RESEARCH STRATEGY

2024-2027

SUDC UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

SUDC UK RESEARCH STRATEGY

SUDC UK is a registered, national charity dedicated to raising awareness, funding research and supporting families affected by Sudden Unexplained Death in Childhood (SUDC).

SUDC is the sudden and unexpected death of a child aged 1-18 years where the cause of death remains unexplained after 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 and under-researched medical tragedies of our time.**

OUR VISION

For SUDC to be predictable and preventable.

OUR MISSION

- To encourage and fund crucial medical research to better understand these tragedies.
- To support families affected by SUDC.
- To improve awareness and understanding of Sudden Unexplained Death in Childhood.

SUDC UK SUPPORTS RESEARCH IN 3 WAYS:

Funds medical research grants to approved projects.

SUDC UK is open for research grant applications which would further understanding of Sudden Unexplained Death in Childhood.

Collaborates with organisations to optimise data collection and influence policy.

We welcome applications from institutions around the world but the research must be expected to significantly impact UK children/ families and this must be explained in the application. Collaboration with at least one UK-based investigator is preferable.

Guidance and referrals to SUDC research programmes, with the aim of finding answers for families and preventing future deaths.

The Research Strategy sits beneath the SUDC UK Strategy and is fundamental to meeting the key strategic aims of the charity.

CALL TO ACTIONS WHY WE NEED RESEARCH:

Sudden Unexplained Death in Childhood (SUDC) is the sudden and unexpected death of a child, between 1 and 18 years of age, which remains unexplained after a thorough case investigation is conducted. This must include; examination of the death scene, performance of a complete post-mortem, and a review of the child and family's medical history

(Medically defined by Krous et al in 2005).

- SUDC is a category of death that eludes our scientific understanding today.
- We do not currently know of any way to reduce the risk of Sudden Unexplained Death in Childhood.
- At this time, no-one can predict or prevent these deaths; neither parents nor medical professionals.
- A crude search on PubMed reveals that there have been over 13,000 publications for SIDS (Sudden Infant Death Syndrome) and even more for sudden deaths in adults, However, for SUDC there have been less than 80 publications.

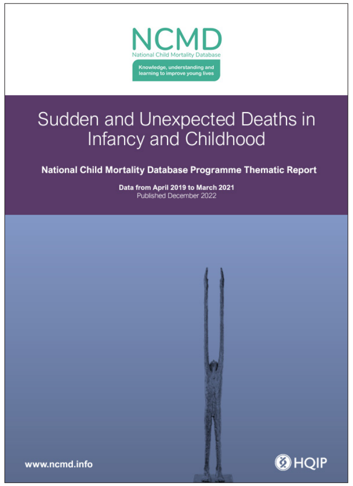
(July 2024)

PHOTOGRAPH: PEXELS/ARTEM PODREZ

WHAT THE EXPERTS ARE SAYING:

> “Unexpected death of a child of any age is perhaps the greatest tragedy any family can experience. I give my strongest possible support to the work of SUDC UK - supporting bereaved families and facilitating research aimed at understanding and preventing unexpected deaths of children. I am convinced that with the right research we will soon be able to prevent many such deaths.”

PROF. PETER FLEMING CBE
CLINICAL LEAD IN THE SIDS BACK TO SLEEP CAMPAIGN



NCMD
National Child Mortality Database
Knowledge, understanding and learning to improve young lives

Sudden and Unexpected Deaths in Infancy and Childhood

National Child Mortality Database Programme Thematic Report

Data from April 2019 to March 2021
Published December 2022

www.ncmd.info
HQIP

> “What this tells us is that research in this area is now a priority. It is crucial that we identify those factors which contribute to unexpected death in children over one year old.”

BARONESS KENNEDY
NATIONAL CHILD MORTALITY DATABASE THEMATIC REVIEW 2022

WHAT OUR COMMUNITY TELL US:

Please watch our charity video - Only Research will stop this.

Only research can stop this.

The wonderful work of @SUDCUK1 who research sudden unexplained death in children and support families like ours.

Helping contribute to the research and support you all give families is something I'm ever keen for

As grandparents to a beautiful boy, who we lost suddenly at 13 months old, we want to donate to your organisation to help support the research into this devastating loss, where there are currently no answers. We applaud the work that you do.

Funding should be made available for research so others don't have to suffer the way my son and his partner have and are still going through.

HOW OUR UNDERSTANDING OF SUDC HAS EVOLVED

SUDC UK was founded in 2017 and, in line with our mission by the end of 2023 it had granted £545,196 funding to global SUDC scientific research to further understanding of Sudden Unexplained Death in Childhood. SUDC UK is the national affiliate of a global charity called the SUDC Foundation (sudc.org).

£545,196

TOTAL SCIENTIFIC RESEARCH FUNDING TO DATE

- To date, there has been limited research specifically into SUDC in the UK but we have worked hard with national bodies such as a UK registry steering group led by Professor Peter Fleming CBE and more recently the National Child Mortality Database and NHSE to champion data collection, tissue retention and genetic analysis so that national data is available for impactful UK-based SUDC research.

- The majority of our funding so far has been to the largest global database of SUDC cases – the SUDC Registry and Research Project (www.sudcrrc.org) which collates cases (including from the UK, some directly referred by SUDC UK). This project has published papers raising awareness of the association between SUDC and febrile seizures. An association which has since been corroborated by an NCMD thematic population-based review co-authored by SUDC UK.

- Due to the improved interest and infrastructure for UK-based SUDC research and our growing income, we would now like to diversify the projects we grant to and have evolved our application and decision-making process.

SUDCRRC

SUDC Registry and Research Collaborative

RESEARCH, PRESS RELEASES | JANUARY 4, 2024

Seizures Identified as Potential Cause of Sudden Unexplained Deaths in Children

IMAGE: KOTO_FEJA / GETTY

WHERE ARE WE NOW AND WHERE DO WE WANT TO BE

1

We still understand very little about the causes of these sudden deaths of seemingly healthy children. We will fund projects which will further the understanding of Sudden Unexplained Death in Childhood.

There is an association with febrile seizures and SUDC but this is still poorly understood. Febrile seizures are common in children and we do not understand which children are at risk.

≫ We will fund research which helps further understanding of this association and could lead to preventable measures.

2

If preventable measures are identified, the evidence base must support the NHS and public health to implement guidance and strategies to reduce deaths.

≫ We will fund research which has the potential to influence national guidance/pathways aiming to educate and save lives.

3

SUDC is most likely to be a heterogeneous group of multiple underlying causes with different contributing factors.

≫ We will fund research which supports the understanding of SUDC and includes a wide range of themes such as genetics, proteomics, infection, neurology, cardiology and physiology and pathology.

WHERE ARE WE NOW AND WHERE DO WE WANT TO BE

4 SUDC is rare, there are established registries such as the SUDCRRC which includes approximately 10% UK cases and there is a statutory process for data collection in England, including SUDC-specific fields to learn from these deaths (developed in collaboration with SUDC UK in 2022).

» We will aim to fund and encourage research using different data sources including:

- registry data where there are a sufficient number of collated cases and data points.
- national population-based data that could reveal new information or corroborate theories to help drive change.

5 Certification of unexplained child death is inconsistent and families affected by SUDC may find an explanation through the initial investigation or genetic analysis. The mechanism of death for SUDC may be similar with that of other categories, such as SUDEP or SADS and those affected at different ages, e.g. SIDS.

» We will fund research that includes these categories of death so long as the impact for SUDC is clear and understanding SUDC is a priority of the project.

Support for families – SUDC supports improved care for families via our advocacy efforts and through collaboration with professionals and families.
We do not fund research to improve support for families.

WHAT TYPES OF RESEARCH GRANTS DO WE OFFER?

Our vision is to STOP SUDC and we are dedicated to funding high quality research that makes a meaningful difference to the SUDC community, both now and in the future.

We offer a broad range of funding options so that we can:

- Invest in SUDC scientific research
- Build capacity in SUDC research by supporting researchers throughout their career, in particular early to mid-career.
- Support research at all stages of development, from nurturing novel ideas to enabling established work to continue.
- Ensure that the impact of our investment will be seen both in the short and medium to longer term.
- Respond flexibly to the funding needs of applicants. We are happy to part-fund or completely fund a project. We are also willing to co-fund longer or higher-cost projects with other charities and have previous experience of doing this through our affiliate, the SUDC Foundation.

PHOTOGRAPH: PEXELS/THIRDMAN

HOW DO WE CHOOSE WHICH RESEARCH WE ARE GOING TO FUND?

SUDC UK will only fund research which will:

- Contribute towards the prevention of SUDC
- Accelerate the change which will enable children to live with a reduced risk of SUDC

- All applications are assessed in relation to the four SUDC priorities for research, the person, project, place, and price

- Recommendations for funding are made by our Research Review Panel (RRP). The RRP is an independent panel of experts, including scientists and bereaved parents, who provide impartial advice to the Board of Trustees. The RRP adheres to our conflict of interest policy.

- SUDC UK is guided by the Association of Medical Research Charities (AMRC). All applications are assessed in accordance with their principles of expert review:
proportionality, independence, diversity, rotation, impartiality and transparency. .

> Further information on grant application procedures and our conflict of interest policy can be found in our Research Process Handbook, linked on the research section of our website.

PHOTOGRAPH: PEXELS/ARTEM PODREZ

WHAT IS THE IMPACT OF SUDC UK RESEARCH?

A family affected by SUDC suddenly loses their child and there is no explanation for this traumatic and devastating loss. No-one can tell them why. Families need to understand why their child has died and they urgently want to stop this happening to other children.

With no current prevention strategies, SUDC research is crucial to prevent deaths in the future. Research into unexplained infant death has resulted in an 80% reduction in these tragedies and we believe that through SUDC research there is such potential to save the lives of older children.

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Thank you for reading.
To discuss further, please contact info@sudc.org.uk
www.sudc.org.uk