

Citizen Participation and Public Petitions Committee
Wednesday 29 May 2024
10th Meeting, 2024 (Session 6)

PE2082: Improve the support provided to families affected by cot death

Introduction

Petitioner Kevin McIver

Petition summary Calling on the Scottish Parliament to urge the Scottish Government to stop promoting The Lullaby Trust to Scottish families for cot death support, as this charity only provides support to families who live in England and Wales; and improve the practical support available to families by prioritising the promotion of The Scottish Cot Death Trust who have been supporting families since 1985.

Webpage <https://petitions.parliament.scot/petitions/PE2082>

1. This is a new petition that was lodged on 14 February 2024.
2. A full summary of this petition and its aims can be found at **Annexe A**.
3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B**.
4. Every petition can collect signatures while it remains under consideration. At the time of writing, 13 signatures have been received on this petition.
5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered. A response has been received from the Scottish Government and is included at **Annexe C** of this paper.

Action

6. The Committee is invited to consider what action it wishes to take on this petition.

Clerks to the Committee
May 2024

Annexe A: Summary of petition

PE2082: Improve the support provided to families affected by cot death

Petitioner

Kevin McIver

Date Lodged

14 February 2024

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to stop promoting The Lullaby Trust to Scottish families for cot death support, as this charity only provides support to families who live in England and Wales; and improve the practical support available to families by prioritising the promotion of The Scottish Cot Death Trust who have been supporting families since 1985.

Previous action

Written to our MSP.

Background information

I am a parent who lost a child to cot death.

When we had another baby, support was provided by The Scottish Cot Death Trust. The Scottish Cot Death Trust hand out free baby monitors to help prevent cot death. They also offer free CPR and first aid training, and access to a Bereavement Support Worker to support families.

Now we have had another child and, on all literature, the Scottish Government promotes The Lullaby Trust, who do not offer support or help to Scottish families, only to those living in England and Wales. What is the point of promoting an England-based charity? As the saying goes “charity begins at home”, but clearly the Scottish Government don’t see this. As a parent of a child who passed with cot death/SIDS (Sudden Infant Death Syndrome), I am angered our government doesn’t provide more support to a Scotland-based charity. Our NHS in Scotland should not be sending any money south of the border.

Annexe B: SPICe briefing on petition PE2082



Background

Cot death or Sudden Unexpected Death in Infancy (SUDI) are the terms used when healthy infants die suddenly and unexpectedly with no apparent reason for their death.

Known risk factors for SUDI include avoidable and unavoidable factors:

- Male gender
- Second born or later
- Small for gestational age or prematurity
- Prone and side sleeping position
- Unsafe bedding
- Parental smoking and substance use
- Co-sleeping

Prevention campaigns over the years have focused on reducing avoidable risk factors. This has included highlighting the increased risk of co-sleeping and encouraging caregivers to place infants on their backs to sleep (e.g. the Back to Sleep campaign).

Despite a reduction in the number of SUDIs over the years, it is still the most common cause of death in infants between 1 and 12 months old. In Scotland, there are around 40 SUDIs every year which equates to a death every 9 days.

Scottish Cot Death Trust

The [Scottish Cot Death Trust](#) describes itself as 'the only charity in Scotland dedicated to the sudden and unexpected death of babies and young children'.

The Trust provides funding for research as well as campaigns and education on how to reduce the risks. It also provides bereavement support to anyone affected by SUDI.

In [its most recent return to the Office of the Scottish Charity Regulator](#) (OSCR), the Trust details its income for 2022/23 was £203,695. This income came from a mixture of donations, fundraising, grants and investments.

Scottish Government Action

The petition is calling for the Scottish Government to stop supporting the Lullaby Trust. This may be referring to the fact that the Scottish Government recently developed new [advice on safe sleeping](#) along with the [Lullaby Trust](#), the UNICEF Baby Friendly Initiative and the Baby Sleep Information Source.

A recent [statement from the Solicitor General for Scotland on safe sleeping](#) also includes the Lullaby Trust helpline number.

In its annual return to OSCR, the Scottish Cot Death Trust highlights differences between the Scottish Government's messaging on safe sleeping, and that promoted by the Trust:

“We continue to operate in a landscape where there is variation between the safe sleep messages of Scottish Government and the Trust, particularly relating to bed-sharing. We recognise that mixed messages can be confusing for parents but believe our position on safe sleep remains guided by the strongest evidence [...] Although there is a variation in our messaging, we hope to strengthen our relationship with Scottish Government where our positions align.”

However, the Scottish Government does also support the Scottish Cot Death Trust by providing grant funding for the National Coordinator role within the organisation.

The Lullaby Trust is registered as a charity in England and Wales.

Kathleen Robson
SPICe Research
12 March 2024

Annexe C: Written submission

Scottish Government submission of 12 March 2024

PE2082/A: Improve the support provided to families affected by cot death

Thank you for asking for the Scottish Government's view on the public petition [PE2082: Improve the support provided to families affected by cot death](#) calling on the Scottish Parliament to urge the Scottish Government to stop promoting The Lullaby Trust to Scottish families for cot death support, as this charity only provides support to families who live in England and Wales; and improve the practical support available to families by prioritising the promotion of The Scottish Cot Death Trust who have been supporting families since 1985.

The loss of a baby is a traumatic event that can have a profound impact on families. The Scottish Government recognises this impact and is clear that women and their families who have experienced baby loss must be provided with the right information, care and support taking into account their individual circumstances.

This response will outline the Scottish Government's commitment to delivering that support and its current involvement with The Lullaby Trust, the Scottish Cot Death Trust and other pregnancy and baby loss charities in Scotland.

It's important to clarify from the outset that whilst the Scottish Government worked in partnership with The Lullaby Trust to develop and deliver national Safer Sleep for Babies resources, we do not promote The Lullaby Trust as a baby loss support organisation because, as mentioned in public petition PE2082, they do not provide a baby loss support service in Scotland.

The Scottish Government and NHS Scotland Safer Sleep resources were developed in partnership with the Lullaby Trust, the UNICEF Baby Friendly Initiative and internationally recognised safer sleep experts including BASIS, the Baby Sleep Information Source based at Durham University. Healthcare Improvement Scotland and the Chair of the National Hub for Reviewing and Learning from the Deaths of Children and Young People were also involved in their development, along with charities working in Scotland such as Bliss, Twins Trust and Held In Our Hearts.

The resources include a guide for parents and carers, a quick reference card which compliments the parent guide and a guide for health professionals that they can use to talk to parents about safer sleep. The parent and carers guide is available in the 18 most commonly used languages in Scotland. Accessible easy read, British Sign Language, audio and Braille versions are also available. The information provided in the resources which includes advice on bed sharing is clear, consistent with advice given across the whole of the UK and based on current research and evidence. The information is in line with Royal College of Midwives guidance and National Institute for Health and Care Excellence (NICE) clinical guidelines on postnatal care, which is clear that parents should be given information on bed sharing and health professionals must have open conversations with parents about this.

The Scottish Cot Death Trust were invited to become involved in the development of these resources but declined to do so.

The Scottish Government is also committed to supporting families who have experienced pregnancy and baby loss by delivering high-quality, sensitive bereavement care and provide funding to Sands UK to develop the National Bereavement Care Pathways for pregnancy and baby loss in Scotland (NBCP). Sands UK worked with health professionals, bereaved parents, baby loss charities and Royal Colleges to deliver the pathways, putting voices of bereaved parents at the heart of the development of the pathways.

The pathways provide health professionals with evidence based care and describe best practice for bereavement care following a miscarriage, ectopic and molar pregnancy, termination of pregnancy for fetal anomaly, stillbirth, neonatal death, or the sudden unexpected death of an infant (SUDI). The Scottish Cot Death Trust led and developed the National Bereavement Care Pathway for SUDI and its Executive Director Lynsey Kidd sits on the NBCP Core Group and is currently co-leading work ensure that the SUDI pathway remains up to date.

A link to the NBCP can be found here: [Home | SANDS \(nbcpscotland.org.uk\)](https://www.nbcpscotland.org.uk).

Additionally, the Scottish Government has provided the Scottish Cot Death Trust, with grant funding of £12,414.56 in financial year 2023/24 to deliver their SUDI simulation and SUDI awareness training.

I hope that this reassures the Committee that the Scottish Government does not promote The Lullaby Trust to Scottish families for SUDI support and that we are working with the Scottish Cot Death Trust to support families in Scotland, through the NBCP and by funding their SUDI simulation and SUDI awareness training.

**Maternal and Infant Health
Children and Families Directorate**