

# SUDC-UK

England & Wales · Charity number 1175413

## Details

---

**Other names** SUDC UK

**Status** Registered

**Legal form** CIO

**Registered** 2017-10-27

**Register** [View on the Charity Commission register](#)

## Contact

---

**Address** C/O Mayfield & Co  
2 Merus Court  
Meridian Business Park  
Leicester  
LE19 1RJ

**Phone** 07500905395

**Email** [info@sudc.org.uk](mailto:info@sudc.org.uk)

**Website** [www.sudc.org.uk](http://www.sudc.org.uk)

## Activities

---

**Objects:** (1) THE OBJECTS OF THE CIO ARE TO PROMOTE AWARENESS OF SUDDEN UNEXPLAINED DEATH IN CHILDHOOD AND TO RELIEVE THE NEEDS OF FAMILIES AND INDIVIDUALS AFFECTED BY THE SUDDEN UNEXPLAINED DEATH OF A CHILD, IN PARTICULAR BY SUPPORTING THE SUDC FOUNDATION, INCLUDING BY MEANS OF:(A) PROVIDING INFORMATION, ADVANCING AND FUNDING MEDICAL RESEARCH, AND ADVOCATING FOR ISSUES RELATING TO SUDDEN UNEXPLAINED DEATH IN CHILDHOOD; (B) PROVIDING SUPPORT TO FAMILIES AND INDIVIDUALS AFFECTED BY THE SUDDEN UNEXPLAINED DEATH OF A CHILD; (C) SUPPORTING THE CHARITABLE PURPOSES AND ACTIVITIES OF THE SUDC FOUNDATION;(D) ENGAGING IN OTHER RELATED CHARITABLE AND EDUCATIONAL ACTIVITIES AS DETERMINED BY THE BOARD OF DIRECTORS.(2) NOTHING IN THIS CONSTITUTION SHALL AUTHORISE AN APPLICATION OF THE PROPERTY OF THE CIO FOR THE PURPOSES WHICH ARE NOT CHARITABLE IN ACCORDANCE WITH SECTION 7 OF THE CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND) ACT 2005 AND SECTION 2 OF THE CHARITIES ACT (NORTHERN IRELAND) 2008.

**Activities:** Fundraising, supporting others to fundraise, attending medical conferences, developing resources for families, funding research, consulting on relevant guidelines, raising awareness of SUDC, SUDC UK and the The SUDC Foundation, Advocating the better care and support for families, educating and supporting

professionals.

## Classification

- **How:** Makes Grants To Organisations, Provides Other Finance, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** The Advancement Of Health Or Saving Of Lives, Other Charitable Purposes
- **Who:** Other Charities Or Voluntary Bodies, The General Public/mankind

## Geography

- United States
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£400,650	£139,215	-	-
2023-12-31	£299,839	£271,727	-	-
2022-12-31	£278,813	£226,013	-	-
2021-12-31	£115,062	£123,941	-	-
2020-12-31	£105,510	£67,148	-	-

## Trustees

Name	Role	Appointed
HELEN LOUISE CHARALAMBOUS	Chair	2017-10-27
Anne Elizabeth Milliken		2022-09-22
CAMILLA LOUISE GOODEN		2017-10-27
Christopher Philip Bingham		2024-01-09
Madeleine Anne Finn		2024-01-09

**SUDC-UK**

England & Wales - Charity number 1175413

---

# Accounts

---

# SUDC UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation



## ANNUAL REPORT & ACCOUNTS 2024

Annual Report and Financial Statements  
For the Year Ended 31 December 2024

SUDC UK – registered charity in England and Wales 1175413

## CONTENTS

A message from our founders .....	3
About us .....	4
Our strategy 2021-2024 .....	4
Our values .....	4
2024 Impact in numbers .....	6
Grants to medical research .....	7
Supporting families .....	10
Raising awareness .....	12
Professional awareness and advocacy .....	14
Engagement in SUDC research .....	18
Fundraising .....	20
Sustainability .....	22
Our future .....	23
Annual report and unaudited financial statements .....	24
Trustees report .....	25
Independent examiner's report .....	26
Statement of financial activities .....	27
Balance sheet .....	28
Notes to the financial statements .....	29

## SUDC UK TRUSTEES REPORT

### SUDC UK Reference and Administrative Details

Charity name	SUDC UK	Organisation of the Charity	CIO - ASSOCIATION Registered 27 Oct 2017 as amended on 11 Jul 2023
Charity number	1175413		
Trustees	Camilla Gooden Helen Charalambous Anne Elizabeth Milliken (The SUDC Foundation) Madeleine Finn Chris Bingham	Committee	The SUDC UK Board of Trustees at the date of the approval of this Report were: Chris Bingham Helen Charalambous Madeleine Finn Camilla Gooden Anne Elizabeth Milliken
Accountant	Mayfield & Co 2 Merus Court Meridian Business Park Leicester Leicestershire LE19 1RJ		

# A MESSAGE FROM OUR FOUNDERS

As we reflect on 2024, it is impossible for the founders not to feel pride and gratitude. We can only achieve such milestones thanks to SUDC UK's staff, volunteers, ambassadors, advisors and supporters.

A decade ago, when our children died, Sudden Unexplained Death in Childhood was a phenomenon that lacked presence in national guidance, medical training and awareness. SUDC UK is committed to filling this gap, so other families avoid the same sense of isolation and confusion.

Thankfully, SUDC UK is making progress to address this most under-recognised medical tragedy and create meaningful change. In 2024, SUDC UK-funded research gained global attention while a BBC Panorama episode amplified our message, and national media shone a light on the truths families have long wanted to share. A parliamentary event drew 150 advocates and QUINTET, a £1.2 million government-funded project, launched to enhance support for bereaved families.

We supported families individually, advocated at regional and national events, and earned glowing feedback for our expertise. By providing charity representation for Child Death Overview Panels, delivering the key worker role, supporting researchers, and aiding the 2023 genetic test launch, we have deepened our knowledge, skills and insight in SUDC-related challenges.

During 2024, the charity drove noticeable advancements in care for SUDC-bereaved families. We received more medical referrals, and bereaved families are accessing our support earlier in their journey. We also received more proactive requests for training and collaborations, and five different lead investigators applied for SUDC UK grants. We are hopeful for further improvement in essential care via projects like QUINTET and our advocacy.

At an organisational level, our income increased by 32% in 2024 to £400,650. We expanded our staff, board of trustees, scientific advisors, and launched a new research strategy. SUDC UK has committed to invest £297,781 more into SUDC research as a result of fundraising in 2024. We are proud of our evolving international collaborations and have founded an international working group for SUDC, with 20 experts who convene regularly at meetings co-chaired by our CEO.

2025 will be pivotal as we expand our research efforts and shape an ambitious long-term strategy to guide SUDC UK's impact.

Meeting with other families and seeing their courage, resilience, shared experiences and passion, will forever inspire us – these families, propelled by their love for their children, have driven the extraordinary advances you will read about in this report.



Camilla Gooden,  
Dr Nikki Speed and  
Helen Charalambous  
at the first ever  
parliamentary event  
for SUDC at the House  
of Commons

*Nikki*

Dr Nikki Speed CEO

*Helen*

Helen Charalambous

*Camilla*

Camilla Gooden

# ABOUT US

SUDC UK is a registered, national charity dedicated to funding research, raising awareness 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 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 by learning more in this report and at [www.sudc.org.uk](http://www.sudc.org.uk).

[WATCH OUR CHARITY VIDEO HERE](#)

## OUR STRATEGY 2021-2024

In 2021, we launched a three-year strategy shaped in collaboration with bereaved parents and dedicated volunteers. This year we exceeded our targets for each area of our plan.

Our strategy focuses on four key objectives:



**1** Raising the funds necessary to successfully impact the future prediction and prevention of SUDC by granting to medical research



**2** Easing the experience of SUDC-bereaved families in the UK



**3** Activism for improved awareness of SUDC and funding for medical research



**4** Supporting UK family and professional engagement in SUDC research

## OUR VALUES

### Collaboration with families

Founded by bereaved parents, SUDC UK values the opinions and efforts of families affected by SUDC and the charity collaborates with this community to further its mission

### Collaboration with medical professionals and child death experts

SUDC UK believes close collaboration with the SUDC Foundation and other related national organisations will help further SUDC UK's mission

### Collaboration with the scientific community

SUDC UK believes funding, international collaboration, consistent data collection and increased professional engagement in SUDC research is crucial for Sudden Unexplained Death in Childhood to become predictable and preventable

### Information and Empowerment

SUDC UK believes accurate and consistent information should be available to all families affected by the sudden unexpected and often unexplained death of a child, so they are informed and empowered, and understand how to access relevant national and international resources



## Expanded SUDC UK Advisory Board

To guide us, in October 2024 we expanded our **Expert Advisory Board**, inviting world-renowned leaders in sudden child death to provide critical insight on complex issues affecting families and child health.

This strategy ensures our efforts and investment deliver impact — now and into the future.

- **Professor Mike Campbell**  
Emeritus Professor of Medical Statistics, Sheffield
- **Professor Marta Cohen OBE**  
Consultant Paediatrician, Sheffield
- **Professor Peter Fleming CBE**  
Emeritus Professor of Paediatrics, Bristol
- **Dr Joanna Garstang**  
Consultant Community Paediatrician, Birmingham
- **Laura Gould MSc MA, PT**  
NYU Grossman School of Medicine
- **Dr Samantha Holden**  
Consultant Paediatrician, Southampton
- **Professor Finbar O’Callaghan**  
Professor of Paediatric Neuroscience, Institute of Child Health
- **Professor Mary Sheppard**  
Cardiac Pathologist, St George’s Hospital
- **Professor Sanjay Sisodiya**  
Professor of Neurology, UCL
- **Dr Jan Till**  
Paediatric Electrophysiologist, Royal Brompton Hospital
- **Professor Carola Vinuesa**  
Professor of Immunology/Genetics, Francis Crick Institute

SUDC UK remains grateful and very proud to be supported by our Patron, **Jenni Thomas OBE**, who hosts our bereavement retreats, supports team well-being and guides our support services. Details of all our advisors can be found at [www.sudc.org.uk/sudc-uk-team](http://www.sudc.org.uk/sudc-uk-team)

# 2024 IMPACT IN NUMBERS

**332** SUDC UK family members to date



**49**

newly registered members this year



**88**

parent/carers and siblings attended SUDCUK in-person events

**60**

professional conferences, meetings or training.



**17**

SUDC UK articles, including 6 in the national press



**677**

supportive direct interactions with registered families



**£547,869**

invested in SUDC research

including a

**£100,000**

grant paid in 2024

and an additional

**£297,781**

designated to support research supported by our research review process in the next open call.

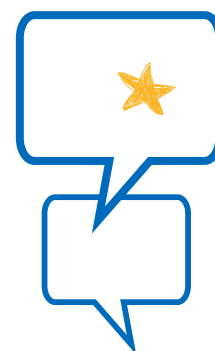
**5**

families referred to SUDC research projects for further investigation and to contribute to wider learning to help prevent future deaths



**20**

families successfully supported with NHS whole genome sequencing referral



**28**

new families received 1-1 SUDC UK support over zoom



# GRANTS TO MEDICAL RESEARCH

Driving research, searching for answers.

SUDC UK is the only UK charity dedicated to helping families find answers after the sudden, unexplained death of a child aged between 1 and 18 years. At the heart of our mission is a clear goal: to fund vital research to understand and prevent SUDC.

Thanks to the generous support of our community, SUDC UK has invested over £547,000 to date—including a £100,000 grant payment in 2024 as provided for in our 2023 accounts—in the Sudden Unexplained Death in Childhood Registry and Research Collaborative (SUDCRRC). This global, multidisciplinary initiative, based at NYU Langone (New York), brings together leading experts in pathology, cardiology, infectious disease and related fields, to investigate the causes of these tragic SUDC deaths and work towards their prevention. By combining insights from clinicians, researchers, pathologists, and coroners the SUDCRRC is helping to uncover answers once thought impossible — and paving the way for prevention.

We are proud to be the only UK organisation referring families to this international SUDC research programme, with 5 new families enrolled in 2024.


[READ ABOUT THE RESEARCH HERE](#)

Together, we are turning loss into action — advancing research, informing policy, and strengthening support to drive meaningful and lasting change.

*“I find myself on a quest to find out why my beautiful, healthy boy fell asleep with my ultimate aim to be for his legacy to live on and help save other children in the future.”*

An SUDC mum

In 2024, SUDC UK designated an additional

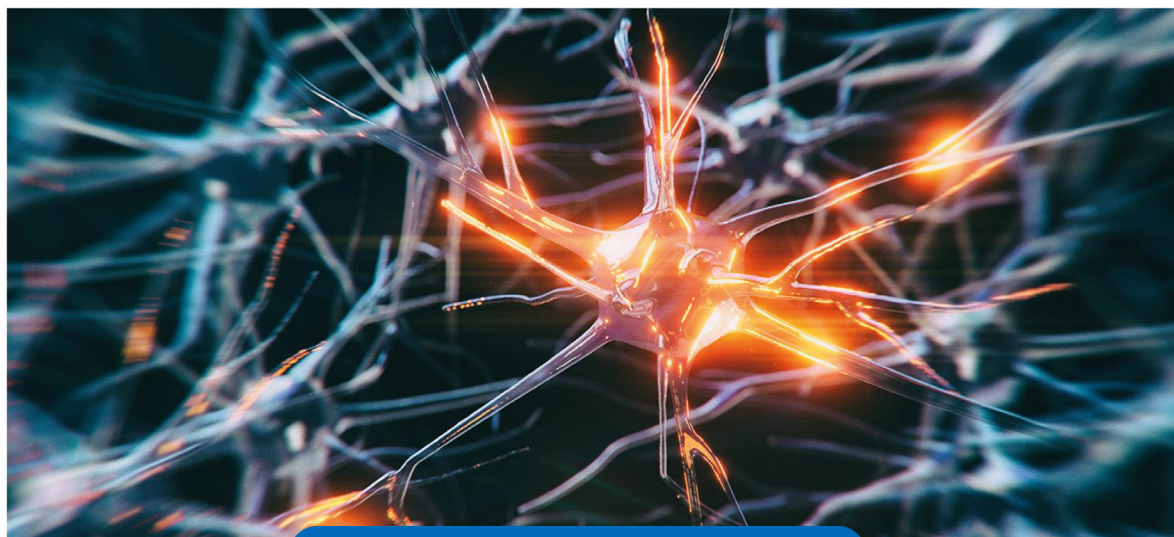


**£297,781**

to support research approved by our research review process in the next open call.

RESEARCH, PRESS RELEASES | JANUARY 4, 2024

## Seizures Identified as Potential Cause of Sudden Unexplained Deaths in Children



[CLICK HERE FOR FULL PRESS RELEASE](#)

### NEW EVIDENCE:

#### Febrile seizures may play a key role in SUDC

In January 2024, research funded by SUDC UK led to a significant scientific breakthrough. This pioneering study by the SUDCRRRC analysed audio-visual recordings from seven toddlers who died suddenly and without explanation.

Strikingly, despite the absence of any prior seizure history in most cases, clear febrile seizure activity was identified near the time of death—providing the strongest evidence to date of a potential link between convulsions and these tragic, unexplained deaths.

This landmark discovery underscores the urgent need for further research into the role of seizures in SUDC, with the potential to advance understanding, improve risk identification, and ultimately help prevent future deaths.

SUDC UK also supported the parents of Louis Rogers to

“ Our study, although small, offers the first direct evidence that seizures may be responsible for some sudden deaths in children, which are usually unwitnessed during sleep ”



Laura Gould, study lead investigator and a research assistant professor at NYU Langone.

advocate for changes in the wording of their NHS trust’s patient information leaflet for febrile seizures. The collaboration with the trust was appreciated by the paediatric and neurology team and this leaflet is now used in SUDC UK training to promote consistent and accurate patient information for all families if their child experiences a febrile seizure.

“ I was astonished to find out that 30% of children who die suddenly and unexpectedly have had febrile seizures. This new research into SUDC and seizures is urgently needed to prevent any more families losing a child ”

SUDC mum

## NEW RESEARCH STRATEGY:

### SUDC UK Open Call 2024

SUDC UK reinforced our commitment to advancing SUDC research by joining the **Association of Medical Research Charities (AMRC)** as an Introductory Member — a recognised mark of excellence in UK research funding. This affiliation strengthens our credibility with universities, government bodies, and funders, as we work towards achieving full AMRC Membership in 2025.

In 2024, SUDC UK launched its first formal **Research Strategy** — a bold commitment to fund breakthrough studies that could save children's lives.

#### Our mission is to:

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

#### We prioritise research that:

- Explores the link between SUDC and febrile seizures to identify preventable measures
- Influences national guidelines and NHS pathways to educate and protect families
- Advances understanding across genetics, neurology, cardiology, pathology, and more

In Autumn 2024, we launched our first **global research grant call**, inviting international projects aimed at making a meaningful impact on the lives of children in the UK. Our funding supports all stages of research — from early ideas to established studies — and helps foster the next generation of SUDC researchers.

We have formed an **SUDC UK Research Review Panel** — a vital step in driving forward scientific understanding of SUDC.

Led by Professor Rachel Chambers, Professor of Respiratory Cell & Molecular Biology, UCL, this bespoke research review panel brings together expert professionals and bereaved family representatives to rigorously assess research proposals and recommend funding to our SUDC UK Board of Trustees. We are proud to commit and designate up to £297,781 to research projects, set to launch in 2025 — and we look forward to sharing updates as this crucial work begins. SUDC UK received 5 applications for funding during this grant round and we believe this group of medical research applications was a result of SUDC UK's years of engagement efforts and impactful previous grant awards.



RESEARCH STRATEGY  
2024-2027

SUDC UK  
Sudden Unexplained Death in Childhood  
an affiliate of the SUDC Foundation

[READ THE RESEARCH STRATEGY HERE](#)

## 2024 Research Review Panel Members

#### Meeting Chair

- **Professor Rachel Chambers**, Professor of Respiratory Cell and Molecular Biology. Director of the Centre for Inflammation and Tissue Repair and Co-Head of the Department of Respiratory Medicine, UCL

#### Expert Panel Members

- **Professor Finbar O'Callaghan**  
Professor of Paediatric Neuroscience, Institute of Child Health
- **Dr Rachel Moon**  
Professor of Pediatrics, University of Virginia, USA
- **Professor Peter Sidebotham**  
Emeritus Professor of Child Health, Warwick Medical School
- **Professor Jeanine Young**  
Professor of Nursing, Sunshine Coast AUS

#### Family Voice Representatives

- **Clare Pitts**
- **Nathan Robinson**

Both representatives are bereaved parents affected by SUDC and they are currently ambassadors for SUDC UK. SUDC UK warmly and gratefully acknowledges their important contribution to this meeting and impact on medical research, in memory of their children, Alfie Robinson and Harry Pitts. Thank you.

#### Trustees as observers

- **Chris Bingham**
- **Helen Charalambous**



## SUPPORTING FAMILIES

Supporting bereaved families who have suddenly and unexpectedly lost their child — and the professionals who care for them — is at the heart of SUDC UK’s mission.

In 2024, we continued to create safe, meaningful spaces for connection and remembrance through events like our much-loved **family days**, **Stars for Our Children**, a **counsellor-led retreat weekend**, and our **annual SUDC Dads’ meal**. We also launched a vital new resource at the start of the school year — a UK-specific **SUDC guide for schools**, developed with member families and experts.

families at every step of the child death review process, ensuring they are never alone in navigating this difficult journey. In addition, our face-to-face and virtual events help connect families, while our advocacy work pushes for better, more consistent bereavement care across the UK.

In 2024, 88 bereaved individuals (55 adults and 33 children) attended SUDC UK events.

### Bereavement support and advice

SUDC UK provides dedicated, personal support to families facing the unimaginable.

Through phone, email, and one-to-one Zoom calls, we provide guidance and emotional support to families from the moment of discovery, through the complex and often traumatic medical investigation — including genetic screening — and throughout the long, uncertain wait for a coroner’s report. We stand beside

“SUDC UK supported us when we felt totally alone, but also, crucially, helped us navigate the systems and find answers. We will only be able to do this for other families if we continue to raise funds and do more research.”

SUDC parent

### Honouring and connecting

In 2024, we hosted two family days at ZSL Whipsnade Zoo and Yorkshire Wildlife Park, welcoming families - including siblings - from across the UK. These gatherings offered families a rare chance to connect with others who truly understand the unique pain of SUDC. These days culminated in coming together to hang stars in loving memory of SUDC children. As one parent said: “We felt welcomed with care, open arms, and complete understanding.”



“ A gentle, helpful weekend... I'd recommend it to anyone considering going. ”

SUDC mum



“ So, with this little star, and the hope it brings to me during my grieving process is just pure kindness, and so thoughtful. ”

SUDC parent



“ As a primary school teacher, it's brilliant and as a mum hugely helpful, the language is carefully and gently worded and it feels accessible. ”

SUDC mum

Once again, SUDC families united virtually through our Stars for Our Children activity – a powerful expression of remembrance, community, and hope. Every registered SUDC UK family received a star, to decorate and hang indoors or outside in honour of their child. This event is an annual heartfelt reminder that their child is remembered, and that no SUDC family is ever alone.

### Comfort and understanding

For #WaveOfLight2024, SUDC UK co-founders lit a candle for every registered family – a powerful tribute to all loved and missed children, and to those who grieve them.

In September, our annual SUDC Dads' meal offered a relaxed, supportive space for fathers to connect, share, and remember – with others who truly understand.

### NEW: SUDC Support in Schools

Thanks to funding from the Big Give Christmas Challenge, we launched 'SUDC Support in Schools' – a practical, compassionate guide for families and educators

navigating sudden and unexpected child loss.

The project was led by Amy Haynes—a bereaved SUDC sibling and teacher—who dedicated her Master's thesis to this vital topic. The resulting Support for Schools booklet was shaped by insights from primary and secondary teachers, counsellors, and members of the SUDC community – including, importantly, the voices of SUDC siblings themselves. It offers family stories, practical guidance, and a ready-to-use meeting template to foster open, compassionate communication between parents and schools.

### TO ORDER THE SUDC SUPPORT GUIDE

In October, we hosted our annual 'Reflect, Restore, Renew' Retreat, held in memory of Autumn Garwood – a gentle, supportive space for 12 recently bereaved parents to connect and reflect. Guided by compassionate experts, including Jenni Thomas OBE, Nicki Whitworth (SLOW), and SUDC mum Eleanor Wroath, who led her therapeutic 'Gardening for Grief' workshop, the weekend offered comfort, understanding, and community.

ONE

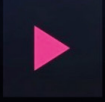
*“ I had honestly never heard of this before watching Panorama, we get a lot of awareness of SIDS, there needs to be more awareness of SUDC. So brave of the families ”*

*Member of the public*



## Panorama

Sudden Child Deaths: The Search for Answers



*“ I just want to quickly say what fantastic work SUDC UK has done in raising awareness through the Panorama documentary. I feel like it has really had an impact and it's all thanks to the hard work you all put in every day. Thank you. ”*

*SUDC parent*



# RAISING AWARENESS

SUDC UK works tirelessly to raise the profile of this category of death and to engage professionals, politicians and the public in supporting the cause and all affected families.

## SUDC UK on the BBC

On Monday 5th February, SUDC received national coverage like never before. SUDC was discussed across multiple BBC platforms, including online articles on the BBC homepage, BBC Breakfast TV, Radio 5 Live and Panorama investigated Sudden Unexplained Death in Childhood in “Sudden Child Deaths: The Search for Answers.”

[WATCH THE PROGRAMME HERE](#)

Supported and guided by SUDC UK over 9 months, this investigative documentary explored critical issues such as research, awareness, and family support — following a family’s journey from the sudden unexpected loss of their child through to the inquest. It captured a compassionate postmortem report meeting- that was arranged and supported by SUDC UK- and underscored the vital role of skilled key worker support. The broadcast significantly raised awareness of SUDC, helping more families access support and educating professionals.

Within 3 days of the programme SUDC UK had 7 new family registrations providing connection and support, our social media Facebook engagement increased by 2000%,

SUDC UK’s reach increased by 535% attracting 11.5K visitors to our page (91% were new, non-followers).

Very special thanks to Jodie and Gavin Dacres who created an incredible legacy for their son, Addy, through the impact of Panorama.

## SUDC UK at Parliament

On 18th March 2024, SUDC UK marked a historic milestone with the launch of National SUDC Awareness Day, hosted at a Parliamentary Reception in the House of Commons.

Supported by SUDC UK Volunteer, Julia Rogers, in memory of her son, Louis, Art of The Possible Agency, Butterfly Photography, CoCreate, Calvermont PR and Service Graphics, the event brought together 130 influential figures—including MPs, NHS and Department of Health and Social Care leaders, Royal College representatives, senior police and ambulance officials, Senior Coroners, expert clinicians, child death review professionals, hospices, leading charities, and SUDC UK Ambassador families.

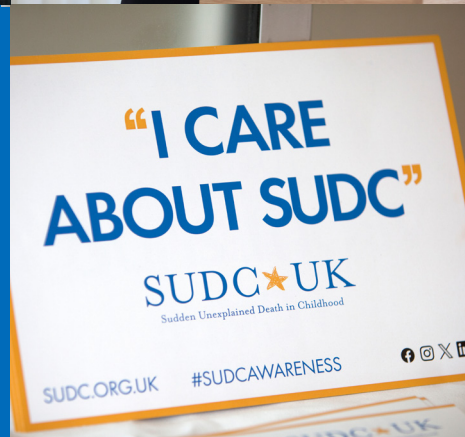
It was a powerful tribute to collaboration, expertise, and courage — recognising our recent progress, while calling for urgent action. Together, we honoured the children we have lost and renewed our shared commitment to driving change for



[FOR MORE DETAILS](#)



**“ It had huge resonance, I am so pleased awareness is being raised on SUDC....Thinking of you, thank you for your work, it matters hugely. ”**  
 SUDC parent



families, children, and the professionals who support them in this vital field.

## Let's all talk about SUDC

In 2024, courageous SUDC families stepped forward to share their stories — and their bravery sparked national awareness.

Thanks to them, SUDC gained powerful media coverage across BBC News, ITV, RTÉ, Times Radio, BBC Radio 4, The Sun, Daily Mirror, Woman's Own, and more. Engagement also soared across social media during Wave of Light, Child Grief Awareness Week, and the Big Give Christmas Campaign.

## Social media momentum

Social media made waves in 2024, with rising engagement across all platforms — especially during SUDC Awareness

Month and the September campaign push. Our first-ever Instagram Live featured CEO Nikki Speed supporting an ultra-marathon fundraiser, helping us connect with new audiences in real time.

In March, during SUDC Awareness Month, our 'I Care About SUDC' campaign sparked national momentum:

- 116 awareness packs sent to supporters and professionals
- 6 press features — 3 national and 3 local — spotlighted brave SUDC families
- Strong growth across all social channels, with Instagram engagement up 28%, and Twitter impressions rising 50–75%

Our SUDC UK Ambassadors played a vital role — giving talks in hospitals, running events like celebrity football matches and golf days, and amplifying our message online.

Together, these diverse national and local voices have helped bring sudden unexplained childhood death out of the shadows — and into the spotlight.



# PROFESSIONAL AWARENESS AND ADVOCACY

SUDC UK is a lifeline for families facing the sudden, unexplained death of a child.

We work to ensure every UK SUDC-bereaved family hears about us — through professional referrals, our website, or public awareness campaigns — within days of their loss.

To improve understanding and response, we've developed a dedicated **education programme for UK professionals**, raising awareness of SUDC and the support we offer.

Each year, more families are connecting with us sooner, allowing us to provide guidance and support through this profoundly challenging time. We guide families and professionals through the child death investigation process, genetic testing, sibling screening, and facilitate access to expert counselling.

In 2024, we provided **direct advocacy for 28 families**, helping them navigate grief, confusion, and isolation. With continued training and awareness, we're working towards a future where **no family faces SUDC alone**.

When there is no dedicated local resource, SUDC UK acts as an NHS-designated key worker for families and in

2024 we supported 6 families, supporting them as their single point of contact as they try to cope after their child's death and advocating for them in the Child Death Review Process, giving them a voice and opportunity to have questions answered and impact local learning.

SUDC UK was also invited to support the North West London and Hertfordshire Child Death Overview Panels in 2024. We attended 8 meetings, including strategic meetings, providing specialist insight and perspective from a sudden child bereavement charity.

## Advocacy achievements

In August 2024, SUDC UK was invited to attend a national meeting led by the NHS England Children and Young People Team Director, Professor Simon Kenny, to discuss the role of key workers for bereaved families. This was a direct result of our Parliamentary meeting in March. Our CEO presented to all Integrated Care Board leads in England and invited the lead SUDC Lancashire Nurse and the Designated Doctor for Child Death from Oxfordshire to



**“ Thanks again for all your help to drive the right conversations. I wouldn't have the knowledge about what we could or should have access to otherwise. ”**

*SUDC mother in 2024*



co-present to explain successes and challenges regarding effective key worker provision. The advocacy for trained and well-resourced key worker provision was impactful, leading to discussion on the importance of bereavement support in the developing NHS 10 year plan. We are very grateful to the professionals who supported this meeting.

SUDC UK advocates for NHS Genetics for every family and policy that aim to uncover risk factors, deepen understanding, and ultimately help prevent future tragedies.

In 2024 we were proud to continue championing a landmark change in a genetic project, which focused exclusively on SIDS and SUDC. For the first time, when a child's death remains unexplained after post-mortem and professional review, families in England are now offered advanced genetic investigation as part of the pathway. This 'super panel' test is in the National Genomics Test directory: R441 for SIDS and SUDC. This represents a crucial step forward ensuring that, where science allows, families can begin to search for answers.

Families have told SUDC UK that genetic testing not only provides reassurance but also helps with expert medical care. This initiative seeks to identify new genetic insights into sudden, unexplained infant and child deaths—offering renewed hope for answers and prevention.

It is also about more than data—it's about giving hope, driving discovery, and preventing future tragedies.

Due to the impact of this recently launched test, SUDC

**“ When a child dies without warning or explanation, there can be no greater shock nor sadness for the family left behind. The void that is irrevocably created by a such a loss defies any sense of 'normal' and professionals dealing with families need guidance and support to, in turn, best support newly bereaved parents and carers.**

**SUDC UK provides such a lifeline. In addition to the laudable work they do directly with families, stepping in where few others are equipped or trained to, they are a beacon to healthcare workers who desperately need a sense of direction and structure in order to care for families in these unimaginable circumstances. For those of us who have an additional designated role in ensuring rigorous review and analysis of every child death, SUDC UK, with their vast knowledge and experience, provides an accessible standard that defines best practice. Children and families deserve no less.**

**This charity is one that has become integral to those of us working towards the goal of supporting families through these tragedies and learning from each and every sad death. We could not do our work without SUDC UK. It's that simple.”**

*Dr Alison Shefler Designated Doctor for Child Death Oxfordshire*



**“ I provide these talks to community groups, ending each talk remembering Frankie; providing SUDC awareness information and raising funds for SUDC UK. ”**

*Brian Topping*

SUDC UK was invited once again to present at the national Association of Child Death Review Professionals Conference and share a recorded zoom call between our CEO and an **SUDC Ambassador and parent, Dr Emily Cooper**, with the 200 influential attendees. This presentation led to other opportunities and requests to share this emotional and impactful video which clearly explains the importance of this work.

## Improving Child Death Reviews

### A Milestone for Compassionate Care

In July 2024, SUDC UK supported the launch of materials for more compassionate child death reviews across England.

For nearly two years, SUDC UK has proudly contributed as a key stakeholder in a groundbreaking research project aimed at improving the review process following the tragic death of a child. In July, Dr Joanna Garstang and her team launched a powerful new toolkit designed to support professionals in the key worker (single point of contact) role—ensuring families receive consistent, compassionate care from the start. At the launch the project was brought to life at an inspiring in-person event attended by 170 professionals. Hannah Johnston,

**“ As a paediatrician, you have opened my eyes to the rare yet devastating SUDC cases and the experiences of the family both at the time and going forward. ”**

*Dr Claire Roome*

SUDC UK’s Communications Manager, courageously shared the story of her little boy, William. Her words were a powerful reminder of why our work matters—and why families deserve time, care, and dedicated support at every step.

[➔ MORE INFORMATION HERE](#)

As already highlighted, in December, for the third year in a row, SUDC UK had a strong presence at the **Association of Child Death Review Professionals conference**, meeting with nurses, paediatricians, police, senior coroners and other bereavement workers and charities. Huge thanks to our incredible SUDC UK ambassadors: Liam Walsh for supporting our stand, and Dr Emily Cooper.

## Extending our reach across the UK

In 2024, we made major strides in increasing awareness in Scotland. Ambassador Daisy McKenzie has been a driving force — raising awareness in memory of her son Albie and delivering talks across the country. She has helped build strong ties with key organisations, including Health Improvement Scotland and the Scottish National Hub. SUDC UK



presented to all Child Death Review leads across Scotland and joined Child Bereavement UK’s Scottish Bereavement Network’s autumn event to continue strengthening national collaboration.

SUDC UK is very excited by the development of our new regional medical education programme. Our Ambassador, Brian Topping, is at the heart of this progress — inspiring local training and raising vital awareness. Brian championed, arranged and supported a program of medical education events across Lancashire. Supported by SUDC UK, Brian delivered 9 impactful training presentations to over 200 medical staff, police and Coroners offices in collaboration with our CEO and the local SUDC lead nurse, Jo Birch.

Building on this momentum, we plan to train additional Ambassadors to expand our reach even further.

Together, we are breaking the silence on SUDC, building partnerships, and driving change — across all corners of the UK.

## Professional training

In 2024, SUDC UK attended over 60 professional meetings to advocate for families and raise awareness of SUDC. 34 of these have been direct training sessions, providing information about SUDC facts and the impact on families, research, guidelines, care recommendations and resources.

- Regional study days with child death experts
- International meetings with researchers
- Presentations in Parliament

“ I heard from a CDOP [Child Death Overview Panel] recently that their first R441 (genetic) test that they sent for a family picked up a known condition! This just underlines how important it is that this should be offered for everyone in such a situation. I know it won't bring the child back for that family, but I hope it will help them to have an answer and that might help in their grieving process. They would not have been able to provide the answer for this family without all your hard work in this area. You know I think you are amazing and what SUDC UK does makes such a difference but I wanted you to know that it's working ”

Vicky Sleep, Deputy Director of the National Child Mortality Database, May 2024

- Presentations with Scottish and English national NHS leads
- National St John’s Ambulance
- National Institute of Health Visitors webinar
- Emergency Paediatrician meetings

## Local team training

A key achievement this year was SUDC UK’s collaboration with Essex Police to produce an informative video outlining the police response to sudden, unexpected child deaths. The video not only explains the local investigative process but powerfully shows how a compassionate approach and clear communication can ease trauma and provide critical support to families in their most vulnerable moments.



# ENGAGEMENT IN SUDC RESEARCH

SUDC research continues to be critically underfunded and widely overlooked on a global scale — a gap SUDC UK is determined to close.


We are driving meaningful progress by empowering UK families and professionals to engage with and contribute to essential research. Our efforts ensure families are kept informed of all relevant studies, while we actively strengthen partnerships with charities and organisations committed to advancing research and supporting those affected. Together, we are building the momentum needed to uncover answers, transform understanding, and ultimately, save lives.

## A step forward for SUDC research awareness

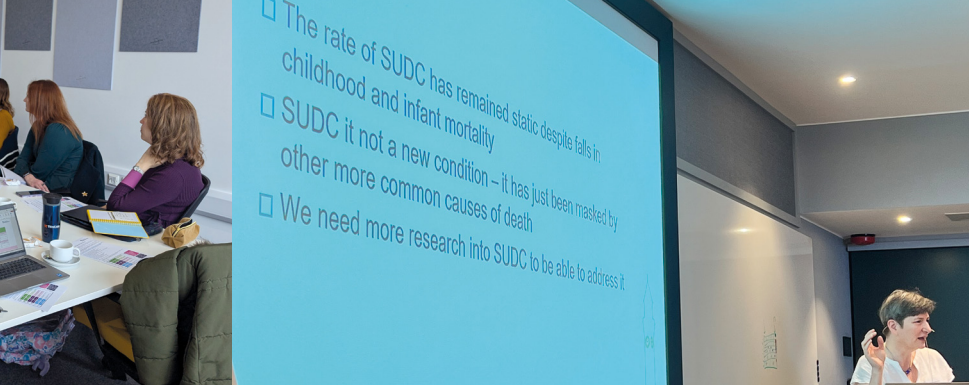
A new research publication in a BMJ journal by our expert advisor, paediatrician, and researcher Dr Joanna Garstang shines a critical spotlight on SUDC in the UK. We fully endorse the article’s conclusions and are grateful for the awareness this important research will generate. (British Medical Journal, Incidence of sudden unexplained death in childhood for children aged 1–14 years in England and Wales during 2001–2020: an observational study) <https://adc.bmj.com/>

[READ THE RESEARCH HERE](#)

**“ The incidence of SUDC has remained static despite overall child mortality almost halving in the last two decades. SUDC is now more widely recognised due to improved investigation, but there has been limited research into SUDC; potential causes and associated risk factors remain unknown. As the relative proportion of child deaths due to SUDC increases, child health professionals must be aware of SUDC to support bereaved families. ”**



*Dr Joanna Garstang, expert advisor*



“ 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. ”

Professor Peter Fleming CBE, our expert advisor, explains the vital need for SUDC research

## SUDC UK driving global impact

SUDC is a global issue—and solving it demands international collaboration. Over the past year, SUDC UK has played a pivotal role in elevating the global conversation, ensuring SUDC is no longer sidelined in scientific and clinical communities.

This year, history was made with the launch of the first-ever International Working Group for Sudden Unexplained Death in Childhood, which is co-chaired by our CEO, Nikki Speed, and Laura Gould, Co-Principal Investigator at the SUDCRRC. Going forward, this groundbreaking working group will meet regularly under the banner of The International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) — creating a vital new forum for international researchers, charities, and clinicians to collaborate and accelerate progress for the cause—all with SUDC UK’s leadership and a strong voice for families.

Following advocacy and successful networking at last year’s event, SUDC also featured prominently at this year’s conference on “Sudden infant death and pediatric forensic challenges” in Soria Moria, Oslo. Highlights included a presentation of WGS R441, showcasing SUDC UK’s impact, and the attendance of leading UK cardiologist Professor Mary Sheppard, whose involvement was facilitated by SUDC UK. SUDC UK supported three travel grants to the conference for SUDC researchers, Peter Fleming CBE, Joanna Garstang and Declan McGuone to present their research and support discussions that were vital for progress.

This year, in a pivotal shift, SUDC research featured prominently in nearly every session, culminating in the very first dedicated SUDC session, chaired by and including a presentation from our CEO, Dr Nikki Speed. The energy and engagement around SUDC was palpable.

With continued global partnership, advocacy, and resolve, we are driving SUDC to the forefront of international research efforts.

## Bereavement support research

In December 2024, SUDC UK was honoured to champion the launch of a major national initiative aimed at transforming bereavement care for families affected by sudden unexpected death in infancy and childhood.

As a proud co-applicant and co-investigator on QUINTET — a pioneering £1.2 million, three-year study funded by the NIHR and led by the University of Southampton — we are expediting efforts to investigate inequities in end-of-life care following sudden and unexpected deaths in children and young people.

This impactful collaboration unites leading bereavement charities, including SUDC UK, 2Wish, Shooting Stars Hospice, and Forget Me Not Hospice, alongside prominent UK academic institutions and the National Child Mortality Database.

SUDC UK had a significant impact on the success of this funding application and we will be leading on project recruitment and engagement.

[READ THE RESEARCH HERE](#)



## FUNDRAISING

In 2024, we set out to grow our income by 5% — and proudly achieved a 32% increase, thanks to an extraordinary year of community-led fundraising and awareness.

This success reflects the dedication, creativity, and compassion of SUDC families, friends, and supporters across the country. From high-profile national campaigns like the Big Give – powered by generous pledgers and donors- to personal challenges and local events, our community came together with unwavering commitment and generosity.

### What made the difference:

- **Incredible individual efforts**, like one passionate supporter and Ambassador, Nicola Buchan, running an astonishing 18 marathons in 18 days, a sponsored walk from London to Manchester, a Hiking to the Stars climb up Kilimanjaro by SUDC Ambassador Claire Smith and a remarkable year-long fundraising campaign of quizzes, coffee mornings, and community events.
- **Challenge events** brought hundreds together — running, climbing, riding, swimming, hiking, even skydiving — all in honour of the children we've lost and the families we support.

Events included the Royal Parks Half Marathon, Great

North Run, RideLondon 100, the London Landmarks Half Marathon, Great South Run and the Croyde Ocean Triathlon

- **Collaborations and partnerships** without which, we could not deliver our mission. Organisations like The Oliver's Wish Foundation, Friends of Frankie, UK Games Expo for Autum Garwood, The Matthew Cowley Foundation and The Amy Robinson Foundation provided powerful support throughout the year.
- **Community and corporate events**, from charity balls and quizzes to school-led activities and boxing matches — helped raise awareness and vital funds while bringing people together.
- **Volunteers and pro bono professionals** donated time, talent, and energy, making national campaigns like the **Big Give Christmas Campaign** possible and impactful.

Our heartfelt thanks go to our incredible supporters, volunteers -including pro bono professionals- and everyone who contributed time, energy, and generosity. These combined efforts have enabled us to exceed expectations in raising both awareness of SUDC and the support available to affected families across the UK.



# SUSTAINABILITY

Support from phenomenal community fundraising and generous donations has enabled the charity to employ staff and evolve its services, awareness activities and events for families.

This year we have strengthened the SUDC UK team, with Lorna McKay in a new permanent part-time role, supporting fundraising & events, and new Trustees Madeleine Finn and Chris Bingham, who bring valuable expertise in education and finance to our board.



Lorna McKay



Chris Bingham



Madeleine Finn

## Ambassador and Volunteer roles

SUDC UK is supported by a group of passionate and highly skilled SUDC UK Ambassadors and operational volunteers.

SUDC UK Ambassadors are committed individuals who are formally invited to support SUDC UK in a variety of ways in long term support. These include fundraisers and major donors, advocates who present at or attend medical events, those who would be called upon to support local or national press, or individuals who connect SUDC UK with new opportunities, local MPs or NHS teams in line with our current strategy. They collaborate with SUDC UK to inspire and educate people about the cause and our charity, raising important awareness. Ambassadors discuss the work we do, the services we have to offer, and signpost individuals to SUDC UK.

In addition to SUDC UK Ambassadors, we also have a group of SUDC UK Volunteers who support the charity in a defined role or who are contracted to support a particular project. SUDC UK's operations have performed successfully in collaboration with our volunteers, many of whom have supported the charity for years.

We would like to thank each and every person for their time, expertise, generosity and the difference they have made. The progress and impact shared in this report would not have been achieved without you! We also acknowledge that there are so many others who have had incredible impact in 2024 and proceeding years.

Thank you!

Thank you to the SUDC Foundation ([www.sudc.org](http://www.sudc.org)) supporting UK family registration and your generous collaboration throughout 2024.

## Volunteers and Ambassadors in 2024

- |                  |                         |
|------------------|-------------------------|
| Beewan Athwal    | Laura Mullen            |
| Emily Bowes      | Kat Patterson           |
| Nicola Buchan    | Brooke Petersen         |
| Samantha Cowley  | Ben Pitts               |
| Jodie Dacres     | Clare Pitts             |
| Gavin Dacres     | James Potter            |
| Anna Dowling     | Lucy Potter             |
| Rob Dowling      | Dominic Potts           |
| Jackie Garwood   | Laura Robinson          |
| Laura Gibson     | Nathan Robinson         |
| Lucy Godding     | Kieran Robinson         |
| Jo Griffiths     | Julia Rogers            |
| Sarah Grogan     | Christian Rogers        |
| Vanessa Grzywacz | Lucy Salter             |
| Laura Gulliver   | Kimberley Shepherd      |
| Sarah Hackney    | Natalie Sheraton        |
| Mikala Hatfield  | Claire Smith            |
| Harry Hatfield   | Tom Speed               |
| Amy Haynes       | Fiona Strachan          |
| Natalie Hughes   | Joe Strachan            |
| Katie Jones      | Brian Topping           |
| Adrian Kirby     | Laura Trahearn          |
| Sarah Laurent    | John Trahearn           |
| Sally Law        | Kate Walsh              |
| Claire Love      | Niamh Walsh             |
| Bex Luisi        | Liam Walsh              |
| Daisy McKenzie   | Eleanor Moriarty Wroath |
| Ryan Moore       |                         |

## Other generous supporters

- |                            |                           |
|----------------------------|---------------------------|
| Art of The Possible Agency | Nicola Whitworth          |
| Richard Bilton, BBC        | Service Graphics          |
| Claire Kendall, BBC        | The Hospital Saturday     |
| Butterfly Photography      | Fund                      |
| Calvermont PR              | TPS visual Communications |
| CoCreate                   | UK Games Expo             |
| Joanna Vitiv, Feather.ink  |                           |
| Henry Schein               |                           |



## OUR FUTURE

As we look ahead to 2025, we are building on the powerful momentum of a transformative year—marked by growing **public awareness**, deeper **professional engagement**, and vital **scientific progress**.

Our commitment remains clear: to lead with **compassion**, drive **collaboration**, and be recognised as the **leading voice** on sudden unexplained deaths in childhood. We will continue to deliver against our strategic goals, rooted in our core values and strengthened by meaningful UK and international partnerships.

2025 will mark a pivotal year as we deepen our research efforts and shape an ambitious long-term strategy to guide SUDC UK’s national impact.

In 2025, we aim to amplify our impact through a new Ambassador event, expanded PR outreach, and a more diverse approach to fundraising. To support these ambitions, we plan to appoint a part-time Trusts Manager to build strategic relationships and unlock new sources of funding.

By building on these developments, we are establishing a strong foundation for meaningful growth and are eagerly anticipating an exciting, impactful year ahead.

### Your support is making a difference

SUDC UK may be small—with just four part-time staff and 11 dedicated volunteers—but our impact is mighty. What fuels us is that we understand the unmet need; we have purpose, passion, and the unwavering belief that we can change the future for families affected by sudden unexplained deaths in childhood.

With the support of our SUDC families, expert advisors, partner charities, committed professionals, researchers and donors we are raising awareness, improving care, and driving the search for answers.

Together, we are shining a light on the challenges of SUDC and building a future where every affected family receives the understanding, answers, and support they deserve.

**Together, we are a powerful force for change - and we’re only just getting started.**

# ANNUAL REPORT AND UNAUDITED FINANCIAL STATEMENTS

For the year ended 31 December 2024



## Legal and administrative information

Trustees C Gooden  
H Charalambous  
A Milliken  
C Bingham (Appointed 9 January 2024)  
M Finn (Appointed 9 January 2024)

Charity number (England and Wales) 1175413

Independent examiner Thomas Mayfield BA FCA  
Mayfield & Co (Accountants) Ltd  
2 Merus Court  
Meridian Business Park  
Leicester  
LE19 1RJ

## TRUSTEES REPORT For the year ended 31 December 2024

The trustees present their annual report and financial statements for the year ended 31 December 2024.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the charity's governing document, the Charities Act 2011, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)".

### Objectives and activities

#### Public benefit

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charitable incorporated organisation should undertake, and we confirm we have reviewed our activities, and they are all undertaken with a view to us providing a public benefit.

### Financial review

#### Summary

- The statement of financial activities shows total income for the year of £400,650 up from £299,839 and total expenditure of £139,215 down from £271,727. This leaves a total surplus of £261,435 for the year, which is down to a timing difference between income generation and spending because of the timing of when we have committed the grant funding.
  - We have transferred £297,781 from our unrestricted funding to designated reserves as we have specifically reserved this amount for future spending to support research in 2025 (as articulated on page 6 of this report).
- We finish the year with total reserves of £403,217 carried forward and split between Unrestricted Funds of £105,436 and Designated Funds of £297,781.

#### Reserves policy

Reserves to sustain the charity are calculated by adding together the minimal operating costs to sustain the charity and progress our mission in 2025 (including emergency salary fund for charity sustainability and systems and membership costs), and any restricted funds.

The expectation is that the above, under normal circumstances will be funded using 2025 income. However, to mitigate risk & keep the charity sustainable if income is limited, this reserve amount will be kept as a designated fund in a 60 -day access CAF account during 2025.

The trustees consider that reserves at this level will ensure that, in the event of a significant drop in funding, they will be able to continue the charity's current activities while consideration is given to ways in which additional funds

may be raised. SUDC UK'S financial performance will be tracked by the CEO and critically reviewed quarterly by the board of trustees.

### Structure, governance and management

#### The charity is a company limited by guarantee

On the 27 October 2017 SUDC-UK was registered with the Charity Commission as a Charitable Incorporated Organisation.

The trustees who served during the year and up to the date of signature of the financial statements were:

C Gooden, H Charalambous, A Milliken, C Bingham (Appointed 9 January 2024), M Finn (Appointed 9 January 2024)

The composition of the Board of Trustees is governed by the CIO's constitution. The Board meets quarterly, or more frequently, if required. There are sub committees covering Research, finance and Communication. A manager, appointed by the Trustees, is responsible for day-to-day activities and meets with the chair of trustees monthly.

#### Recruitment and appointment of trustees

Trustees are elected annually at the Annual General Meeting. The Trustees may co-opt further trustees during the year who will serve until the following Annual General Meeting. All members are circulated with invitations prior to the Annual General Meeting, advising them of the names due to resign and requesting nominations for the Annual General Meeting

The Trustees report was approved by the Board of Trustees

Signed by:

*Helen Charalambous*

C11C395C508F46A...

H Charalambous

Trustee

Date:

29 October 2025

# INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF SUDC UK

I report to the trustees on my examination of the financial statements of SUDC UK (the charity) for the year ended 31 December 2024.

## Responsibilities and basis of report

As the trustees of the charity you are responsible for the preparation of the financial statements in accordance with the requirements of the Charities Act 2011.

I report in respect of my examination of the charity's financial statements carried out under section 145 of the Charities Act 2011. In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the Charities Act 2011.

## Independent examiner's statement

Since the charity's gross income exceeded £250,000, the independent examiner must be a member of a body listed in section 145 of the Charities Act 2011. I confirm that I am qualified to undertake the examination because I am a member of ICAEW, which is one of the listed bodies.

Your attention is drawn to the fact that the charity has prepared the financial statements in accordance with the relevant version of the Statement of Recommended Practice applicable to charities preparing their financial statements in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) in preference to the Accounting and Reporting by Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has now been withdrawn. I understand that this has been done in order for the financial statements to provide a true and fair view in accordance with UK Generally Accepted Accounting Practice. I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1 accounting records were not kept in respect of the charity as required by section 130 of the Charities Act 2011.
- 2 the financial statements do not accord with those records; or
- 3 the financial statements do not comply with the applicable requirements concerning the form and content of financial statements set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the financial statements give a true and fair view, which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the financial statements to be reached.

Signed by:

*Thomas Mayfield BA FCA*

8A0F559745FF406...

Thomas Mayfield BA FCA

Mayfield & Co (Accountants) Ltd

2 Merus Court

Meridian Business Park

Leicester

LE19 1RJ

Date: 28 October 2025

## Statement of financial activities including income and expenditure account

For the year ended 31 December 2024

	Notes	Unrestricted funds general 2024 £	Unrestricted funds designated 2024 £	Total 2024 £	Unrestricted funds general 2023 £
<b>Income from:</b>					
Donations and legacies	3	399,824	-	399,824	299,421
Investments	4	826	-	826	418
<b>Total income</b>		400,650	-	400,650	299,839
<b>Expenditure on:</b>					
Charitable activities	5	139,215	-	139,215	271,727
<b>Total expenditure</b>		139,215	-	139,215	271,727
<b>Net income</b>		261,435	-	261,435	28,112
Transfers between funds		(297,781)	297,781	-	-
<b>Net movement in funds</b>		(36,346)	297,781	261,435	28,112
<b>Reconciliation of funds:</b>					
Fund balances at 1 January 2024		141,782	-	141,782	113,670
<b>Fund balances at 31 December 2024</b>		105,436	297,781	403,217	141,782

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure derived from continuing activities.

## Balance sheet

as at 31 December 2024

	Notes	2024		2023	
		£	£	£	£
<b>Current assets</b>					
Debtors	10	1,270		-	
Cash at bank and in hand		406,383		247,233	
		<u>407,653</u>		<u>247,233</u>	
<b>Creditors: amounts falling due within one year</b>	11	(4,436)		(105,451)	
<b>Net current assets</b>			<u>403,217</u>		<u>141,782</u>
<b>The funds of the charity</b>					
Unrestricted funds - general	13		105,436		141,782
Unrestricted funds - designated	12		297,781		-
			<u>403,217</u>		<u>141,782</u>

The financial statements were approved by the trustees on

Signed by:

*Helen Charalambous*

29 October 2025

H. Charalambous  
Trustee

# Notes to the financial statements

## For the year ended 31 December 2024

---

### 1 Accounting policies

#### Charity information

SUDC UK was granted charitable status on the 27 October 2017 as a Charitable Incorporated Organisation (CIO).

#### 1.1 Basis of preparation

The financial statements have been prepared in accordance with the charity's governing document, the Charities Act 2011, FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)". The charity is a Public Benefit Entity as defined by FRS 102.

The charity has taken advantage of the provisions in the SORP for charities not to prepare a statement of cash flows.

The financial statements have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to provide a true and fair view. This departure has involved following the Statement of Recommended Practice for charities applying FRS 102 rather than the version of the Statement of Recommended Practice which is referred to in the Regulations but which has since been withdrawn.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £.

The financial statements have been prepared under the historical cost convention, [modified to include the revaluation of freehold properties and to include investment properties and certain financial instruments at fair value]. The principal accounting policies adopted are set out below.

#### 1.2 Going concern

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. Thus the trustees continue to adopt the going concern basis of accounting in preparing the financial statements.

#### 1.3 Charitable funds

Unrestricted funds are available for use at the discretion of the trustees in furtherance of their charitable objectives.

Restricted funds are subject to specific conditions by donors or grantors as to how they may be used. The purposes and uses of the restricted funds are set out in the notes to the financial statements.

Endowment funds are subject to specific conditions by donors that the capital must be maintained by the charity.

#### 1.4 Income

Income is recognised when the charity is legally entitled to it after any performance conditions have been met, the amounts can be measured reliably, and it is probable that income will be received.

Cash donations are recognised on receipt. Other donations are recognised once the charity has been notified of the donation, unless performance conditions require deferral of the amount. Income tax recoverable in relation to donations received under Gift Aid or deeds of covenant is recognised at the time of the donation.

Legacies are recognised on receipt or otherwise if the charity has been notified of an impending distribution, the amount is known, and receipt is expected. If the amount is not known, the legacy is treated as a contingent asset.

# Notes to the financial statements

For the year ended 31 December 2024

---

## 1 Accounting policies

### 1.5 Expenditure

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.

Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges are allocated on the portion of the asset's use.

### 1.6 Cash and cash equivalents

Cash and cash equivalents include cash in hand, deposits held at call with banks, other short-term liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within borrowings in current liabilities.

### 1.7 Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measures at their settlement value with the exception of bank loans, which are subsequently measured at amortised cost using the effective interest method.

#### **Basic financial assets**

Basic financial assets, which include debtors and cash and bank balances, are initially measured at transaction price including transaction costs and are subsequently carried at amortised cost using the effective interest method unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest. Financial assets classified as receivable within one year are not amortised.

#### **Basic financial liabilities**

Basic financial liabilities, including creditors and bank loans are initially recognised at transaction price unless the arrangement constitutes a financing transaction, where the debt instrument is measured at the present value of the future payments discounted at a market rate of interest. Financial liabilities classified as payable within one year are not amortised.

Debt instruments are subsequently carried at amortised cost, using the effective interest rate method.

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of operations from suppliers. Amounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Trade creditors are recognised initially at transaction price and subsequently measured at amortised cost using the effective interest method.

#### **Derecognition of financial liabilities**

Financial liabilities are derecognised when the charity's contractual obligations expire or are discharged or cancelled.

### 1.8 Employee benefits

The cost of any unused holiday entitlement is recognised in the period in which the employee's services are received.

Termination benefits are recognised immediately as an expense when the charity is demonstrably committed to terminate the employment of an employee or to provide termination benefits.

## Notes to the financial statements

For the year ended 31 December 2024

### 2 Critical accounting estimates and judgements

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised where the revision affects only that period, or in the period of the revision and future periods where the revision affects both current and future periods.

### 3 Income from donations and legacies

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Donations and gifts	399,824	299,421
<b>Donations and gifts</b>		
General Giving	394,317	295,593
Gift Aid tax reclaimed	5,507	3,828
	<u>399,824</u>	<u>299,421</u>

### 4 Income from investments

	Unrestricted funds 2024 £	Unrestricted funds 2023 £
Interest receivable	826	418
	<u>826</u>	<u>418</u>

## Notes to the financial statements

For the year ended 31 December 2024

### 5 Expenditure on charitable activities

	Unrestricted fund 2024 £	Unrestricted fund 2023 £
<b>Direct costs</b>		
Staff costs	78,665	49,138
Cost of sales	4,963	3,400
Accountancy	-	870
Advertising/Promotion	2,015	1,587
Events	18,050	14,263
Bank charges	-	4,802
Computer costs	3,732	1,634
Conferences	-	177
Contractor costs	1,065	4,357
Gifts	720	467
Insurance	573	283
Printing, postage and stationery	4,502	3,199
Office expenses	1,696	2,518
Professional fees	1,120	3,354
Entertainment	624	465
Travel and subsistence	3,188	3,904
Other charitable expenditure	4,004	5,113
	<u>124,917</u>	<u>99,531</u>
Grant funding of activities (see note 6)	3,165	172,196
<b>Share of support and governance costs (see note 7)</b>		
Governance	11,133	-
	<u>139,215</u>	<u>271,727</u>
	<u>139,215</u>	<u>271,727</u>
<b>Analysis by fund</b>		
Unrestricted funds - general	<u>139,215</u>	<u>271,727</u>

### 6 Grants payable

	Unrestricted fund 2024 £	Unrestricted fund 2023 £
Grants to institutions:		
SUDCRRC Grant	-	172,196
Grants to individuals (3 grants)	<u>3,165</u>	<u>-</u>

## Notes to the financial statements

### For the year ended 31 December 2024

#### 6 Grants payable

The charity paid a grant in 2024 which was reserved in 2023. No new grants were approved in 2024 and so there were no new grants provided for 2024.

The trustees approved a new grants programme in March 2025 and so these grants will feature next year.

In 2023 there were 3 grants provided to SUDCRRC for the following purposes:

£100,000 for Phenotyping, genetic analyses and blinded multidisciplinary case reviews, creation of SUDC biorepository

£31,766 for Project 'Video Recordings of Sudden Deaths in Toddlers'

£40,430 for Project 'Febrile Seizure Characteristics in Sudden Unexplained Death in Childhood'

In 2024 there were 3 grants provided to individuals for travel for research purposes.

#### 7 Support costs allocated to activities

	2024 £	2023 £
Governance costs	11,133	-
<b>Analysed between:</b>		
Unrestricted fund	11,133	-
	<b>2024</b> £	<b>2023</b> £
<b>Governance costs comprise:</b>		
Staff costs	4,140	-
Independent examiner's fees	1,500	-
Bank charges	5,493	-
	11,133	-

#### 8 Trustees

None of the trustees (or any persons connected with them) received any remuneration or benefits from the charity during the year.

#### 9 Taxation

The charity is exempt from taxation on its activities because all its income is applied for charitable purposes.

## Notes to the financial statements

For the year ended 31 December 2024

### 10 Debtors

	2024	2023
	£	£
Amounts falling due within one year:		
Prepayments and accrued income	1,270	-
	<u>1,270</u>	<u>-</u>

### 11 Creditors: amounts falling due within one year

	2024	2023
	£	£
Other taxation and social security	2,096	2,116
Trade creditors	513	2,065
Other creditors	327	100,400
Accruals and deferred income	1,500	870
	<u>4,436</u>	<u>105,451</u>

### 12 Unrestricted funds - designated

These are designated funds which have been set aside out of unrestricted funds by the trustees for specific purposes.

	At 1 January 2024	Transfers	At 31 December 2024
	£	£	£
Funds for Designated Projects and Research	-	297,781	297,781
	<u>-</u>	<u>297,781</u>	<u>297,781</u>

The trustees have decided to allocate funds of £297,781 for future designated projects and research.

### 13 Unrestricted funds

The unrestricted funds of the charity comprise the unexpended balances of donations and grants which are not subject to specific conditions by donors and grantors as to how they may be used.

	At 1 January 2024	Incoming resources	Resources expended	Transfers At 31 December 2024	
	£	£	£	£	£
General funds	141,782	400,650	(139,215)	(297,781)	105,436
	<u>141,782</u>	<u>400,650</u>	<u>(139,215)</u>	<u>(297,781)</u>	<u>105,436</u>
<b>Previous year:</b>	<b>At 1 January 2023</b>	<b>Incoming resources</b>	<b>Resources expended</b>	<b>Transfers At 31 December 2023</b>	
	£	£	£	£	£
General funds	113,670	299,839	(271,727)	-	141,782
	<u>113,670</u>	<u>299,839</u>	<u>(271,727)</u>	<u>-</u>	<u>141,782</u>

## Notes to the financial statements

For the year ended 31 December 2024

### 14 Analysis of net assets between funds

	Unrestricted funds general 2024 £	Unrestricted funds designated 2024 £	Total 2024 £
<b>At 31 December 2024:</b>			
Current assets/(liabilities)	105,436	297,781	403,217
	<u>105,436</u>	<u>297,781</u>	<u>403,217</u>
	<u><u>105,436</u></u>	<u><u>297,781</u></u>	<u><u>403,217</u></u>
	Unrestricted funds general 2023 £	Unrestricted funds designated 2023 £	Total 2023 £
<b>At 31 December 2023:</b>			
Current assets/(liabilities)	141,782	-	141,782
	<u>141,782</u>	<u>-</u>	<u>141,782</u>
	<u><u>141,782</u></u>	<u><u>-</u></u>	<u><u>141,782</u></u>

### 15 Related party transactions

There were no disclosable related party transactions during the year (2023 - none).

# SUDC★UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

**SUDC-UK**

England & Wales - Charity number 1175413

---

# Accounts

---

# SUDC UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

## **ANNUAL REPORT & ACCOUNTS 2023**

Annual Report and Financial Statements

For the Year Ended 31 December 2023

SUDC UK – registered charity in England and Wales 1175413

# CONTENTS

Reference and Administrative Details	2
Trustees' Report	3
Independent Examiner's Report	16
Statement of Financial Activities	17
Balance Sheet	18
Notes to the Financial Statements	19

---

## SUDC UK Reference and Administrative Details

Charity name	SUDC UK	Accountant	Carter & Co 19 Warren Park Way Enderby Leicester LE19 4SA
Charity number	1175413		
Trustees	Camilla Gooden Helen Charalambous Anne Elizabeth Milliken (The SUDC Foundation)		



# SUDC UK TRUSTEES' REPORT

## Organisation of the Charity

CIO - ASSOCIATION Registered 27 Oct 2017  
as amended on 11 Jul 2023

## Committee

The SUDC UK Board of Trustees at the date of the approval  
of this Report were:

Camilla Gooden

Helen Charalambous

Anne Elizabeth Milliken

# SUDC UK

## Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

### ABOUT US

Founded by bereaved mothers in November 2017, SUDC UK is an independent, national charity registered in England and Wales, dedicated to Sudden Unexplained Death in Childhood. SUDC UK operates consistently with the mission and broad global strategic objectives of our international affiliate, the SUDC Foundation. The SUDC Foundation is represented by a Trustee on the SUDC UK board.

Tragically, the incidence of sudden unexplained death in childhood (SUDC) is unchanging. The Office of National Statistics estimates that 40 children are affected every year in England and Wales alone: 1-2 seemingly healthy children are dying suddenly every fortnight without reason. SUDC has had limited attention and investment and there has been minimal research to understand these tragedies. Currently, we cannot predict SUDC or identify which children are at risk and SUDC deaths continue to devastate families year on year. There is such potential to save lives and change these statistics. With collaboration, expertise and bravery we are influencing change to stop children dying without reason.

Since our launch in 2017, we have been working to understand the needs of affected families and professionals. We support, advise and advocate for SUDC families nationwide, championing consistent, compassionate medical care with urgency and equality. Our charity is expertly supported by SUDC Foundation resources and services. Our expert advisory board of unrivalled UK professionals and academics has expertise and influence in SUDC and relevant specialist areas in community paediatrics, pathology and child death review. Their expert active participation in SIDS and SUDC research projects and conferences optimises national and global collaboration. Working together, we will improve SUDC medical education, optimise UK data collection, influence policy and promote and fund scientific research to improve care and save lives.

In 2021 SUDC UK implemented a 3-year strategy in consultation with a focus group of bereaved SUDC parents and volunteers, keeping the focus on our aim of eliminating sudden, unexplained death in children and young people from 1-18 years while raising awareness and supporting bereaved families in the UK.

### OUR STRATEGY OUTLINES 4 KEY OBJECTIVES:



Raising the funds necessary to successfully impact the future prediction and prevention of SUDC by granting to medical research



Easing the experience of SUDC-bereaved families in this country



Activism for improved awareness of SUDC and funding for medical research



Supporting UK family and professional engagement in SUDC research

# OUR VALUES



## Collaboration with families

Founded by bereaved parents, SUDC UK values the opinions and efforts of families affected by SUDC and it collaborates with this community to further its mission



## Collaboration with medical professionals and child death experts

SUDC UK believes close collaboration with the SUDC Foundation and other related national organisations will help further SUDC UK's mission



## Collaboration with the scientific community

SUDC UK believes funding, international collaboration, consistent data collection and increased professional engagement in SUDC research is crucial for Sudden Unexplained Death in Childhood to become predictable and preventable



## Information and Empowerment

SUDC UK believes accurate and consistent information should be available to all families affected by the sudden unexpected and often unexplained death of a child, so they are informed and empowered, and understand how to access relevant national and international resources

# 2023 IMPACT IN NUMBERS

**254** SUDC UK registered family members to date representing 155 families.



**72**

newly registered members this year representing 51 families.



**50%**

annual increase in the number of families registered with SUDC UK.

**24**

professional conferences, meetings or training.



**29**

SUDC UK articles, including 12 in the national press, hard copy and online.



**62%**

increase in SUDC UK funds available to directly support scientific research.



**£172,196**

invested in SUDC research

and an additional

**£85,000**

designated

to support UK research approved by our research review process in the next open call.

**5**

families referred to SUDC research projects for further investigation and to contribute to wider learning to help prevent future deaths.

**32**

of the 51 families who registered in 2023 were supported with individual case advocacy or 1-1 support.

**60**

parents/carers and 29 siblings attended SUDC UK in-person family events.

# GRANTS TO MEDICAL RESEARCH

We are proud to be the only charity in the UK helping families to find answers when their child has died suddenly and without reason. In 2023, we granted £172,196 to the SUDC Research and Registry Collaborative, a global, ground-breaking project comprising more than 30 multidisciplinary investigators who are working together to understand and prevent sudden unexplained deaths in children. Our member families are so grateful for the learnings that have already impacted medical education and care.

“ I find myself on a quest to find out why my beautiful, healthy boy fell asleep with my ultimate aim to be for his legacy to live on and help save other children in the future. ”

An SUDC mum



This brings our total grant to date of  
**£545,196**  
 to the SUDCRRC as a huge achievement.

In 2023, SUDC UK also designated an additional  
**£85,000**  
 to support UK research approved by our research review process in the next open call.

# SUPPORTING FAMILIES

## Supportive events

We connect bereaved families across the UK with others who understand the devastation of SUDC. We had the privilege of hosting **two family days** this year - at London Whipsnade Zoo, and a new additional location, Yorkshire Wildlife Park - as well as our annual virtual event in June, "Stars for Our Children" as a positive act of remembrance and community.

In October, we also hosted an '**Reflect, Restore, Renew' Retreat**, in memory of Autumn Garwood. This supportive event provided time and space for 12 recently bereaved parents to meet, listen and share with others who have suddenly lost a child, guided by caring and supportive experts.

September marked our first SUDC Dad's meal, where 7 fathers met in a relaxed and safe place, for dinner and drinks.

**“ The grief of losing a child can sometimes be the loneliest place and due to SUDC being so uncommon there are very few people that can understand. Meeting others further into this journey helps so much and shows no matter how heart-breaking life is at the moment, there is still a future ”**

*An SUDC Dad*

## Advocacy

Every year, more families are accessing support and connecting with SUDC UK earlier in their journey. The sudden, unexplained death of a child over the age of one who otherwise appears healthy has profound, enduring effects on the health and wellbeing of affected families. The direct support SUDC UK provides is vital, as the sudden and unexplained nature of SUDC exacerbates feelings of confusion, anger, guilt and isolation. We help bereaved families - and professionals responsible for their care - navigate the complex child death investigation, genetic analysis and sibling screening and signpost to expert counselling. We directly support and advocate for UK families as they navigate the child death process and grieve the loss of their child. This year alone, **32** of the **51** families who registered in 2023 requested and were



supported with individual case advocacy or 1-1 support. Further training and increased awareness activities are sure to continue this hopeful trend, so that no family grieves alone.

In 2023 SUDC UK **began acting as the official key worker** in Oxfordshire, consistent with the role described in English statutory guidance for the child death process. We supported two families in this way and attended our first child death review meeting, acting as a voice for the family with essential feedback to help local learning and accurate data collection for the regional Child Death Overview Panel (CDOP) and National Child Mortality Database (NCMD).



# RAISING AWARENESS

## Public Awareness

2023 has seen more SUDC coverage for SUDC than ever before. Public awareness is crucial. It makes a difference to those affected and brings hope and visibility to the cause.

January launched with a momentous milestone for the charity, **an historic, inaugural Westminster Hall parliamentary debate on SUDC**, led by the Rt Hon Kwasi Kwarteng, MP on behalf of his constituents Julia and Christian Rogers. The first debate on this topic, SUDC UK were invited to brief the parliamentary research unit and we helped our community engage MPs with consistent key messages. All MPs in attendance supported the key issues, shared the devastating stories of their constituents and reiterated the need for SUDC research, medical education and public information. This was a top story on BBC online news.

In March, for our SUDC Awareness Campaign, SUDC families and friends arranged for their local landmarks to light up in SUDC colours, including Barrow in Furness Town Hall in memory of a little girl and Blackpool Tower in memory of a little boy, and all other precious SUDC children.

This year, our many courageous families have shared their own stories and SUDC coverage has been widespread, including radio, tv and press features, including: BBC news and online, Times Radio, RTÉ Radio 1 (Ireland), BBC Radio 4's World at One Show, ITV New Granada, Daily Mirror, Sunday World (Ireland), Woman's Own and Fabulous magazine.

**“ The words ‘Sudden Unexplained Death in Childhood’ have never been spoken before in Parliament and SUDC is now on the government agenda. We hope meaningful actions and more debates will follow. This was an important day in history for children. ”** SUDC UK CEO, Nikki Speed



## Professional awareness

SUDC UK eases the experience of SUDC-bereaved families in this country. We ensure that all UK SUDC-bereaved families are aware of SUDC UK prior to, or immediately following their loss via professional referral, our website or SUDC UK charity public awareness campaigns.

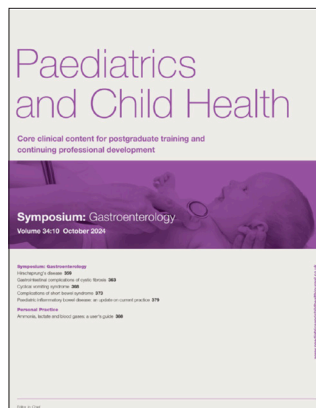
To improve awareness of SUDC facts and resources and enhance professional engagement with SUDC UK, we have developed an education programme for UK professionals.

This year SUDC UK recruited three registered parents, who are also police professionals, to support the **College of Policing** to update their SUDC investigator training. This training now includes SUDC UK resources and impactful videos of SUDC parents sharing their experience.

In May, SUDC UK scientific advisor, eminent paediatrician and SIDS/SUDC expert Peter Fleming CBE presented a keynote talk entitled "Understanding Sudden Unexpected Death in Children over 1 Year of Age" at the **Royal College of Paediatrics and Child Health (RCPCH) 2023 conference**. SUDC UK was honoured to co-author this **national NCMD report** which reviews national population data on unexpected child death for the first time.

In July, we celebrated the inaugural government-led **Round Table meeting on Sudden Explained Death in Childhood**. The meeting was convened following the Westminster Hall debate led by the Rt Hon Kwasi Kwarteng MP to bring together

expert organisations to discuss SUDC. Advocated for by SUDC UK and hosted by NHS England and the DHSC, the aim of the Round Table was to agree on actions, both collective and within organisations, to improve training and awareness of SUDC. SUDC UK presented at the event it was attended in-person by representatives of over 20 different professional organisations including Clinical Royal Colleges, Police and NCMD.



We are really excited about the outcomes from this national professional meeting, where we were able to act as a voice for SUDC families. We highlighted the need for coordinated thoughtful, timely processes and care in the aftermath of a SUDC tragedy. We are proud to be impacting national guidelines on child death, with progress towards national training, improved Joint Agency Response (JAR) guidelines and an appropriate and consistent care pathway.

In September, our CEO Nikki Speed and Jo Garstang **co-authored a paper** featuring in Paediatric Child Health, aimed at paediatric trainees. This provides a valuable new SUDC UK resource and is essential reading for child death review professionals and paediatricians.

Throughout the year SUDC UK were invited to consult on the Royal College of Pathology SUDC guidelines which were published in November 2023. These now include links to charity resources and videos and up-to date investigation and care recommendations.



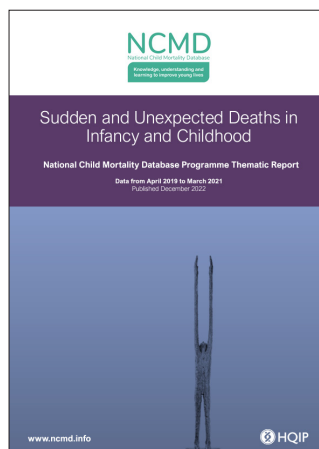
## ENGAGEMENT IN SUDC RESEARCH

There is under investment and a lack of dedication to SUDC scientific research globally, but we exist to change this and passionately support UK family and professional engagement in SUDC research. We share information on all known and relevant current research projects with families and strengthen the professional relationship with other charities and organisations who fund and support SUDC-related research and/or support SUDC families.

In December 2022, a ground-breaking report from the National Child Mortality Database recommended research into SUDC should be prioritised. Realising that this report is important for families, and everyone deeply affected by SUDC, we supported a webinar in January, where families heard directly from the report authors about the findings and had an opportunity to ask questions or just listened anonymously. During this webinar, hosted by The Lullaby Trust, our SUDC expert advisor, Professor Peter Fleming CBE unpacked the key findings of the report, before being joined by a panel of the report's authors including SUDC UK, to answer questions.

We are proud to be the **ONLY** organisation in the UK helping to refer families to the SUDC Registry and

Research Collaborative (SUDCRRC) project for enrolment, with 5 families enrolled in research in 2023. Our member families are so grateful for the learnings that have already impacted medical education and care, including raising an association with febrile seizures.



Professor Peter Fleming CBE, Expert SUDC advisor

**SUDCRRC**  
SUDC Registry and Research Collaborative

In March, a call to action regarding information and care following febrile seizures generated more valuable SUDC press coverage. [A Prevention of Future Deaths Report](#) concerning the sudden, unexpected death of Louis Rogers’ highlighted that in a third of SUDC cases there is a medical history of febrile seizures. The association between febrile seizures and SUDC needs further investigation and, in our training, SUDC UK will continue to highlight the importance of collecting child death review data on febrile seizures and the following the NICE guidance for febrile seizure management. We will also continue to encourage scientific research to understand the link between febrile seizures and unexplained deaths in the hope of identifying which children are at risk.

SUDC UK is immensely proud to have supported a scientific review of the evidence on febrile seizures and their association with mortality, neurodevelopment, and neuropathology. This new publication, written by Laura Gould, SUDCRRC, was supported by the SUDCRRC team led by neurologist, Professor Orrin Devinsky at NYU Langone Health, NY U.S.A. Importantly, the paper reviews the current evidence, suggests next steps for academic work and suggests how professionals should balance reassurance and education for families.

<https://onlinelibrary.wiley.com/doi/10.1111/epi.17720>

SUDC UK supported NCMD to update their data collection forms, create and launch a bespoke supplementary data collection form for sudden unexpected deaths over the age of 1 year. Only with rich and accurate data will we learn from deaths in the hope of preventing them in the future. This is an important milestone for SUDC.

In November, SUDC UK championed, helped launch and implement an initiative for whole genome sequencing and analysis for all unexplained infant and child deaths in England. This means that post-mortem tissues can now be retained for the ‘R441 Test’, where the tissues are analysed for a range of cardiac, neurological, and metabolic genes known to be associated with sudden death. Nationally, we can now do our absolute best scientifically to help families search for answers.

“ ..He updated me about A having R441 genetic testing and that her tissue sample was available and that they would oversee that. I’m sure you have been an integral part in this so thank you so much. ”

An SUDC mum


NewsHub

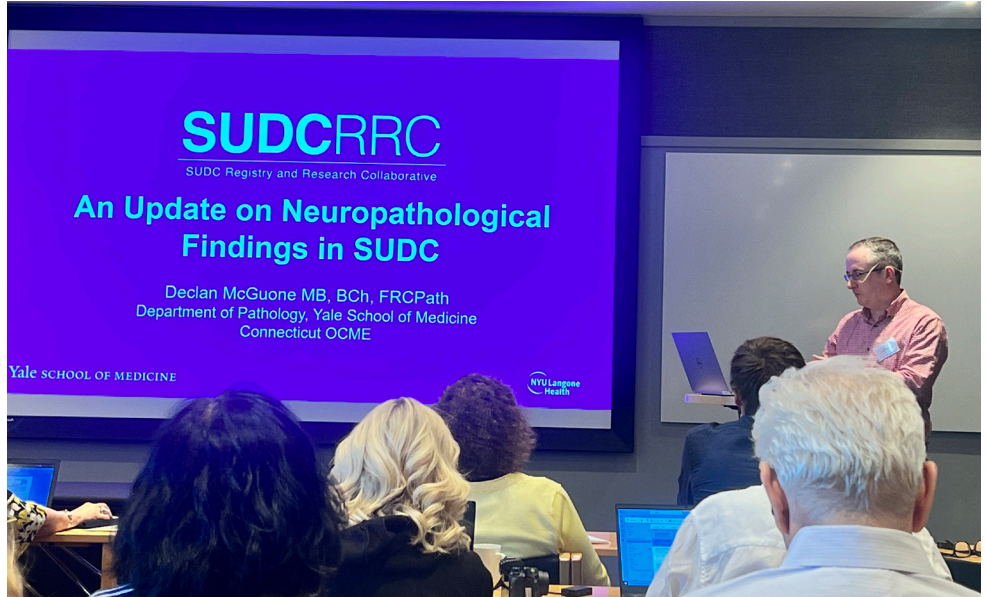
 Filter News by Category v

Q

RESEARCH, PRESS RELEASES | JANUARY 4, 2024

## Seizures Identified as Potential Cause of Sudden Unexplained Deaths in Children





In 2023, SUDC UK contributed to **24 impactful professional events**. For example, training local police, ambulance or paediatric teams, attending meetings as a member of the Northwest London Child Death Overview Panel, leading workshops on SUDC at the national Association of Child Death Review Professionals conference and attending in-person to contribute to the APPG for Bereavement support.

SUDC UK presented two posters and supported a workshop at the **4-day International ISPID Conference in Florence** which provided an important opportunity for experts to further understanding of others' work and connect. In addition to our direct work at this meeting, SUDC UK are so grateful to our scientific advisors and academic researchers who presented their data and advocated for SUDC. Contributions to the conference included:

- Dr Joanna Garstang presented "Sudden Unexplained Death in Childhood (SUDC) in England and Wales: frequency and classification of deaths".
- Peter Fleming CBE presented "Understanding Sudden Unexpected Death in Children Over 1 Year of Age".
- Dr Emily Cooper presented "Identifying Effective Multi-Agency Approaches for Bereaved Families".

During the year, SUDC UK has strengthened links with national bereavement charities and professional groups related to sudden unexpected death. We have supported and consulted on relevant projects and initiatives associated with child mortality and the child death process including the following **two projects**: SUDC UK were a stakeholder in a University of Birmingham project 'Involving parents and staff in learning from child deaths' aimed at producing **evidence-based resources in 2024** to support consistent key worker activity and child death reviews.

Dr Emily Cooper, an SUDC parent, academic and SUDC UK ambassador, led the first national project to examine the impact of the multiagency response on SUDC-bereaved families, funded by the University of Lancashire. SUDC UK were members of the small working group for this project, supporting the methodology, family recruitment, interviews and analysis. The results were also presented by Emily at ISPID 2023 (see above), at the ACDRP National Conference in Manchester and were shared in SUDC UK training as unpublished evidence for care recommendations.

International engagement and collaboration are essential to make SUDC preventable and during May, our scientific advisory board, our CEO, Nikki Speed, and scientific researcher, Laura Gould and Declan McGuone from the SUDC Registry and Research Collaborative (SUDCRRC) joined other international experts at the Sudden infant death and paediatric forensic medicine conference in Oslo, Norway.

International collaboration is integral to progressing understanding of SUDC. The rich 2-day programme provided an important opportunity for different groups to connect and further understand each other's work.

**“The meeting was a complete success because it brought people together from diverse backgrounds and clinical experiences, to engage in constructive discussion on a very complex set of issues...It helped us to prioritise our research agenda”**

*Declan McGuone, Neuropathologist and SUDCRRC researcher*

# FUNDRAISING

In 2023, we have raised  
**£299,839**  
 achieving our financial targets through increased community fundraising and awareness campaigns.

We have seen extraordinary fundraising achievements this year from families, friends and communities include Oliver’s Wish, Friends of Frankie and UK Games Expo. Challenge events: Paris and London Marathons; the Royal Parks, London Landmarks, Keswick and Warrington half marathons; Sheffield 10k, with 31 runners; Chiltern 50 Ultra; Cotswold Way Ultra Challenge; Remembrance Walk; Stride for SUDC Awareness; Dublin mini marathon; Wicklow gaol break; cycling and The Great Race, a penny farthing endurance competition.

Community events have included coffee mornings and afternoon teas, a Brownies sponsored silence and dedicated fundraising from the farming community.

We have started to diversify income streams, with Nationwide, our first SUDC UK Advocacy Corporate Champion thanks to a Nationwide Community Grant. December marked our second Big Give Christmas Challenge, raising funds for sibling support and resources in schools.

Support from phenomenal community fundraising and generous donations have enabled the charity to employ staff and evolve its services, awareness activities and events for families. This year we have strengthened the SUDC UK team, with three new permanent part-time roles, supporting communications and administration to support growth and sustainability of our charity.

Volunteers continue to be vital to the work of SUDC UK working to support all our workstreams: operations, communications, advocacy, support, fundraising and events. We are grateful for the donated skill, knowledge and time from all our volunteers.





## OUR FUTURE

In 2024, we hope to benefit from the incredible momentum created this year from heightened public and professional awareness and scientific collaborative progress. We will continue to deliver against our strategic objectives, adhering to our charity values and continually improving our processes and service delivery. To help maintain our performance and support further growth we are recruiting a new staff member to manage SUDC UK fundraising and events.

SUDC UK is leading engagement in the infrastructure necessary to help identify the gaps and priorities for SUDC research. Internally, we are preparing to join the Association of Medical Research Charities and evolve the SUDC UK research strategy in preparation for the next strategic cycle (2025-2027)

In 2024 we will also be implementing our plan to create a Schools SUDC Toolkit resource to help families and school professionals and building on our work with the Government and national influencers.

## Your support is making a difference

SUDC UK is still a very small charity, with only 3 part-time members of staff and 15 volunteers. We punch above our weight because we are passionate, we understand the unmet need, we have a strong belief that we can make a difference and because we have incredible expert advisors, partner charities, professionals, researchers, and supporters - who champion and create change, all on the same journey to raise SUDC awareness, improve care and search for answers.

In 2023 the following volunteers and organisations generously gave time, skills and expertise to SUDC UK operations and projects: Vanessa Grzywacz, Julia Rogers, Emily Cooper, Sally Law, Tom Speed, Jo Griffiths, Eleanor Moriarty Wroath, Will Empson, Sarah Laurent, Art Of The Possible Agency (Kat, Tim, Lucy and Caoimhe), Calvermont PR (Laura Gibson). We deeply appreciate their impactful support - thank you!

# INDEPENDENT EXAMINER'S REPORT OF THE TRUSTEES OF SUDC UK

We report on the accounts of the Trust for the period ended 31 December 2023, which are set out on pages 17 to 22.

## Respective responsibilities of trustees and examiner

The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is our responsibility to:

- Examine the accounts under section 145 of the 2011 Act;
- Follow the procedures laid down in the General Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act;
- State whether particular matters have come to our attention.

## Basis of independent examiner's report

Our examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

## Independent examiners statement

In connection with my examination, no matter has come to my attention:

1) Which gives us reasonable cause to believe that in any material respect the requirements:

- to keep accounting records in accordance with section 130 of the Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met; or

2) to which, in our opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

DocuSigned by:

Neil Davis

4B394C80489A4BA...

.....  
Carter & Co  
19 Warren Park Way  
Enderby  
Leicester  
LE19 4SA

Date: 29 October 2024

## SUDC UK

Statement of Financial Activities for the Year Ended 31 December 2023

		Unrestricted Funds	Restricted Funds	Total Funds 2023	Total Funds 2022
	Note	£	£	£	£
<b>Incoming resources</b>					
Incoming resources from generated funds					
Voluntary income	2	299,839		299,839	278,813
Total incoming resources		299,839	-	299,839	278,813
<b>Resources expended</b>					
Costs of generating funds					
Costs of generating voluntary income	3	271,727		271,727	226,013
Total resources expended		271,727	-	271,727	226,013
Net movement in funds		28,112	-	28,112	52,800
<b>Reconciliation of funds</b>					
Total funds brought forward		113,670		113,670	60,870
Total funds carried forward		141,782	-	141,782	113,670

All incoming resources and resources expended derive from continuing activities.  
The charity has no recognised gains or losses for the year other than the results above.

The notes on pages 18 to 20 form an integral part of these financial statements.

# SUDC UK

Balance Sheet as at 31 December 2023

		2023	2022
	Note	£	£
<b>Current assets</b>			
Cash at bank and in hand		247,233	120,913
<b>Current Liabilities</b>			
Other Creditors	4	105,451	7,243
Net assets		141,782	113,670
 <b>The funds of the charity:</b>			
<b>Restricted funds</b>			
Family Retreats			
<b>Unrestricted funds</b>			
Unrestricted income funds		141,782	113,670
Total charity funds		141,782	113,670

Approved by the Board on 28th September 2023 and signed on its behalf by:

Helen Charalambous  
Trustee

Signed by:  
*Helen Charalambous*  
C11C395C508F46A...

on date:

29 October 2024

The notes on pages 18 to 20 form an integral part of these financial statements.

# SUDC UK

Notes to the Financial Statements for the Year Ended 31 December 2023

## 1 Accounting policies

### Basis of preparation

The financial statements have been prepared under the historical cost convention on a Receipts and Payments basis and in accordance with the Statement of Recommended Practice 'Accounting and Reporting by Charities (SORP 2019)', issued in January 2019, applicable accounting standards and the Charities Act 2011.

### Fund accounting policy

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity.

Restricted funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Designated funds are unrestricted funds set aside at the discretion of the trustees for specific purposes.

Further details of each fund are disclosed in note 7 and 8.

### Incoming resources

Donations are recognised when they are received.

Incoming resources from tax reclaims are included in the statement of financial activities when received.

Investment income is recognised on a receipts basis.

### Resources expended

All expenditure is accounted for on a payments basis and has been classified under headings that aggregate all costs related.

Costs of generating funds comprise the costs associated with attracting voluntary income and investment management fees.

### Support costs

Support costs include central functions.

# SUDC UK

.....continued

Notes to the Financial Statements for the Year Ended 31 December 2023

## 2 Voluntary Income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £	Total Funds 2022 £
<b>Donations and legacies</b>				
General Giving	295,593		295,593	277,342
Gift Aid tax reclaimed	3,828		3,828	1,254
	<hr/>	<hr/>	<hr/>	<hr/>
	299,421		299,421	278,596
<b>Bank interest received</b>				
	418		418	217
	<hr/>	<hr/>	<hr/>	<hr/>
	299,839		299,839	278,813

## 3 Total resources expended

	2023 £	2022 £
<b>Direct costs</b>		
SUDCRRC Grant	172,196	160,000
Cost of sales	3,400	2,716
Advertising/Promotion	1,587	2,422
Cost of labour	49,138	25,674
Contractor costs	4,357	5,245
Conferences	177	-
Events	14,263	12,062
Office expenses	2,518	3,508
Printing, posting and stationery	3,199	2,698
Professional fees	3,354	2,610
Travel and subsistence	3,904	674
Accountancy	870	840
Bookkeeping	5,113	-
Bank Charges	185	184
Just Giving fees	4,176	3,845
Kindlink fees	391	344
Paypal fees	36	10
Stripe fees	14	9
Gifts	467	308
Entertainment	465	577
Insurance	283	420
Computer costs	1,634	1,868
	<hr/>	<hr/>
	271,727	226,013

# SUDC UK

Notes to the Financial Statements for the Year Ended 31 December 2023

.....continued

4 Creditors	2023	2022
	£	£
Creditors	2,065	6,403
Accruals	870	840
SUDCRRC Approved Grant	100,000	-
PAYE creditor	2,116	-
Pension creditor	400	-
	105,451	7,243

## 5 Related parties

### Controlling entity

The charity is controlled by the trustees

## 6 Analysis of funds

	Incoming Resources	Resources expended	At 31 st December 2023
	£	£	£
<b>General Funds</b>			
Donations and Legacies	299,839	(271,727)	28,112
	299,839	(271,727)	28,112
<b>Restricted Funds</b>			
	299,839	(271,727)	28,112

## 8 Net assets by fund

	Unrestricted Funds	Restricted Funds	Total Funds 2023
	£	£	£
Current assets	247,233	-	247,233
Creditors	(105,451)	-	(105,451)
Net assets	141,782		141,782

## SUDC UK

### Statement of financial activities by fund Year Ended 31 December 2023

	Restricted Income Fund 2023	Restricted Income Fund 2022	Unrestricted Income Fund 2023	Unrestricted Income Fund 2022
	£	£	£	£
<b>Incoming resources</b>				
Incoming resources from generated funds				
Voluntary income			299,421	278,596
Bank interest received			418	217
Total incoming resources			299,839	278,813
<b>Resources expended</b>				
Costs of generating funds				
Costs if generating voluntary income			271,727	226,013
Total resources expended			271,727	226,013
Net movement in funds			28,112	52,800
<b>Reconciliation of funds</b>				
Total funds brought forward		1,562	112,108	59,308
Total funds carried forward		1,562	140,220	112,108

This page does not form part of the statutory financial statements

# SUDC UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

**SUDC-UK**

England & Wales - Charity number 1175413

---

# Accounts

---

Charity registration number: 1175413

## **SUDC UK**

**Annual Report and Financial Statements  
For the Year Ended 31 December 2022**

*Carter & Co*

19 Warren Park Way  
The Warrens Business Park  
Enderby, Leicester  
LE19 4SA

telephone (0116) 224 0400  
fax (0116) 224 0399

[www.carteraccountants.co.uk](http://www.carteraccountants.co.uk)

# **SUDC UK**

## **Contents**

Reference and Administrative Details	1
Trustees' Report	2 to 5
Independent Examiner's Report	6
Statement of Financial Activities	7
Balance Sheet	8
Notes to the Financial Statements	9 to 11

The following pages do not form part of the statutory financial statements:

Statement of Financial Activities per Fund	12
--	----

## **SUDC UK**

### **Reference and Administrative Details**

**Charity name** SUDC UK

**Charity number** 1175413

**Trustees** Camilla Gooden  
Helen Charalambous  
Laura Gould Crandall (The SUDC Foundation) – Resigned  
22<sup>nd</sup> September 2022  
Anne Elizabeth Milliken (The SUDC Foundation) – Appointed  
22<sup>nd</sup> September 2022

**Accountant** Carter & Co  
19 Warren Park Way  
Enderby  
Leicester  
LE19 4SA

# SUDC UK

## Trustees' Report

### Organisation of the Charity

The Charity is constituted by Trust Deed dated 27<sup>th</sup> October 2017

### Committee

The Members of the Committee at the date of the approval of this Report were:

Camilla Gooden

Helen Charalambous

Anne Elizabeth Milliken

### Objects of the Charity

- The Trustees continued to hold funds for the work of SUDC UK to improve awareness and understanding of Sudden Unexplained Death in Childhood
- To fund crucial medical research to better understand these tragedies

### Summary of Accounts

- **Raising awareness** – A core part of SUDC UK's mission is to raise awareness of SUDC. To do this, SUDC UK works with bereaved families, the public, the press and other professionals to support the distribution of accurate information.
- **Funding research** – SUDC UK appreciates the incredible fundraising efforts of our community and the donations we receive. SUDC UK grants funds to research projects that aim to further our understanding of SUDC. It also works with professionals who have an interest in sudden unexplained death to help encourage and optimise research.
- **Supporting families** – Upon registration, families are immediately connected to the expert professional and peer bereavement support services of our affiliate, the SUDC Foundation. SUDC UK provides practical resources, information and signposting following the loss of a child, hosts events for families and creates a supportive community. SUDC UK also directly supports families by advocating for them on an individual case as they navigate the official child death process and consider further investigations. With consent, SUDC UK refers families to research projects when appropriate.
- **Medical education** – SUDC UK attends medical conferences and other relevant meetings to provide up-to-date, helpful and consistent information on SUDC.
- **Collaborating to improve policy** – SUDC UK acts as a voice for families, improving national policy and services. To do this, SUDC UK works with other organisations, consults on relevant guidelines and initiatives, and is a founding charity member of the national All-Party Parliamentary Group for Bereavement.

## Achievements and Performance

- In January 2022, SUDC UK publicly launched its new SUDC UK strategy document for 2022-2024.
- In February, The SUDC UK team expanded by hiring a part-time administrator for the charity (contractor). More volunteers joined to assist with event planning and communications.
- In March, SUDC UK ran an awareness campaign for 'SUDC Awareness month'. Public images of influential professionals (e.g. pathologists, paediatricians and Coroners) holding the campaign 'Shine a light on SUDC' increased professional and public awareness and supported the credibility of SUDC UK.
- In April, family stories and interviews with SUDC professionals were shared on the ITV evening news in various regions of the UK. Throughout 2022, awareness-raising press increased with stories in national newspapers, including The Daily Mirror, The Express, the Mail online, the Sun online and BBC online.
- SUDC UK held a Family Day at Whipsnade Zoo on the 11<sup>th</sup> June. Families connected, spent quality time together and felt less isolated. They hung wooden stars for their children on a memorial tree SUDC UK planted in 2019 in remembrance.
- A supportive virtual family event entitled 'Stars for Our Children' was also held to unite and comfort families across the country and to raise awareness across social media.
- SUDC UK was awarded a grant of £43,000 from the Clothworkers Foundation. The charity was nominated to present to a member of the organisation who then championed for SUDC UK to secure the funds.
- Through restricted funds, SUDC UK supported and helped organise the SUDC UK Autumn Retreat for parents to 'Reflect, Restore and Renew' with emotional support from experts including our patron, Jenni Thomas OBE.
- SUDC UK was supported by a creative agency to make an impactful new charity video which shares key facts and the experience of families affected by SUDC.
- Bereaved mothers united to climb Mount Snowdon in memory of their children, raising funds and awareness for the cause. This SUDC UK event resulted in a successful 'Mothers united in hope campaign' with local press and radio secured by our PR agency, who agreed to work pro-bono for SUDC UK. The participants found the event incredibly supportive.
- As leading experts on SUDC, SUDC UK were invited to deliver training sessions at relevant national meetings. For example, at the inaugural meeting of the Association of Child Death Review Professionals and to the Nurses for Child Death Review Peer Support Network.

- SUDC UK continued its membership and meeting attendance for the All-Party Parliamentary Group for Bereavement and National Grief Awareness Week, the Child Bereavement Network, the Public Engagement Network for the National Child Mortality Database, ISPID (The International Society for the Study and Prevention of Perinatal and Infant Death), the UK Baby Loss Alliance and the National Bereavement Alliance
- In November, SUDC UK ran a 'Big Give Christmas Campaign' with a suite of short impactful videos to raise awareness and encourage donations.
- Supported Baby Loss Awareness Week and the global 'Wave of Light' community event, National Grief Awareness Week and Children's Grief Awareness Week by attending the preparation meetings and supporting these events on social media.
- SUDC UK consulted on the UK commission on Bereavement and attended the launch of its report 'Bereavement is Everyone's Business'.
- SUDC UK co-authored the first ever national thematic review on sudden unexpected death in childhood (SUDIC) in collaboration with the National Child Mortality Database, the Lullaby Trust and a charity called Elliot's Footprint. This thematic review report was published in December 2022. It revealed that 19% of children die suddenly and without an immediately apparent explanation and provided clear national recommendations for training, SUDC research and agency collaboration.
- SUDC UK'S CEO and some of the families we serve were invited to two important meetings. The first with RT Hon Kwasi Kwarteng MP and the second with the NHS Clinical Director for Children and Young People, Prof. Simon Kenny. We presented information on SUDC and the key issues and engaged them in supporting our cause.
- Positive plans were outlined in a supportive letter from the CEO of the NHS. *"As part of the Children and Young People Transformation Programme, NHS England are reviewing information that could be provided to families and professionals around Sudden Unexplained Death in Childhood (SUDC). This work will be carried out in consultation with families, parents and carers affected by SUDC and with the National Child Mortality Database (NCMD), SUDC charities (including SUDC UK) and relevant Professional groups."*
- Planning began for the first ever parliamentary debate on SUDC which was to take place in early 2023. SUDC UK encouraged our supporters to write to their MPs, briefed the Department of Health and Social Care and circulated resources to help deliver a clear and consistent message.
- Our proactive fundraising enabled SUDC UK to grant £160,000 to research ([www.sudcrrc.org](http://www.sudcrrc.org)) to improve understanding of SUDC and enable families to pursue further investigations into their child's cause of death. This is an increase from a grant of £85,000 in 2021 and brings our total funds granted to this global project to £373,000.

### **Charity Funds**

The funds of the Charity are administered by the Committee to meet the objectives of the Charity. The Committee consider that the overall financial position of the Charity is satisfactory and that the Charity is able to meet its obligations.

### **Risk Assessment**

The Committee have considered the risks to which the Charity may be exposed and systems are in place to mitigate those risks.

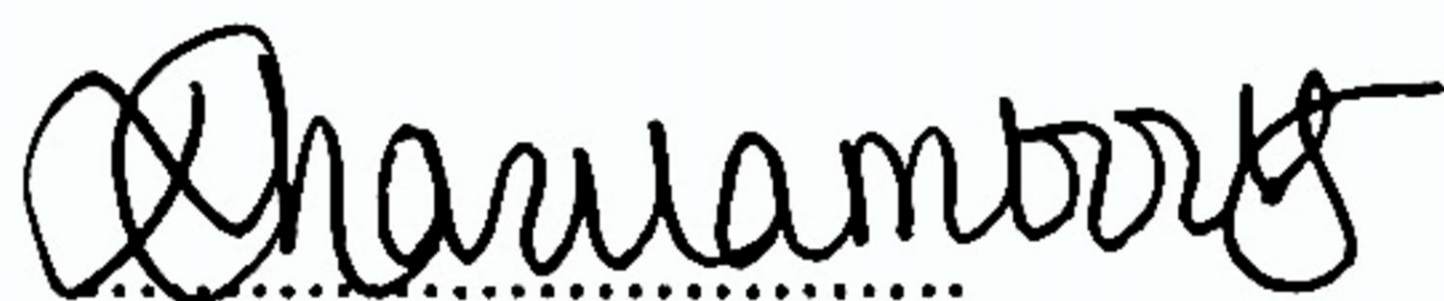
### **Financial Position**

The Statement of Financial Activities is set out on the following pages.

The investments held are in accordance with the Committee's powers which are widely drawn.

Signed on behalf of the Committee

Approved by the Trustees on 28<sup>th</sup> September 2023 signed on their behalf by:



Helen Charalambous  
Trustee

**Independent Examiner's Report of the Trustees of  
SUDC UK**

We report on the accounts of the Trust for the period ended 31 December 2022, which are set out on pages 6 to 11.

**Respective responsibilities of trustees and examiner**

The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is our responsibility to:

- Examine the accounts under section 145 of the 2011 Act;
- Follow the procedures laid down in the General Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act;
- State whether particular matters have come to our attention.

**Basis of independent examiner's report**

Our examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

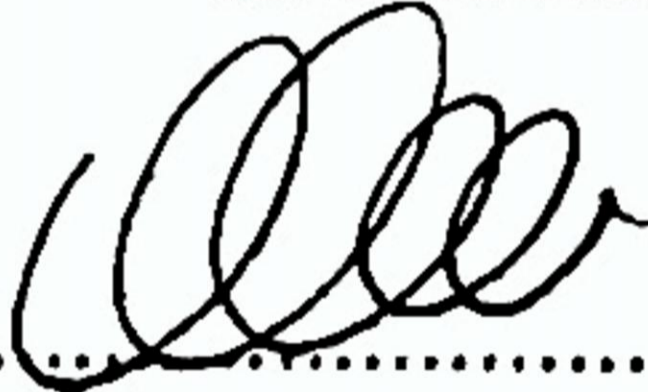
**Independent examiners statement**

In connection with my examination, no matter has come to my attention:

- 1) Which gives us reasonable cause to believe that in any material respect the requirements:
  - to keep accounting records in accordance with section 130 of the Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met; or

- 2) to which, in our opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



.....  
Carter & Co  
19 Warren Park Way  
Enderby  
Leicester  
LE19 4SA

28<sup>th</sup> September 2023

SUDC UK

Statement of Financial Activities for the Year Ended 31 December 2022

	Unrestricted Funds	Restricted Funds	Total Funds 2022	Total Funds 2021
Note	£	£	£	£
<b>Incoming resources</b>				
Incoming resources from generated funds				
Voluntary income	2	278,813	278,813	115,062
Total incoming resources		<u>278,813</u>	<u>278,813</u>	<u>115,062</u>
<b>Resources expended</b>				
Costs of generating funds				
Costs of generating voluntary income	3	224,451	1,562	226,013
Total resources expended		<u>224,451</u>	<u>1,562</u>	<u>226,013</u>
Net movement in funds		54,362	- 1,562	- 8,879
<b>Reconciliation of funds</b>				
Total funds brought forward		59,308	1,562	60,870
Total funds carried forward		<u>113,670</u>	<u>-</u>	<u>60,870</u>

All incoming resources and resources expended derive from continuing activities.

The charity has no recognised gains or losses for the year other than the results above.

The notes on pages 8 to 10 form an integral part of these financial statements.

SUDC UK

Balance Sheet as at 31 December 2022

		2022	2021
	Note	£	£
<b>Current assets</b>			
Cash at bank and in hand		<u>120,913</u>	<u>146,924</u>
<b>Current Liabilities</b>			
Other Creditors	4	7,243	86,054
Net assets		<u>113,670</u>	<u>60,870</u>
<b>The funds of the charity:</b>			
<b>Restricted funds</b>			
Family Retreats		-	1,562
<b>Unrestricted funds</b>			
Unrestricted income funds		<u>113,670</u>	<u>59,308</u>
<b>Total charity funds</b>		<u>113,670</u>	<u>60,870</u>

Approved by the Board on 28th September 2023 and signed on its behalf by:



Helen Charalambous  
Trustee

The notes on pages 8 to 10 form an integral part of these financial statements.

## **SUDC UK**

### **Notes to the Financial Statements for the Year Ended 31 December 2022**

#### **1 Accounting policies**

##### **Basis of preparation**

The financial statements have been prepared under the historical cost convention on a Receipts and Payments basis and in accordance with the Statement of Recommended Practice 'Accounting and Reporting by Charities (SORP 2019)', issued in January 2019, applicable accounting standards and the Charities Act 2011.

##### **Fund accounting policy**

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity.

Restricted funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Designated funds are unrestricted funds set aside at the discretion of the trustees for specific purposes.

Further details of each fund are disclosed in note 7 and 8.

##### **Incoming resources**

Donations are recognised when they are received.

Incoming resources from tax reclaims are included in the statement of financial activities when received.

Investment income is recognised on a receipts basis.

##### **Resources expended**

All expenditure is accounted for on a payments basis and has been classified under headings that aggregate all costs related.

Costs of generating funds comprise the costs associated with attracting voluntary income and investment management fees.

##### **Support costs**

Support costs include central functions.

**SUDC UK**

**Notes to the Financial Statements for the Year Ended 31 December 2022**

.....continued

**2 Voluntary income**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £	Total Funds 2021 £
<b>Donations and legacies</b>				
General Giving	277,342		277,342	112,207
Gift Aid tax reclaimed	1,254	-	1,254	2,855
	<u>278,596</u>	<u>-</u>	<u>278,596</u>	<u>115,062</u>
<b>Bank interest received</b>	217		217	-
	<u>278,813</u>	<u>-</u>	<u>278,813</u>	<u>105,510</u>

**3 Total resources expended**

	2022 £	2021 £
<b>Direct costs</b>		
SUDCRRC Grant	160,000	85,000
Cost of sales	2,716	1,184
Advertising/Promotion	2,422	1,291
Cost of labour	25,674	19,658
Contractor costs	5,245	-
Events	12,062	3,461
Family Retreats (Restricted Funds)	-	3,963
Office expenses	3,508	3,808
Printing, posting and stationery	2,698	1,972
Professional fees	2,610	1,349
Travel and subsistence	674	-
Accountancy	840	810
Bank Charges	184	209
Just Giving fees	3,845	-
Kindlink fees	344	-
Paypal fees	10	-
Stripe fees	9	-
Gifts	308	279
Entertainment	577	53
Insurance	420	96
Computer costs	1,868	808
	<u>226,013</u>	<u>123,941</u>

SUDC UK

Notes to the Financial Statements for the Year Ended 31 December 2022

.....continued

**4 Creditors**

	2022 £	2021 £
Creditors	6,403	-
Accruals	840	810
SUDCRRC Approved Grant	-	85,000
PAYE creditor	-	175
Pension creditor	-	69
	<u>7,243</u>	<u>86,054</u>

**5 Related parties**

**Controlling entity**

The charity is controlled by the trustees.

**6 Analysis of funds**

	Incoming resources £	Resources expended £	At 31 December 2022 £
<b>General Funds</b>			
Donations and Legacies	278,813	(224,451)	54,362
	<u>278,813</u>	<u>(224,451)</u>	<u>54,362</u>
<b>Restricted Funds</b>			
	-	- 1,562.00	- 1,562
	<u>278,813</u>	<u>(226,013)</u>	<u>52,800</u>

**8 Net assets by fund**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Tangible assets	-	-	-
Debtors	-	-	-
Current assets	122,475	- 1,562	120,913
Creditors	(7,243)	-	(7,243)
Net assets	<u>115,232</u>	<u>- 1,562</u>	<u>113,670</u>

**SUDC UK**

**Statement of financial activities by fund Year Ended 31 December 2022**

	<b>Restricted Income Fund 2022  £</b>	<b>Restricted Income Fund 2021  £</b>	<b>Unrestricted Income Fund 2022  £</b>	<b>Unrestricted Income Fund 2021  £</b>
<b>Incoming resources</b>				
Incoming resources from generated funds				
Voluntary income	-	-	278,596	115,062
Bank interest received	-	-	217	-
<b>Total incoming resources</b>	<u>-</u>	<u>-</u>	<u>278,813</u>	<u>115,062</u>
<b>Resources expended</b>				
Costs of generating funds				
Costs of generating voluntary income	-	-	226,013	123,941
<b>Total resources expended</b>	<u>-</u>	<u>-</u>	<u>226,013</u>	<u>123,941</u>
<b>Net movement in funds</b>	- 1,562	- 3,963	52,800	- 8,879
<b>Reconciliation of funds</b>				
Total funds brought forward	<u>1,562</u>	<u>5,525</u>	<u>59,308</u>	<u>69,749</u>
Total funds carried forward	<u>-</u>	<u>1,562</u>	<u>112,108</u>	<u>59,308</u>

This page does not form part of the statutory financial statements

**SUDC-UK**

England & Wales - Charity number 1175413

---

# Accounts

---

Charity registration number: 1175413

# **SUDC UK**

Annual Report and Financial Statements  
For the Year Ended 31 December 2021

## **SUDC UK**

### **Contents**

Reference and Administrative Details	1
Trustees' Report	2 to 4
Independent Examiner's Report	5
Statement of Financial Activities	6
Balance Sheet	7
Notes to the Financial Statements	8 to 10
The following pages do not form part of the statutory financial statements:	
Statement of Financial Activities per Fund	11

## **SUDC UK**

### **Reference and Administrative Details**

<b>Charity name</b>	SUDC UK
<b>Charity number</b>	1175413
<b>Trustees</b>	Camilla Gooden Helen Charalambous Laura Gould Crandall (The SUDC Foundation)
<b>Accountant</b>	Carter & Co 19 Warren Park Way Enderby Leicester LE19 4SA

# SUDC UK

## Trustees' Report

### Organisation of the Charity

The Charity is constituted by Trust Deed dated 27<sup>th</sup> October 2017

### Committee

The Members of the Committee at the date of the approval of this Report were:

Camilla Gooden

Helen Charalambous

Laura Gould Crandall

### Objects of the Charity

- The Trustees continued to hold funds for the work of SUDC UK to improve awareness and understanding of Sudden Unexplained Death in Childhood
- To fund crucial medical research to better understand these tragedies

### Summary of Accounts

- **Raising awareness** – A core part of SUDC UK's mission is to raise awareness of SUDC. To do this, SUDC UK works with bereaved families, the public, the press and other professionals to support the distribution of accurate information.
- **Funding research** – SUDC UK appreciates the incredible fundraising efforts of our community and the donations we receive. SUDC UK grants funds to research projects that aim to further our understanding of SUDC. It also works with professionals who have an interest in sudden unexplained death to help encourage and optimise research.
- **Supporting families** – Upon registration, families are immediately connected to the expert professional and peer bereavement support services of our partner organisation, the SUDC Foundation. SUDC UK provides practical resources, information and signposting following the loss of a child, hosts events for families and creates a supportive community. SUDC UK also directly supports families by advocating for them on an individual case as they navigate the official child death process and consider further investigations. With consent, SUDC UK refers families to research projects when appropriate.
- **Medical education** – SUDC UK attends medical conferences and other relevant meetings to provide up-to-date, helpful and consistent information on SUDC.
- **Collaborating to improve policy** – SUDC UK acts as a voice for families, improving national policy and services. To do this, SUDC UK works with other organisations, consults on relevant guidelines and initiatives, and is a founding charity member of the national All-Party Parliamentary Group for Bereavement.

# **SUDC UK**

## **Trustees' Report**

### **Achievements and Performance**

- Launched SUDC UK's new 3-year strategy to help predict and prevent SUDC.
- First SUDC UK employee and evolving services. SUDC UK now supports families with 'case advocacy' meaning practical support, helping them navigate the child death process, communicate with professionals and the Coroner's Office and understand their options for research. Where appropriate, SUDC refers families to the SUDCRRRC.
- Launched the SUDC Memorial Garden based at Twigs Community Gardens and our uplifting fundraising resources for 'Afternoon Tea for SUDC' community events
- Ran an awareness campaign for 'SUDC Awareness month' in March, raising our profile with the public, professionals and families measured by increased contact and referral
- Active member of the professional steering group for child deaths and invited to be a working group member for a National Child Mortality Database thematic review on SUDIC, attended meetings and continued to advocate for the needs of families, improved awareness and research
- Led the development of a video resource to explain the important tissue retention process for parents. This video has been recommended as a resource by the Coroner's Society and the NCMD
- Held a virtual family event 'Stars for Our Children' to support families feeling increasingly isolated due to COVID restrictions and raise awareness
- Investment in behind-the-scenes operations, database and resources to optimise impact and services
- Paediatrician and Chair of the Association of Child Death Review Professionals, Dr Jo Garstang, Joined the SUDC UK advisory board presenting new opportunities for professional awareness and communication with Genomics England to understand and support UK genetic investigation for SUDC.
- Funded and supported the first SUDC UK Autumn Retreat for parents to 'Reflect, Restore and Renew' with emotional support from experts including our patron
- Collaborated with sudden death charities to meet with the Minister of State at the Department of Health and Social Care and raised awareness of the impact of SUDC
- Supported Babyloss Awareness Week and the 'Wave of Light' community event

**SUDC UK**  
**Trustees' Report**

- First 'Big Give Christmas Challenge' raises important funds
- A donor impact statement reveals the progress made by the SUDC Registry and Research project which is part-funded by SUDC UK

**Charity Funds**

The funds of the Charity are administered by the Committee to meet the objectives of the Charity. The Committee consider that the overall financial position of the Charity is satisfactory and that the Charity is able to meet its obligations.

**Risk Assessment**

The Committee have considered the risks to which the Charity may be exposed and systems are in place to mitigate those risks.

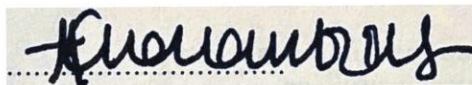
**Financial Position**

The Statement of Financial Activities is set out on the following pages.

The investments held are in accordance with the Committee's powers which are widely drawn.

Signed on behalf of the Committee

Approved by the Trustees on 28<sup>th</sup> September 2022 signed on their behalf by:



Helen Charalambous  
Trustee

**Independent Examiner's Report of the Trustees of  
SUDC UK**

We report on the accounts of the Trust for the period ended 31 December 2021, which are set out on pages 6 to 10.

**Respective responsibilities of trustees and examiner**

The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is our responsibility to:

- Examine the accounts under section 145 of the 2011 Act;
- Follow the procedures laid down in the General Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act;
- State whether particular matters have come to my attention.

**Basis of independent examiner's report**

Our examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

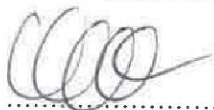
**Independent examiners statement**

In connection with my examination, no matter has come to my attention:

- 1) Which gives us reasonable cause to believe that in any material respect the requirements:
  - to keep accounting records in accordance with section 130 of the Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met; or

- 2) to which, in our opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



.....  
Carter & Co  
19 Warren Park Way  
Enderby  
Leicester  
LE19 4SA

28<sup>th</sup> September 2022

**SUDC UK**

**Statement of Financial Activities for the Year Ended 31 December 2021**

	<b>Unrestricted Funds</b>	<b>Restricted Funds</b>	<b>Total Funds 2021</b>	<b>Total Funds 2020</b>
<b>Note</b>	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
<b>Incoming resources</b>				
Incoming resources from generated funds				
Voluntary income	2	115,062	115,062	105,510
Total incoming resources		115,062	115,062	105,510
<b>Resources expended</b>				
Costs of generating funds				
Costs of generating voluntary income	3	119,978	123,941	67,148
Total resources expended		119,978	123,941	67,148
Net movement in funds	-	4,916	8,879	38,362
<b>Reconciliation of funds</b>				
Total funds brought forward		64,224	69,749	31,387
Total funds carried forward		59,308	60,870	69,749

All incoming resources and resources expended derive from continuing activities.

The charity has no recognised gains or losses for the year other than the results above.

The notes on pages 8 to 10 form an integral part of these financial statements.

SUDC UK

Balance Sheet as at 31 December 2021

		2021	2020
	Note	£	£
<b>Current assets</b>			
Cash at bank and in hand		146,924	118,687
<b>Current Liabilities</b>			
Other Creditors	4	86,054	48,938
Net assets		60,870	<u>69,749</u>
<b>The funds of the charity:</b>			
<b>Restricted funds</b>			
Family Retreats		1,562	5,525
<b>Unrestricted funds</b>			
Unrestricted income funds		59,308	64,224
<b>Total charity funds</b>		<u>60,870</u>	<u>69,749</u>

Approved by the Board on 22: 21 and signed on its behalf by:



Helen Charalambous  
Trustee

The notes on pages 8 to 10 form an integral part of these financial statements.

## SUDC UK

### Notes to the Financial Statements for the Year Ended 31 December 2021

#### 1 Accounting policies

##### **Basis of preparation**

The financial statements have been prepared under the historical cost convention on a Receipts and Payments basis and in accordance with the Statement of Recommended Practice 'Accounting and Reporting by Charities (SORP 2005)', issued in March 2005, applicable accounting standards and the Charities Act 2011.

##### **Fund accounting policy**

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity.

Restricted funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Designated funds are unrestricted funds set aside at the discretion of the trustees for specific purposes.

Further details of each fund are disclosed in note 7 and 8.

##### **Incoming resources**

Donations are recognised when they are received.

Incoming resources from tax reclaims are included in the statement of financial activities when received.

Investment income is recognised on a receipts basis.

##### **Resources expended**

All expenditure is accounted for on a payments basis and has been classified under headings that aggregate all costs related.

Costs of generating funds comprise the costs associated with attracting voluntary income and investment management fees.

##### **Support costs**

Support costs include central functions.

**SUDC UK**

**Notes to the Financial Statements for the Year Ended 31 December 2021**

.....continued

**2 Voluntary income**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2021 £</b>	<b>Total Funds 2020 £</b>
<b>Donations and legacies</b>				
General Giving	112,207		112,207	105,510
Gift Aid tax reclaimed	2,855	-	2,855	-
	<u>115,062</u>	<u>-</u>	<u>115,062</u>	<u>105,510</u>
<b>Grants</b>				
Grants - other agencies	-	-	-	-
	<u>115,062</u>	<u>-</u>	<u>115,062</u>	<u>105,510</u>

**3 Total resources expended**

	<b>2021 £</b>	<b>2020 £</b>
<b>Direct costs</b>		
SUDCRRRC Grant	85,000	48,159
Cost of sales	1,184	
Advertising/Promotion	1,291	685
Cost of labour	19,658	7,140
Childcare	-	2,541
Events	3,461	154
Family Retreats (Restricted Funds)	3,963	2,475
Office expenses	3,808	685
Printing, posting and stationery	1,972	864
Professional fees	1,349	3,195
Travel and subsistence	-	390
Accountancy	810	780
Bank Charges	209	80
Gifts	279	
Entertainment	53	
Insurance	96	
Computer costs	808	
	<u>123,941</u>	<u>67,148</u>

**SUDC UK**

**Notes to the Financial Statements for the Year Ended 31 December 20201**

.....continued

<b>4 Creditors</b>	<b>2021</b>	<b>2020</b>
	<b>£</b>	<b>£</b>
Accruals	810	780
SUDCRRC Approved Grant	85,000	48,158
PAYE creditor	175	-
Pension creditor	69	-
	<u>86,054</u>	<u>48,938</u>

**5 Related parties**

**Controlling entity**

The charity is controlled by the trustees.

**6 Analysis of funds**

	<b>Incoming resources £</b>	<b>Resources expended £</b>	<b>At 31 December 2021 £</b>
<b>General Funds</b>			
Donations and Legacies	115,062	(119,978)	- 4,916
	<u>115,062</u>	<u>(119,978)</u>	<u>- 4,916</u>
<b>Restricted Funds</b>			
	<u>-</u>	<u>(3,963)</u>	<u>- 3,963</u>
	<u>115,062</u>	<u>(123,941)</u>	<u>- 8,879</u>

**8 Net assets by fund**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2021 £</b>
Tangible assets	-	-	-
Debtors	-	-	-
Current assets	150,887	- 3,963	146,924
Creditors	(86,054)	-	(86,054)
Net assets	<u>64,833</u>	<u>- 3,963</u>	<u>60,870</u>

**SUDC UK**

**Statement of financial activities by fund Year Ended 31 December 2021**

	<b>Restricted Income Fund 2021</b>	<b>Restricted Income Fund 2020</b>	<b>Unrestricted Income Fund 2021</b>	<b>Unrestricted Income Fund 2020</b>
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
<b>Incoming resources</b>				
Incoming resources from generated funds				
Voluntary income	4	8,000	115,062	97,510
Total incoming resources	4	8,000	115,062	97,510
<b>Resources expended</b>				
Costs of generating funds				
Costs of generating voluntary income	3,963	2,475	119,978	64,673
Total resources expended	3,963	2,475	119,978	64,673
Net movement in funds	-	3,963	5,525	4,916
<b>Reconciliation of funds</b>				
Total funds brought forward	5,525	-	64,224	31,387
Total funds carried forward	1,562	5,525	59,308	64,224

This page does not form part of the statutory financial statements



**SUDC-UK**

England & Wales - Charity number 1175413

---

# Accounts

---

Charity registration number: 1175413

## SUDC UK

Annual Report and Financial Statements  
For the Year Ended 31 December 2020



Carter & Co

19 Warren Park Way  
The Warrens Business Park  
Enderby, Leicester  
LE19 4SA

telephone (0116) 224 0400

fax (0116) 224 0399

[www.carteraccountants.co.uk](http://www.carteraccountants.co.uk)

**SUDC UK**

**Contents**

Reference and Administrative Details	1
Trustees' Report	2 to 4
Independent Examiner's Report	5
Statement of Financial Activities	6
Balance Sheet	7
Notes to the Financial Statements	8 to 10

The following pages do not form part of the statutory financial statements:

Statement of Financial Activities per Fund	11
--	----

**SUDC UK**

**Reference and Administrative Details**

**Charity name** SUDC UK  
**Charity number** 1175413  
**Trustees** Camilla Gooden  
Helen Charalambous  
Laura Gould Crandall (The SUDC Foundation)

**Accountant** Carter & Co  
19 Warren Park Way  
Enderby  
Leicester  
LE19 4SA

# SUDC UK

## Trustees' Report

### Organisation of the Charity

The Charity is constituted by Trust Deed dated 27<sup>th</sup> October 2017

### Committee

The Members of the Committee at the date of the approval of this Report were:

Camilla Gooden

Helen Charalambous

Nicola Speed (resigned)

Laura Gould Crandall

### Objects of the Charity

- The Trustees continued to hold funds for the work of SUDC UK to improve awareness and understanding of Sudden Unexplained Death in Childhood
- To fund crucial medical research to better understand these tragedies

### Summary of Accounts

- **Raising awareness** – A core part of SUDC UK's mission is to raise awareness of SUDC. To do this, SUDC UK works with bereaved families, the public, the press and other professionals to support the distribution of accurate information.
- **Funding research** – SUDC UK appreciates the incredible fundraising efforts of our community and the donations we receive. SUDC UK grants funds to research projects that aim to further our understanding of SUDC. It also works with professionals who have an interest in sudden unexplained death to help encourage and optimise research.
- **Supporting families** – Upon registration, families are immediately connected to the expert professional and peer bereavement support services of our partner organisation, the SUDC Foundation. SUDC UK provides practical resources following the loss of a child, hosts events for families and creates a supportive community.
- **Medical education** – SUDC UK attends medical conferences and other relevant meetings to provide up-to-date, helpful and consistent information on SUDC.
- **Collaborating to improve policy** – SUDC UK aims to help improve national policy and services and be a voice for our families. To do this, SUDC UK works with other organisations, consults on relevant guidelines and initiatives, and is a founding charity member of the national All-Party Parliamentary Group for Bereavement.

### Achievements and Performance

- Despite the challenges of lockdowns, SUDC UK continued to support medical education in 2020. We attended meetings with staff at the United Lincolnshire Hospital Trust and the West Midlands Child Death Review team. SUDC UK also presented online to over 300 attendees at the Midlands Child Death Review Network Virtual Conference.

## SUDC UK

### Trustees' Report

- Before 2020, SUDC UK had very limited contact with coroners. A key success of this year was to connect with The Coroners' Society and collaborate in regard to family advocacy and develop an online training module for Coroner's Officers. This module is complete and forms part of Coroner's Officer training in 2021.
- SUDC UK continues to work closely with The Lullaby Trust and in September, both charities collaborated to submit feedback from families as evidence for the Coroner's Service inquiry by the Justice Select Committee. This evidence was developed with insight from SUDC UK-registered families and was supported by Child Bereavement UK and SANDS.
- Throughout the year, SUDC UK continued to attend UK Child Death Registry steering group meetings alongside other charities and healthcare experts. SUDC UK shared information pertinent to families, empowering them and enabling them to join us at a March meeting to consult on plans for a registry. In late 2020, SUDC UK was asked to lead on a video project for the group to support and inform bereaved families.
- SUDC UK is proud to contribute to the All-Party Parliamentary Group for Bereavement and the National Grief Awareness Week initiative by the Good Grief Trust. We continue to advocate for our members and contribute to the collective aim of ensuring the best support for bereaved families.
- As a result of increased awareness of our charity and, very sadly, through new cases, the number of registered families with SUDC UK has risen by 57% over the last 12 months.
- Nikki Speed was contracted as Chief Operating Officer during 2020 to increase resources in line with our increasing workload and activities to further our mission.
- The summer of 2020, SUDC UK was unable to host our planned family day at Whipsnade Zoo, we instead held a virtual family day entitled 'Stars for Our Children'. Families each hung a star to positively recognise how we are united in understanding and remembrance. Another heart-warming event SUDC UK took part in was the Wave of Light in October, where families came together on social media, lighting candles for their loved and missed children.
- A Day Retreat was the first bereavement support event supported by SUDC UK. It was attended by families who had experienced the unexpected death of a child between 1 and 18. This received positive feedback as a very valuable event.
- In line with our mission for awareness of SUDC, SUDC UK collaborated with the NCMD (the National Child Mortality Database) team, significantly raising awareness of our services with child death review professionals across the country via their meetings, newsletter and Twitter. We also supported bereaved families with their awareness efforts in the press.
- SUDC UK's volunteer initiative had a vast impact on the charity in 2020, allowing SUDC UK to broaden its reach and achieve strategic goals. We now have regular part-time volunteers working in a variety of roles including a merchandise manager, family operations volunteer, finance manager and communications volunteer.

## SUDC UK

### Trustees' Report

- Our proactive fundraising enabled SUDC UK to grant £50,000 to research (<https://sudc.org/sudc-registry-research-collaborative/>) to promote understanding of SUDC and enable families to pursue further investigations into their child's cause of death. This is an increase from a grant of £38,494 in 2019. SUDC UK connected Elijah Behr, Consultant Cardiologist and researcher, with the principal lead of the research project at NYU Langone Health (SUDCRRC) to facilitate better understanding and international collaboration between their aligned research projects.
- 2020 saw the creation of our new SUDC UK online shop to support our mission for funds and awareness. It also saw an improvement in the quality of our website content as new resources were discovered.
- New, helpful 'packs' of information were developed and in 2020 we started sending these to newly registered, bereaved families and relevant health care professionals.
- A virtual community hour conference call via Zoom was started in 2020 entitled 'Fundraising together'. This aimed to deliver time together as a community where the focus was fundraising, in line with our mission.

### Charity Funds

The funds of the Charity are administered by the Committee to meet the objectives of the Charity. The Committee consider that the overall financial position of the Charity is satisfactory and that the Charity is able to meet its obligations.

### Risk Assessment

The Committee have considered the risks to which the Charity may be exposed and systems are in place to mitigate those risks.

### Financial Position

The Statement of Financial Activities is set out on the following pages.

The investments held are in accordance with the Committee's powers which are widely drawn.

Signed on behalf of the Committee

Approved by the Trustees on 14<sup>th</sup> October 2021 signed on their behalf by:



Helen Charalambous  
Trustee

**Independent Examiner's Report of the Trustees of  
SUDC UK**

I report on the accounts of the Trust for the period ended 31 December 2020, which are set out on pages 6 to 10.

**Respective responsibilities of trustees and examiner**

The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed.

It is our responsibility to:

- Examine the accounts under section 145 of the 2011 Act;
- Follow the procedures laid down in the General Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act;
- State whether particular matters have come to my attention.

**Basis of independent examiner's report**

My examination was carried out in accordance with the General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

**Independent examiners statement**

In connection with my examination, no matter has come to my attention:

- 1) Which gives me reasonable cause to believe that in any material respect the requirements:
  - to keep accounting records in accordance with section 130 of the Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act

have not been met; or

- 2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



.....  
Carter & Co  
19 Warren Park Way  
Enderby  
Leicester  
LE19 4SA

14<sup>th</sup> October 2021

SUDC UK

Statement of Financial Activities for the Year Ended 31 December 2020

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £	Total Funds 2019 £
<b>Incoming resources</b>					
Incoming resources from generated funds					
Voluntary income	2	97,510	8,000	105,510	60,666
Total incoming resources		<u>97,510</u>	<u>8,000</u>	<u>105,510</u>	<u>60,666</u>
<b>Resources expended</b>					
Costs of generating funds					
Costs of generating voluntary income	3	64,673	2,475	67,148	49,341
Total resources expended		<u>64,673</u>	<u>2,475</u>	<u>67,148</u>	<u>49,341</u>
Net movement in funds		32,837	5,525	38,362	11,325
<b>Reconciliation of funds</b>					
Total funds brought forward		<u>31,387</u>	-	<u>31,387</u>	<u>20,062</u>
Total funds carried forward		<u><u>64,224</u></u>	<u><u>5,525</u></u>	<u><u>69,749</u></u>	<u><u>31,387</u></u>

All incoming resources and resources expended derive from continuing activities.

The charity has no recognised gains or losses for the year other than the results above.


The notes on pages 8 to 10 form an integral part of these financial statements.

SUDC UK

Balance Sheet as at 31 December 2020

		2020	2019
	Note	£	£
<b>Current assets</b>			
Cash at bank and in hand		<u>118,687</u>	<u>70,631</u>
<b>Current Liabilities</b>			
Other Creditors	5	48,938	39,244
Net assets		<u><u>69,749</u></u>	<u><u>31,387</u></u>
<b>The funds of the charity:</b>			
<b>Restricted funds</b>			
Family Retreats		5,525	-
<b>Unrestricted funds</b>			
Unrestricted income funds		<u>64,224</u>	<u>31,387</u>
<b>Total charity funds</b>		<u><u>69,749</u></u>	<u><u>31,387</u></u>

Approved by the Board on 14 October 2021 and signed on its behalf by:

  
 .....  
 Helen Charalambous  
 Trustee

The notes on pages 8 to 10 form an integral part of these financial statements.

## SUDC UK

### Notes to the Financial Statements for the Year Ended 31 December 2020

#### 1 Accounting policies

##### **Basis of preparation**

The financial statements have been prepared under the historical cost convention on a Receipts and Payments basis and in accordance with the Statement of Recommended Practice 'Accounting and Reporting by Charities (SORP 2005)', issued in March 2005, applicable accounting standards and the Charities Act 2011.

##### **Fund accounting policy**

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity.

Restricted funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Designated funds are unrestricted funds set aside at the discretion of the trustees for specific purposes.

Further details of each fund are disclosed in note 7 and 8.

##### **Incoming resources**

Donations are recognised when they are received.

Incoming resources from tax reclaims are included in the statement of financial activities when received.

Investment income is recognised on a receipts basis.

##### **Resources expended**

All expenditure is accounted for on a payments basis and has been classified under headings that aggregate all costs related.

Costs of generating funds comprise the costs associated with attracting voluntary income and investment management fees.

##### **Support costs**

Support costs include central functions.

**SUDC UK**

**Notes to the Financial Statements for the Year Ended 31 December 2020**

.....continued

**2 Voluntary income**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £	Total Funds 2019 £
<b>Donations and legacies</b>				
General Giving	97,510	8,000	105,510	60,666
Gift Aid tax reclaimed	-	-	-	-
	<u>97,510</u>	<u>8,000</u>	<u>105,510</u>	<u>60,666</u>
<b>Grants</b>				
Grants - other agencies	-	-	-	-
	<u>97,510</u>	<u>8,000</u>	<u>105,510</u>	<u>60,666</u>

**3 Total resources expended**

	2020 £	2019 £
<b>Direct costs</b>		
SUDCRRRC Grant	48,159	38,494
Advertising/Promotion	685	2,459
Cost of labour	7,140	-
Childcare	2,541	4,301
Events	154	732
Family Retreats (Restricted Funds)	2,475	-
Office expenses	685	601
Printing, posting and stationery	864	395
Telephone	-	50
Professional fees	3,195	820
Travel and subsistence	390	567
Accountancy	780	750
Bank Charges	80	86
Sundry	-	86
	<u>67,148</u>	<u>49,341</u>

**4 Trustees' remuneration and expenses**

During the year Nicola Speed received childcare to allow them to perform their duties.

SUDC UK

Notes to the Financial Statements for the Year Ended 31 December 2020

.....continued

**5 Creditors**

	2020 £	2019 £
Accruals	780	750
SUDCRRC Approved Grant	48,158	38,494
	<u>48,938</u>	<u>39,244</u>

**6 Related parties**

**Controlling entity**

The charity is controlled by the trustees.

**7 Analysis of funds**

	Incoming resources £	Resources expended £	At 31 December 2020 £
<b>General Funds</b>			
Donations and Legacies	97,510	(64,673)	32,837
	<u>97,510</u>	<u>(64,673)</u>	<u>32,837</u>
<b>Restricted Funds</b>			
	<u>8,000</u>	<u>(2,475)</u>	<u>5,525</u>
	<u>105,510</u>	<u>(67,148)</u>	<u>38,362</u>

**8 Net assets by fund**

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
Tangible assets	-	-	-
Debtors	-	-	-
Current assets	113,162	5,525	118,687
Creditors	(48,938)	-	(48,938)
Net assets	<u>64,224</u>	<u>5,525</u>	<u>69,749</u>

SUDC UK

Statement of financial activities by fund Year Ended 31 December 2020

	Restricted Income Fund 2020  £	Restricted Income Fund 2019  £	Unrestricted Income Fund 2020  £	Unrestricted Income Fund 2019  £
<b>Incoming resources</b>				
Incoming resources from generated funds				
Voluntary income	8,000	-	97,510	60,666
Total incoming resources	<u>8,000</u>	<u>-</u>	<u>97,510</u>	<u>60,666</u>
<b>Resources expended</b>				
Costs of generating funds				
Costs of generating voluntary income	2,475	-	64,673	57,491
Total resources expended	<u>2,475</u>	<u>-</u>	<u>64,673</u>	<u>67,148</u>
Net movement in funds	5,525	-	32,837	11,325
<b>Reconciliation of funds</b>				
Total funds brought forward	-	-	31,387	20,062
Total funds carried forward	<u>5,525</u>	<u>-</u>	<u>64,224</u>	<u>31,387</u>

This page does not form part of the statutory financial statements