

SUDC★UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

Action to Stop Children Dying without Explanation

120

seemingly healthy children have died without explanation since the last SUDC debate three years ago.

Sudden Unexplained Death in Childhood is a leading cause of death in children aged 1-18.

Help us find answers.

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sudc.org.uk

A DEBATE FOR A NATIONAL PLAN FOR SUDC

We need a clear national and government-supported route map to answers. Support the SUDC debate in Spring 2026.

Forty children aged 1-18 years die every year where the cause is completely unexplained despite a thorough investigation. Since SUDC was last debated in parliament the incidence remains unchanged with the same number of children affected each year. Once again, forty seemingly healthy children will die without any warning or explanation during the next 12 months and every year after that unless we act now.



WHAT IS SUDC?

- ★ SUDC is the sudden and unexpected death of a child aged 1-18 years where the cause of death remains unexplained despite a thorough investigation.
- ★ 40 children are affected every year in the UK, more than young child deaths due to traffic accidents, fires or drowning and comparable to 1-2 seemingly healthy children dying every fortnight, often going to sleep and never waking up.
- ★ There is limited awareness and research to understand SUDC and currently, no-one can predict or prevent these deaths. They continue to devastate families year on year.
- ★ Sudden Unexplained Death in Childhood is one of the most under-recognised medical tragedies of our time. Please help us take action to stop children dying without explanation.

SIGNIFICANT MILESTONES:

- There is **precedence** that research significantly reduces unexplained death. Research findings have successfully reduced the rate of unexplained infant death by 80% over the last 30 years.
- UK academics, infrastructure and the national database are well-positioned for **world-leading research**.
- SUDC UK has championed **Whole Genome Sequencing (WGS)** and broad genetic analysis for every family who are told their child's death is unexplained after post mortem. The NHS 10 Year plan has also announced potentially impactful whole birth sequencing.
- National charity, SUDC UK, is currently funding national research using NCMD data to be conducted with the nation's recognised experts in sudden death. This is the **right time to create a national plan**.

CHALLENGES:

- **Patience and waiting for small charity-funded research to prevent these deaths is unacceptable.** 120 seemingly healthy children have died without explanation since the last SUDC debate three years ago.
- There have been 13,000 publications for SIDS (unexplained deaths under 12 months of age) vs 100 publications for SUDC. We need a **co-ordinated and planned 'movement'**, a small amount of research will not move the dial.
- We are a long way from prevention and need to develop a well-defined national plan to pull this all together now – there must be a **clear route map for next steps and milestones with all stakeholders (DHSC, NIHR, Genomics England, NCMD, NHS and SUDC global experts)**.

Aim for the debate to call for a minister-supported formal parliamentary meeting, where scientific experts present data and agree on a national plan with clear milestones.

IMPORTANT POINTS WE EXPECT TO BE RAISED AT THIS MEETING THAT MATTER TO ASSOCIATED PROFESSIONALS AND FAMILIES

- ★ This requires leadership. Once the milestones are agreed, families deserve a biennial report to track progress—funded and commissioned by the Department of Health and Social Care—that specifically details SUDC deaths and current actions against the national plan.
- ★ Quicker post-mortem times and more consistent care for families would improve the quality of child death reviews (essential for data collection) and the availability of genetic information to safeguard siblings and support research.
- ★ There is an association between SUDC and febrile seizures. We need research to better understand this and identify which children are at risk. Patient leaflets after a febrile seizure should contain helpful content.

Please could your office write to SUDC UK to confirm their intention to attend the debate and to raise the related parliamentary questions suggested below:

- Q What clear national plan is in place to prevent Sudden Unexplained Death in Childhood (SUDC)?
- Q How is the Minister supporting the NIHR-funded QUINTET study on care following sudden child deaths to address inequities in the quality and consistency of bereavement care?

For any further information please contact Nikki@sudc.org.uk.