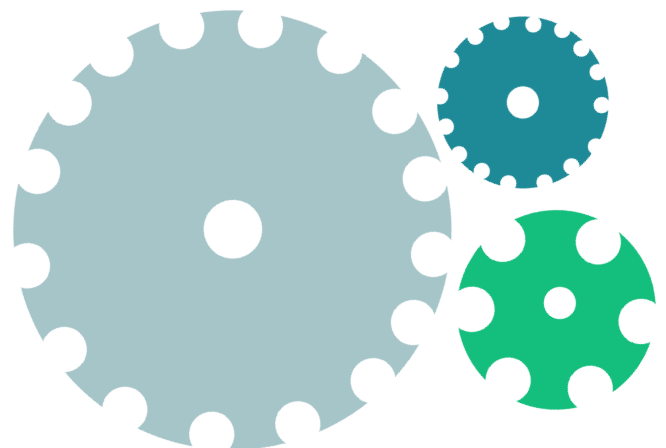


Almost 700 survey responses were received



144

144 original ideas were suggested for research priorities



3x

International workshops taking place in the UK, US and Australia



10x

10 research priorities agreed

### 3. THE LULLABY TRUST'S RESEARCH STRATEGY: 2017-2027

Many parents who have lost a baby suddenly and unexpectedly are committed to raising funds for The Lullaby Trust, often specifically for supporting research, and it is important to them that we commit funding to research that will have the most impact.

The Lullaby Trust was originally founded (as the Foundation for the Study of Infant Deaths) in 1971 and has since raised over £12 million with the help and support of bereaved families. We have funded a wide variety of projects which have informed our understanding of sudden infant death, and allowed us to give evidence based advice on safer sleep to parents. We are proud that The Lullaby Trust has played a major role in reducing sudden infant deaths in this country and believe our commitment to funding research has been instrumental in this.

However, with sudden infant deaths still occurring, our work is not yet done. Sadly, four babies a week die suddenly and unexpectedly in the UK with no cause of death found<sup>vi</sup>. It is vitally important that we pursue research to understand how and why sudden and unexplained infant deaths continue to happen and to devise and test evidence-based approaches to supporting families to reduce the risk of their baby dying.

We passionately believe that our original purpose to identify the causes of sudden infant death and to prevent these tragedies occurring is as relevant now as it was in 1971. Finding answers for grieving families and preventing future infant deaths drives our mission. This can only be achieved by continuing to fund and facilitate high quality research, and ensuring this research is translated into practice, and conveyed to parents, in ways that will help them to use it.

Our latest 10-year research strategy, from 2017 to 2027, builds upon our successful record over 45 years of funding and commissioning research, and translating research into policy and practice. The GAPS project afforded The Lullaby Trust a set of agreed research priorities that provide the backbone for the charity's organisational strategy and wider plans for the next few years. Our main goal is to halve SIDS cases by 2020 and work with others to reduce infant mortality more broadly.

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**Whilst the statistics may show that disadvantaged families are more at risk, the reality is that it can happen to anybody, i.e. to those of us who never smoked, who breast-fed etc. I therefore welcomed the opportunity to have a 'voice' on behalf of the many parents who do not fall into a 'socially disadvantaged' category and to be able to put the case for scientific research that has more focus on the actual cause of death, not just epidemiological and social factors.**

[Bereaved parent]

The research strategy's key objectives are to:

- Contribute to the discovery of how and why babies die suddenly and unexpectedly
- Understand how to effectively minimise the chances of sudden and unexpected infant death
- Develop and evaluate effective ways of conveying this information to parents from all socio-economic and cultural backgrounds with an emphasis on those whose babies are at the greatest risk.

## 4. TIME TO TAKE ACTION

### ▶ 4.1 What The Lullaby Trust Is Doing

- **Directly funding research** – This year, our Scientific Committee issued a call based on the new research strategy and funding has been agreed for two unique projects, focusing on: the microbiome of SIDS and incentivising women to give up smoking in pregnancy
- **Building research collaborations** – We are forming new collaborations and seeking funding for specific projects. This includes working with Professor Peter Fleming at the University of Bristol to support the development of a national patient registry on infant and child deaths. We are also leading a major funding bid with Professor Helen Ball, at the University of Durham, to secure resources for a significant project on safer sleep working with professionals to standardize safe sleep messaging and providing bespoke baby boxes to high risk families to avoid hazardous co-sleeping
- **Partnering with other infant loss organisations** – As part of our wider work on reducing infant mortality, we are committed to working with other infant loss charities, notably Sands, which is dedicated to reducing stillbirths and neonatal deaths in the UK. We are working with Sands, Great Ormond Street Hospital and NHS England to explore the possibility of establishing a comprehensive database containing all post-mortem data on stillbirths and infant deaths across the country
- **Communicating the international research priorities** – We are working hard to communicate the list of research priorities as widely as possible to encourage anyone involved in research, funding or policy-making regarding sudden infant death to focus and take action on the priorities.

### ▶ 4.2 What You Can Do To Help: Let's Target SUDI Together

We now want to see a big push in activity to support, promote and forge ahead with the research priorities agreed by the SUDI community. Only by people taking action together can we make a big difference in tackling SUDI and we encourage you to play your part. Let us all Target SUDI Together:

- Commit to the 10 research priorities for SUDI
- Support our Big Give Christmas Challenge 2017 appeal - Help us to raise funds for research projects across the 10 priorities
- Seek collaboration across the SUDI research community and involve bereaved families in designing and guiding research
- Communicate your research findings in an accessible way
- Translate best practice and new interventions based on research findings
- Use research to influence policy makers and commissioners.

**We need you to start now. Infants are dying unnecessarily and we must step up the momentum and work together to find effective ways to prevent further deaths.**

## ▶ 4.3 The Lullaby Trust Wants To Hear From You

Let us know:

- How you can support our Big Give appeal
- What you are doing to Target SUDI Together
- How we can help foster collaborations or enable network building by connecting the right people
- How we can ensure your voice is heard in SUDI discussions and decision-making
- How we can work with you to drive policy improvements and support the dissemination of evidence-based best practice models.

We want to help wherever we can, so please do get in touch:

Email: [FrancineB@lullabytrust.org.uk](mailto:FrancineB@lullabytrust.org.uk)

Tel: 020 7802 3200

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**I was really impressed at the London workshop by how the opinions and experiences of the parents there were welcomed and valued by the researchers and other professionals. I'm really excited by the 10-year vision that the research strategy sets out. This is particularly because important research topics to ensure that the best safer sleep advice is delivered to parents, and that they are helped to implement it, appear so high in the list of priorities. I believe that this strategy will give parents confidence to support The Lullaby Trust in funding vital research.**

[Mike Wingfield, bereaved parent]

## ACKNOWLEDGEMENTS

We wish to acknowledge many people for their support and expert input in ultimately identifying SUID research priorities and the next steps in addressing them:

- Jennifer and Christopher Reid, founders of Teddy's Wish, whose fundraising in memory of their son Edward enabled the GAPS project to take place
- The Lullaby Trust, American SIDS Institute and Red Nose (formerly Sids and Kids) for additional funding support for GAPS
- The Steering Group that oversaw GAPS and helped write up the research: Ms. Francine Bates (CEO The Lullaby Trust, UK), Dr. Peter S Blair (Reader in Medical Statistics, University of Bristol, UK), Dr. Fern R Hauck (Professor of Family Medicine and Public Health Sciences, University of Virginia School of Medicine, USA), Lucy Lyus (Research and Information Manager, The Lullaby Trust), Dr. Betty L McEntire (CEO, American SIDS Institute, USA) and Associate Prof Leanne Raven (CEO, Red Nose, Australia)



- All bereaved parents and professionals who took part in GAPS and contributed their valuable insight and time
- The Lullaby Trust Scientific Committee chaired by Prof Helen Ball for helping to develop The Lullaby Trust's research strategy
- Dr. Alexis Willett (Punch Consulting), who had the original idea to undertake the GAPS project, helped to coordinate it and communicate the findings.

## REFERENCES

- i. Office for National Statistics Child Mortality in England and Wales: 2015.
- ii. Australian Bureau of Statistics. 3303.0: Causes of Death, Australia, 2015. [Unpublished data provided to authors of the Pediatrics paper on the GAPS project].
- iii. Centers for Disease Control and Prevention. Sudden Unexpected Infant Death and Sudden Infant Death Syndrome. Data and Statistics: 2015.
- iv. These statistics include SIDS cases (ICD-10 code R95), deaths that are ill-defined or of unknown cause (ICD-10 code R99) and cases of accidental strangulation and suffocation in bed (ICD-10 code W75).
- v. Hauck FR, Tanabe KO. International trends in sudden infant death syndrome: stabilization of rates requires further action. Pediatrics. 2008;122(3):660-666.
- vi. The Lullaby Trust SIDS & SUDC Facts and Figures: 2014 <https://www.lullabytrust.org.uk/wp-content/uploads/sids-sudc-facts-and-figures-2014-released-2016.pdf>.
- vii. Fern R. Hauck, Betty L. McEntire et al., Research Priorities in Sudden Unexpected Infant Death: An International Consensus. The Journal of Pediatrics, published online: 27/7/2017 (10.1542/peds.2016-3514 ) <http://pediatrics.aappublications.org/content/early/2017/07/25/peds.2016-3514>

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**Many years have passed since my son died and I feel that the contributions I am able to make to bereaved parents and fundraising have changed in the intervening years. However, I feel more committed than ever to find an explanation for my son's death and I found it stimulating to spend time among the scientific community. Some of the researchers have been involved for many years, others are new, and I am encouraged that they still strive towards the goals of The Lullaby Trust.**

[Bereaved parent]



The Lullaby Trust  
11 Belgrave Road,  
London, SW1V 1RB  
[www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)  
Tel: 020 7802 3200  
Registered charity number: 262191

Members of the  
**amrc**  
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