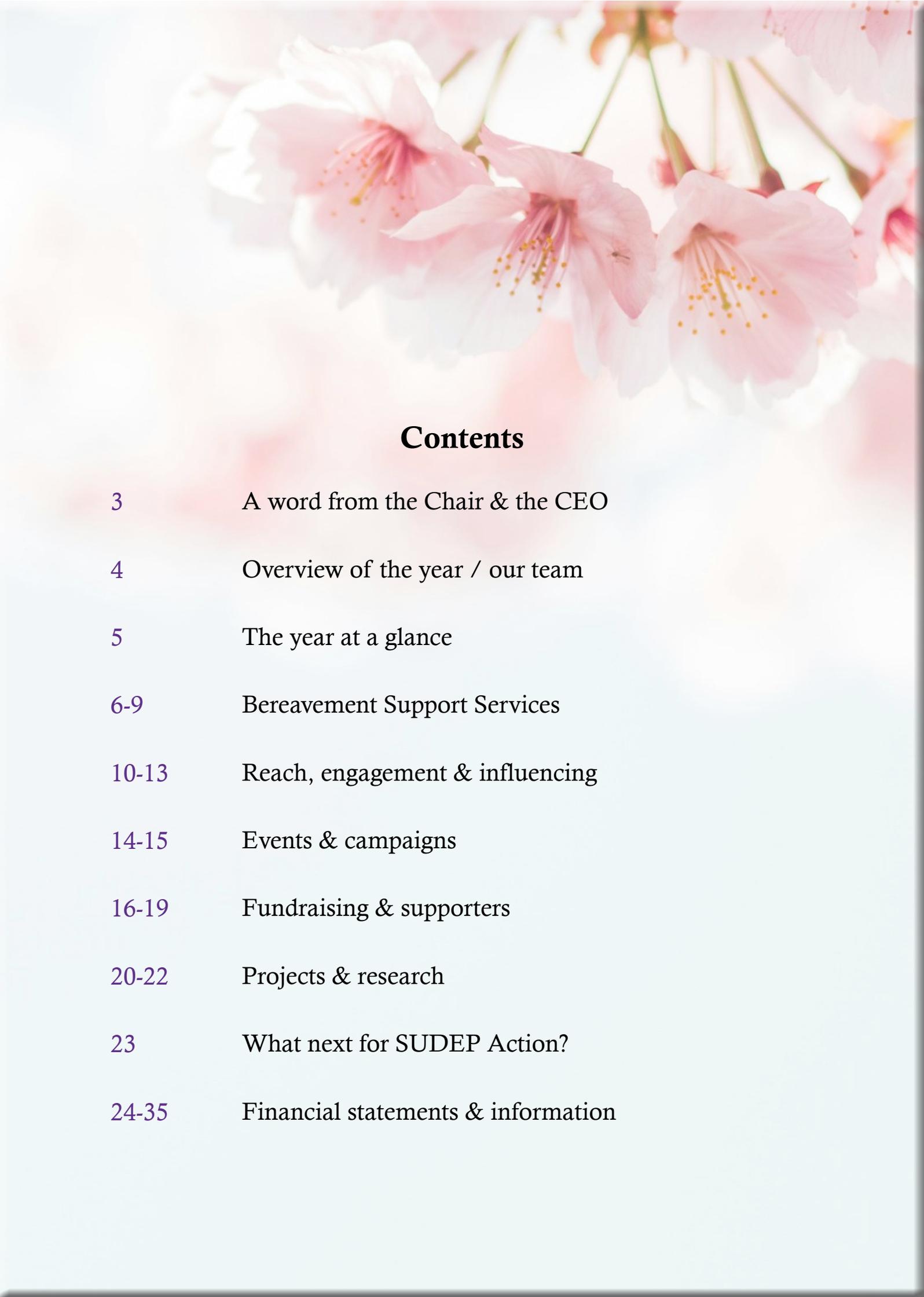




ANNUAL REPORT 2024/2025

SUDEP Action 
Making every epilepsy death count



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John Hirst CBE: Chair

3

“The work that SUDEP Action does is very close to my heart. In 2025 the charity reaches the 30th year since it was founded – and my family mark the 24th year since our son James died. Like the other trustees, I am bound to the work of the charity because we have all suffered that grief of sudden death in our families, and our commitment is underpinned by the conviction that many of them were totally avoidable.

I am immensely proud of the support we provide, the campaigning we do and the services we develop and deliver, and I would like to thank the incredibly dedicated staff, and the many supporters who work with us to raise funds to pay for what we do. I should particularly like to thank four



trustees who, having served for many years with great distinction, retired this year. They are Professor Stephen Brown, Professor Mike Kerr, Graham Faulkner and Mark Phillips. We owe you all a debt of gratitude. I would also like to welcome Dr Owen Pickrell, Professor Ley Sander and Dr Rhys Thomas, distinguished clinicians who have recently

joined the Board of Trustees. We are indeed fortunate they have chosen to work with us.

Whilst the composition of the Board evolves, the work goes on. We rightly acknowledge a year in which much has been done that tops 30 years of achievement by the charity, but we also note with a balance of some frustration and massive determination that there is so much still to do.

We will only be really satisfied when we know that our work is no longer necessary because there are no more avoidable deaths in epilepsy. Until then the work goes on and we thank you for your support in our mission.”

John

Sammy Ashby: CEO

“I have now been in post for 14 months and I’m so proud of the progress the charity has made.

Our new strategy for 2024-2027 was created in collaboration with the staff team, trustees, supporters and our networks. It revolves around polishing our existing services to become even better, propelling the work, reach and impact of the charity forward.

We’re already making fantastic progress, as you’ll read in this report. And there are some very exciting things planned



for the future, such as the launch of a new and improved EpSMon app. However, there is still much work to do to stop preventable epilepsy deaths and make sure we reach

anyone who has been bereaved by epilepsy. Our supporters are at the heart of our work and they give the charity its power, along with the small but mighty staff team. We are determined to see a future where there are no preventable epilepsy deaths.

As we head into our 30th year as a charity, I hope you’ll continue to stand alongside us all of the way.

We won’t stop until epilepsy deaths do.”

Sammy

SUDEP Action wants to see a world where no one dies from epilepsy and where those bereaved are aware of our services.

Our new three-year strategy, starting in 2024-25, defines where we see ourselves today, as well as our vision for where we want to be in the future as we strive to prevent epilepsy deaths. Stopping preventable epilepsy deaths is a huge challenge and one we can't achieve on our own. It will take collaboration, personal experiences, and determination to make this happen. SUDEP Action services are provided for free to anyone who needs them.

In the first year of our strategy we focused on 'polishing' aspects of work that we already do

and improving them, to increase and maximise impact.

This has included:

- Refreshing our information, leaflets and resources.
- Beginning to create a new version of our EpSMon app.
- Sharing the SUDEP and Seizure Safety Checklist with more health professionals.
- Expanding our Bereavement Support services so we can provide more expert and confidential support to anyone bereaved by epilepsy, or fighting for answers through inquests and investigations.
- Raising more awareness of key issues facing our supporters with MPs, policymakers, Government and the NHS.



SUDEP Action has been an essential resource for me since my son died. They have provided emotional support, answered some uncomfortable questions and given clear information and guidance based on years of research in partnership with a range of bodies.



"Keep going, you are all priceless."

3,150

Communications with
Bereavement Services (↑52%)

1,400

Health professionals
engaged with our
training
(↑190%)

75

Families received
personalised support
(↑42%)

1,938

Health professionals
registered to use our
Adult Checklist

366

Health professionals
registered to use our
new Paediatric
Checklist

87

First contacts,
Bereavement

5,501

EpSMon
users

81

Reports to the
EDR

“

SUDEP Action are so understanding, so supportive, so knowledgeable and easy to talk to. I have had an incredibly positive experience accessing support from them.

It has had a massively positive impact on my quality of life following the death of my sister.”

No other charity in the UK, or the world, provides the same level of bereavement services to those who have lost loved ones to epilepsy / SUDEP. Our services are unique, with personalised support tailored to help people navigate the complex processes

they face following a death. Access to these services is free to all who need them. Everyone's grief experiences are different. We understand this and use 30 years' experience to support people on their unwanted, devastating journeys.

Providing telephone support to anyone bereaved by epilepsy is central to our work. This free, confidential service has no time restrictions and is a lifeline for some.

In 2024-2025 there were 3,150 communications with the Bereavement Services team. These were a mix of people new to SUDEP Action and recently bereaved, alongside other longer-term supporters still finding value in speaking with us about their grief and their loss.

Some of these communications were from people engaging with the charity just once, others were repeat users of this service, encompassing both bereaved individuals and professionals working in the field of bereavement.

Over the course of the year we received 87 new individual contacts, engaging with the charity



via Bereavement Services for the first time. Whilst this is a slight drop in the number of new individual contacts compared to the previous year, the number of communications went up by 52% as people return to us year-on-year, often with more complex enquiries.

During 2024-25, we welcomed a new Bereavement Services Officer to the SUDEP Action Team, to enable us to support even more bereaved people. As well as providing ongoing telephone support, our BACP registered counsellor provides counselling sessions to bereaved individuals who are further along their grief journey.

Our Bereavement Support Services team continues to see an increase in demand and complexity of contact. Our casework service has been particularly affected by this, supporting 75 families in the last year with highly personalised support (a 42% increase on the previous year).

“

I was put in contact with them after trying to register my son's death. She has been the ONLY professional available to me in the aftermath of my son's death. She has been able to talk me through the most horrendous experience of my life.”



Many newly-bereaved individuals request counselling early on, believing this is what they need to help them after being signposted to more generic counselling services by the NHS following their loved one's death.

There are other ways to access early, specialist and tailored support. Our

telephone service is open ended and the bereaved are supported by the same person wherever possible. Our services are run by people highly experienced in understanding epilepsy and the complexities that surround a sudden and traumatic epilepsy death, who can help with the after-death investigations that sometimes follow.

To provide the level of support we offer, we work with individuals and families to:

- Gather and review information about the death and the person who has died.
- Work to understand their concerns about their loved one's death.
- Share our experience of inquests and investigations so that they have a realistic idea of what will happen and support them so that they can participate effectively.
- Advocate for proper investigations into their loved one's death as epilepsy deaths may be overlooked in this system.
- Support families throughout (until a decision is made) – including emotional support. For some, this can be a long process lasting months or even years.

Our expertise in epilepsy mortality links in with our experience of the legal and investigative processes after an epilepsy death.

These processes are really tough for families to navigate alone when they are in traumatic grief, as these systems provide little support to those bereaved.

Casework can involve drafting submissions, including for Coroners and NHS investigations, regulatory authorities, the Ombudsman and MPs, suggesting lines

of questioning and strategy, liaising with Coroners and Trusts and supporting families to participate / advocating on their behalf.

We also brief expert witnesses to help provide an overview of the strategy, keeping in mind what the family wishes to achieve / focus on. This can be incredibly complex and varies from case to case.

Much of this work takes place in private, without public awareness or recognition for the significant work needed to get families the answers they deserve.

This year our casework service continued to support the family of Joshua. The inquest process ended with an outcome the family had been fighting for more than three years.

The inquest ruled that Joshua died of SUDEP, even though his epilepsy was never diagnosed.

Joshua's mother Zoe said "The support I have received from SUDEP Action has been invaluable and I could not have got through this process without them. They have been with me since our lovely Joshua passed away in November 2020."



Many of our bereaved supporters want their loved one to be remembered and for their story to be told to help raise awareness. This year we received information relating to epilepsy deaths from 81 people via our Epilepsy Deaths Register (see the Projects and research section for more details).

In addition, the 'My Story'

page on our website is extremely precious to us and helps highlight the often preventable nature of many epilepsy/SUDEP deaths, providing learnings for the future.

This year, Martin and Amanda Walker shared the story of their daughter Amber's death, aged 22. The full story can be found on our website [here](#)



Our aim in telling Amber's story is to make sure that other families don't have to suffer the same loss and grief that we have, because of a lack of openness.



Across the advocacy we have provided throughout 2024-25, these themes remain prevalent:

- SUDEP risk discussions are not taking place between clinician and patient.
- Maternal deaths: Where person-centred conversations about risk and medication are not taking place.
- A failure to understand risks for people with a learning disability / epilepsy in residential care. Also, minimal investigations into deaths.
- Problems with gaining access to specialist care for breakthrough / worsening seizures.
- Issues over access to appropriate medications, which are restricted or unavailable.
- Issues with accurate diagnosis (resulting in delays to treatment or no treatment at all).

We are also seeing an increasing number of the following issues:

- No discussion of SUDEP risk.
- People with epilepsy and a learning disability:
 - not having safe epilepsy-focused care commissioned for them, and

- suffering further discrimination after death when there is minimal investigation.
- Problems with access to specialist care for seizure investigation.

Bereaved families have experienced significant challenges, including:

- Epilepsy/SUDEP being overlooked as a cause of death during inquests or investigations (including deaths where there has been no formal epilepsy diagnosis).
- An inquest not being granted, despite evidence of the death being preventable and/or there being problems with epilepsy care/diagnosis.
- Organisations (such as the NHS and care providers) not responding adequately to concerns about epilepsy care or recognising the need to learn from a death to improve their services.
- SUDEP not being recognised as a cause of death/being confused with other causes.
- Good practice in epilepsy care not being followed, for example, SUDEP risk discussion.

“

SUDEP Action has been vital in providing a wide-ranging service user perspective to inform our approach. NHS Regional Team ”



Epilepsy medicine shortages & accessibility

SUDEP Action has continued to highlight ongoing issues relating to access to epilepsy medicines by:

- Submitting evidence to the All-Party Parliamentary Group on Pharmacy, calling for the Government to act fast to prioritise people with epilepsy and others at risk of sudden death, including warnings that people with epilepsy are especially vulnerable to dying from problems with accessing medication.
- Working alongside Epilepsy Society, Epilepsy Action and Parkinson's UK with a group of 40 cross-party MPs to write to the Health Secretary, calling for an end to ongoing medication shortages.

- Working with various NHS Trusts across the country, supporting them to provide better access to effective medicines and have balanced communications with people with epilepsy. This has also included helping to produce new easy-read resources regarding sodium valproate in 30 languages.

See more:

[Pressure on party leaders to fix medicine shortages](#)

[Coalition of orgs asks for urgent meeting with Health Secretary](#)

[Failing policies are failing people with epilepsy](#)

Because of the sudden, often preventable nature of many epilepsy deaths, our bereaved supporters call for lessons to be learnt and actions taken to stop future deaths from happening. This is a core focus of our work, using press, social media, marketing, campaigns and policy work to spread key messages and raise vital awareness so lives can be saved.

With epilepsy still seen publicly by many as a non-life-threatening health condition (including within Government, the NHS, the Coronial Service and the press), it is an uphill challenge to get our voice heard. This doesn't stop us.

Across the year, change happened as a result of our work.

Pathology guidance

As a result of learnings from SUDEP Action casework, new pathology guidance now includes the recommendation that SUDEP should be considered, and discussed with the Coroner, in deaths where seizure-like events are reported with no formal diagnosis. The guidance, for the first time, also recognises that there may be limited clinical information available at the time of a pathology investigation, so information should be gathered from the family and other sources to obtain as full a history as possible. This means greater recognition for the families.



an earlier decision not to approve the use of Fenfluramine for the treatment of seizures associated with Lennox-Gastaut Syndrome. Jane Hanna, SUDEP Action Director of Policy & Influencing, told the appeal panel that Fenfluramine could be a lifeline for some families without hope, offering up to a 50% reduction of risk in seizures. As a result of SUDEP Action's contribution to the appeal process, NICE has now approved the use of this medication for people in England.

[Read more](#)

NICE Appeal decision on new anti-seizure medication

The National Institute for Health Care and Excellence (NICE) upheld an appeal against

SUDEP Action is currently working with NHS teams across the country, who look after 217,567 people with epilepsy.

We are working to raise awareness of SUDEP / epilepsy deaths, to make improvements to their practices, and to provide practical support tools to communicate and mitigate risk.



It was great to have the opportunity to discuss with other nurses how they speak to families about SUDEP and use real life cases.

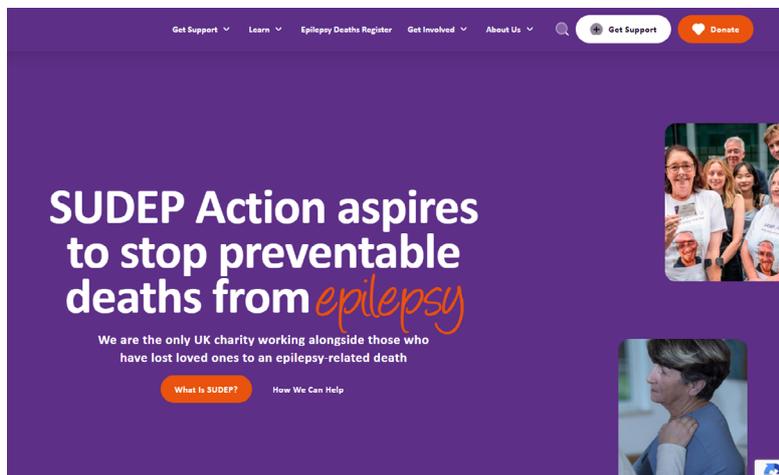


Professional engagement / education

We reached more than 1,400 health and care professionals across the UK, delivering webinars, attending conference sessions, and tailoring training. Examples include: the North West CYP Epilepsy Conference; Solihull County Council webinar; sodium valproate training in the South East; Oxford University medical training and the Roald Dahl Nurses Conference.

These, along with other attended sessions, raised awareness of epilepsy risk among professionals and demonstrated how to access key resources such as the SUDEP and Seizure Safety Checklist and the EpSMon app, that they can use with their patients to help prevent avoidable epilepsy deaths.

We also provide more personalised responses to specific questions when people with epilepsy or health professionals contact us directly for support.



New website

Our new website sudep.org better showcases the work of SUDEP Action, and makes it easier for the bereaved, health professionals and people with epilepsy to access the information they need. Newly designed information leaflets for the general public and health professionals were also made available.



If I hadn't found the website after the loss of my daughter, I wouldn't be the person I am today. Thank you a million times and more.



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Tower tribute to organ donor who saved eight lives



Paul Burnell
UK News
28 March 2025

The name of a young woman with epilepsy who saved eight lives through organ donation will shine out from Blackpool tower on a day dedicated to raising awareness of the condition.

* Click on picture for story

UK charities condemn continued drug shortages

As the UK tackles several drug shortages, UK charities and pharmacists called for urgent action to be taken.

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Tributes pour in for young Hamilton woman as the Town House turns purple for Epilepsy Awareness Days

Twenty-year-old Jessica Jamison died suddenly and unexpectedly from undiagnosed epilepsy in January 2022 - she never received the care and treatments that may have kept her alive

By Andrea Lambour
14.03.2025



Family of Megan Gardiner want answers over medication

7:11PM | 14 JANUARY 2024 | LOCAL | BRISTOL



Megan's (second from left) with sister Toni (left), father Robert and mother Alison at hospital launch (Image: Alison Musker/PA)

By Harry Jamieson
Head of Content
@harryjamieson

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Royal Navy recruit, 20, died after nocturnal seizures

It is hoped lessons can be learned from his tragedy

By David Munnery
10:01, 10 JAN 2024



It is hoped lessons can be learned from his tragedy

A 20-year-old recruit to the Royal Navy died after nocturnal seizures, which he had been treated for. He had been in the Royal Navy, and was serving on the HMS Dryad, but had recently developed symptoms looking like nocturnal seizures.

Radcliffe: Mum to hold fundraiser after daughter died from epilepsy

16:00, 10 JANUARY 2024 | BRISTOL



Samantha Adams (Image: Lynn McGold)

The ethical quagmire of a fetus-harming epilepsy drug

Britain is restricting the use of valproate, charities are alarmed



By Sarah Jones

WHEN BRITAIN'S MEDICALS was 14 she had what she calls "the big, bad one" - the kind of seizure everyone imagines when they think of epilepsy. But her doctors hesitated to give her sodium valproate, a highly effective drug, because it could harm the fetus should she become pregnant. Ms Mulcahy instead spent years on drugs that did not prevent her seizures; her mental health and schooling suffered. "It felt like my unborn, I imagined this was more important than I was," she says, now 30 and, thanks to valproate, seizure-free.

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SHOCK LOSS Mum's heartbreaking tribute to son, 19, who died without warning while revising for exams just weeks before her wedding

Everything you need to know about Sadie's Unexpected Death In February (EUPD), the rare phenomenon behind her tragedy

By Sadie's Family
Published: 06:00, 11 JAN 2024 | Updated: 06:00, 11 JAN 2024



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The NHS is failing epilepsy patients
Sufferers are being denied key drugs



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How shocking shortages and missed diagnoses lead to the preventable death of six innocent people - as special report reveals what you must know to keep yourself safe

By MACCARLANE
PUBLISHED: 11:48, 15 March 2025 | UPDATED: 11:48, 15 March 2025

I speak to over 250 days since Wes Streeting took the reins as Health Secretary (shudder), ironically, to turn our health service around. His first speech was lent and sombre. From today, the policy of this department is that the NHS is one, "the way, leading itself" as the man for it is.

and, in the run-up to the election, the MP for Wford North - then Shadow Health Secretary - claimed he was "careful to say those promises we can keep; putting our time to things where there are people whose lives

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TOP STORIES

1. **Medical mystery**
Concerned family Jones to uncover the real cause of death of their 14-year-old daughter who died after a seizure. Her family friend following his diagnosis with Munchausen's Syndrome.

2. **Teacher hit**
Unsuspecting after a flying pencil a drink as experts issue safety warning for 'gangsters' sweet biscuits

3. **Medical 3C, who was**
in highest command during lockdown other parents had to take her out keys and back her children to class admits (BBC) Online

4. **The health chief**
says 10 month effort with

Online Epilepsy Memorial Day – May

157 tributes via our dedication wall

This annual event provides bereaved supporters worldwide with an opportunity to remember loved ones. A special tribute wall is created online to bring together people's memories and show the world the beautiful faces of those who have died. This serves as powerful reminder of why we cannot stop fighting to prevent epilepsy deaths. On this day we shared a special video of Laurence Richards, pictured, who died from SUDEP, set to music that was specifically written in his memory. We also came together as a community to light an evening candle in memory of those who have died, and this is always a powerful and poignant part of the day.



National Epilepsy Week – May

National Epilepsy Week follows swiftly after Online Epilepsy Memorial Day and is an opportunity for epilepsy charities to come together to raise the profile of epilepsy among the general public.

SUDEP Action Day – October

This year's theme for SUDEP Action Day was 'Our Risks Our Rights'. This allowed us to:

- Highlight the lack of understanding about epilepsy risks.
- Promote the rights of people with epilepsy to care, choices, potentially life-saving medicines, access to services, information, medical reviews and good epilepsy care.
- Explain the rights of the bereaved to have their questions answered and causes of death recognised.

90+ organisations took part in SUDEP Action Day

96 posts across four social media platforms

160K+ Reach of our posts & messaging

Light Up the Sky – December / January



Christmas is challenging for many of our bereaved supporters and we often see an increase in requests for support calls in the weeks leading up to it. However, it's also an important time to remember and reflect. Our Light Up the Sky campaign encourages people to share messages and photographs of lost loved ones to a special tribute wall. These are beautiful, heartbreaking and poignant reminders of what we do. On Christmas Eve our social media timelines were flooded with supporters joining us to light candles simultaneously for those who have died.

We received over 150 tributes to our dedication wall this year.

Coffee Clubs



Attending the Coffee Club meeting today really helped. It was nice to feel comfortable talking about my story and hearing how others are further along this difficult journey. ”

We held eight Coffee Club meetings, an increase on numbers for the previous year. These meetings are run by our fantastic volunteers, and this year we had four new volunteer hosts. Our bereaved community welcomes the opportunity to meet with others similarly bereaved. Coffee Club meetings are free to attend, with SUDEP Action covering any costs for venues and refreshments and organising the bookings.

We rely on the incredible support of individuals, families, teams, and communities who get involved through fundraising and donations made in memory of loved ones. Their efforts make up the majority of our annual income and are central to everything we do.

In addition to our amazing community of fundraisers and supporters, we are also deeply grateful to the grant funders, foundations, companies, and donors whose contributions help make our work possible — supporting our fight for a future without preventable epilepsy deaths, and ensuring that everyone bereaved by epilepsy

can access the specialist support they need. These include:

- Alison Hillman Trust
- Bernard Lewis Family Charitable Trust
- Capitalix
- Gallagher Insurance Community Fund
- John Fowler LLP
- Making Websites Better
- Mr & Mrs Pye Charitable Trust
- The Anne & John Walters Charitable Trust

If you would like to fundraise for SUDEP Action please contact fundraising@sudep.org



The Rowlinson/Inman family: fundraising in memory of Jack

Since the devastating loss of Jack Rowlinson in 2014, his family — including mum Laura, dad Mike, and grandparents Yvonne and Ian Inman — have channelled their grief into action, becoming dedicated supporters of SUDEP Action.

The family has tirelessly raised funds over many years through a series of vibrant and well-loved race nights, bringing their community together to remember Jack and raise awareness of SUDEP. Ian, Jack's grandfather, also played a special role in their efforts — selling his tasty homemade 'fiery Jack' pickle to boost donations.

Sadly, Ian, pictured below right, passed away recently, leaving a huge gap in the family and community. But his passion for supporting SUDEP Action lives on. As the family told us: "We will continue our fundraising for SUDEP Action very soon, as we had orders from Ian — we need to get



the overall total raised to £100,000 before the end of 2025."

Their commitment is both inspiring and humbling. We are so grateful for everything the family has done and continues to do, to honour Jack's memory.





Our fundraisers take on all kinds of challenges to support our work, often in memory of someone who has died. From bake sales to race nights, fun runs to purple balls, they never fail to be creative and committed. By taking part, they not

only raise vital funds but also help spread much-needed awareness of SUDEP and epilepsy-related deaths. Their phenomenal efforts help us save lives and provide our services free of charge to those who need them most.

Whilst we cannot showcase every individual who fundraised for us over the past year, we wholeheartedly recognise and appreciate the amazing efforts of each and every supporter.





Thank you to everyone who supported us — and to the friends, families, and networks who stood alongside them.

The Adult SUDEP & Seizure Safety Checklist, EpSMon app and Epilepsy Deaths Register (EDR)

Our ongoing projects, named above, continued to grow in reach and impact. By the end of March 2025 there were 1,938 health professionals registered to use our [Adult Checklist](#), 5,501 [EpSMon](#) users, and 81 new reports about epilepsy deaths had been made to the Epilepsy Deaths Register (EDR).

We worked with teams from four NHS Trusts across the UK to integrate the Checklist into their systems.

It is also estimated that over 80% of GP surgeries in England now have access to the Checklist through their systems.

Launch of the Paediatric SUDEP & Seizure Safety Checklist

Working in collaboration with Cornwall Partnership NHS Foundation Trust and Young Epilepsy, [the paediatric version of the SUDEP and Seizure Safety Checklist](#) was made available to clinicians in August 2024. This project grew from our appreciation that clinicians needed a tool to help them tailor their conversations with children, young people and their parents, in order to provide the necessary care, support and assessment of risk. By the end of March 2025, 366 clinicians had registered to use the Paediatric Checklist through their systems.

Professor Rohit Shankar MBE, FRCPsych,



pictured, who worked on the Paediatric Checklist, said: “Until a few years ago it was thought that SUDEP was rarer in children than adults. However, this has now been proven wrong. Children are as much at risk of dying of SUDEP as adults. The impact of each child dying of SUDEP is devastating for families, their carers and their professionals who can be scarred for life, wondering if they could have done anything differently. This Paediatric Checklist brings about the guarantee that the latest evidence is communicated to patients and their families. It also empowers clinicians to know what the cumulative risks are.”

"Information is so important for individuals in the management of their epilepsy – in children as much as adults. This checklist will provide a tool for clinicians to start the conversation about risks of mortality."



Prof Helen Cross



SUDEP Action  SUDEP.ORG

The Epilepsy Deaths Register

The Epilepsy Deaths Register (EDR), created and curated by SUDEP Action, is a web-based platform where bereaved families and professionals can provide information about epilepsy-related deaths to help research and improve safety for people with epilepsy. This confidential, online register collects details on deaths with, or suspected to have epilepsy, focusing on the circumstances around the death and the support provided. The information is used in anonymised reports to raise awareness, identify service gaps, and inform the development of new safety tools and practices to prevent future deaths.

The EDR is now the largest research database into epilepsy deaths in the world.

There are often many unanswered questions for families and loved ones after a death. This, along with inquests and investigations, can complicate the trauma and grief further. The value of providing a safe space for the bereaved community to share this information cannot be underestimated.

A total of 81 new reports were made to the EDR in 2024-25. This data (anonymised) is accessible to researchers across the UK, in search of breakthroughs and a better understanding of SUDEP / epilepsy deaths.



- EDR data shows the risk for women changes through different points of their lives, increasing during childbearing years (19 to 49), and decreasing during perimenopause.

- EDR data also shows significantly more medication concerns are present in patients living alone (44%), compared to those in care (8%) or living with others (29%).



The Epilepsy Deaths Register represents a collective voice of people bereaved by epilepsy-related death, united in their wish to protect against preventable loss of life.



Research and collaborations

Research comparing the views of epilepsy professionals in the UK and Norway was published this year, with SUDEP Action part of the research study group. Epilepsy professionals play a critical role in helping people with epilepsy manage their condition – to minimise the risk of preventable death, including SUDEP.

This new research shows that, both in the UK and in Norway, risk discussions are not routinely taking place and that:

- Only 20% of UK epilepsy professionals said they discussed SUDEP with all patients.
- Only 12% of UK epilepsy professionals indicated that they felt SUDEP should always be discussed with all patients.

The main reasons cited for not discussing SUDEP with patients included 'low clinical risk' (50%) and 'not distressing the patient' (44%). The research did show that UK professionals were discussing SUDEP with their patients more frequently than many of their counterparts in other countries. [Read more](#)

SUDEP Action was also involved in presenting a paper on the [top ten research priorities for epilepsy \(in conjunction with the Epilepsy Research Institute\)](#), and a presentation for the International League Against Epilepsy (ILAE) on 'tool development for commissioning safer services for people with a learning disability and epilepsy' – learning from the death of Clive Tracey.



There needs to be more regular risk-orientated SUDEP discussions between epilepsy professionals and their patients. People with epilepsy need to be provided with information to increase understanding of their own risks at all times, not just from one clinical review to the next.



Ben Donovan
SUDEP Action Research Manager



The next charity year (2025/26) will see SUDEP Action reach its 30th year. The charity wasn't started by doctors, researchers, clinicians or medical professionals – it was started by five bereaved women wanting answers on why their loved ones had died suddenly, unexpectedly and without explanation. We've come a long way since 1995 but there's still a long way to go.

In 2025/26 we plan to:

- Put key issues in the national spotlight, working with MPs, policymakers, Government and the NHS.
- Continue to fund vital research.
- Strengthen our international reach through our

worldwide collaborations with Epilepsy Action Australia and Epilepsy Ireland.

- Launch a new version of our EpSMon app.
- Refresh our information, leaflets, resources, training and education services.
- Share an updated version of the SUDEP and Seizure Safety Checklist with more health professionals, both in the UK and internationally.
- Offer more opportunities for those bereaved due to epilepsy to meet together. This will include a memorial service in central London and an expansion of our coffee clubs.
- Continue to provide expert, confidential support to anyone bereaved by epilepsy or fighting for answers through inquests and investigations.



We will continue to make a difference with the ongoing support of our community. We won't stop until deaths do.

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH, 2025

The report that follows covers the work undertaken by SUDEP Action for the year 1st April 2024 to 31st March 2025.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's governing document and the Statement of Recommended Practice, "Accounting and Reporting by Charities in accordance with the Financial Reporting Standard for Smaller Entities" (effective January 2015).

The registered charity name is SUDEP Action. The Charity Registration number 1164250 (England and Wales) and SC047223 (Scotland) was constituted under a Declaration of Trust dated 14th October 2015 as a charitable incorporated organisation (CIO).

The Charity is linked by the Charity Commission to the registered charity Epilepsy Bereaved (Charity Registration number 1164250), which was constituted under a Declaration of Trust dated 14th October 1995 as an unincorporated charity which adopted SUDEP Action as a working name in January 2013.

The trustees of the Board of both charities are the same and the linking of the two charities protects SUDEP Action from loss of legacy income in the future.



CHARITY INFORMATION

CHIEF EXECUTIVE

Samantha Ashby

TRUSTEES

John Hirst CBE (Chair)

Simon Lees

Mark Phillips (retired November 2024)

Alex Stirling

Graham Faulkner (retired August 2024)

Professor Mike Kerr (Vice Chair, retired February 2025)

Rachel Shah (Treasurer)

Professor Stephen Brown (retired February 2025)

Dr Judith Shakespeare

David Sibree

Dr William Owen Pickrell (appointed February 2025)

Over fifty per cent of our trustees have direct experience of being bereaved by epilepsy/SUDEP. All other members of the board have experience of the epilepsy or epilepsy bereaved communities through professional or personal experiences (for example as health professionals or researchers). They use their experiences and knowledge to support the work of the SUDEP Action team.

CHARITY NUMBER

1164250 (England & Wales)

SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

WEBSITE

www.sudep.org

ADDRESS FOR CORRESPONDENCE

18 Newbury Street, Wantage, Oxfordshire, OX12 8DA

ACCOUNTANTS

Chapman Worth Limited, 2 The Old Estate Yard, High Street, East Hendred, Oxfordshire, OX12 8JY

BANKERS

HSBC PLC, 24 Market Square, Witney, Oxfordshire, OX28 6BG

Barclays Bank PLC, Marcham Road, Abingdon, Oxfordshire, OX14 1UB

United Trust Bank Ltd, One Ropemaker Street, London, EC2Y 9AW

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES, FOR THE YEAR ENDED 31 MARCH, 2025

I report on the accounts of the Charity for the year ended 31 March 2025, which are set out on pages 27 to 35.

RESPECTIVE RESPONSIBILITIES OF THE TRUSTEES AND EXAMINER

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) of the Charities Accounts (Scotland) Regulations 2006 (the 2006 Regulations) and that an independent examination is needed. The charity is preparing accrued accounts and I am qualified to undertake the examination by being a qualified member of the ICAEW.

It is my responsibility to:

- (i) examine the accounts under section 145 of the Charities Act 2011 and under section 44(1)© of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- (ii) to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- (iii) to state whether particular matters have come to my attention.

BASIS OF INDEPENDENT EXAMINER'S STATEMENT

My examination was carried out in accordance with general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. 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, and seeking explanations from the 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 EXAMINER'S STATEMENT

In the course of my examination, no matter has come to my attention:

- (a) which gives me reasonable cause to believe that in any material respect, the trustees have not met the requirements to ensure that:
 - (i) proper accounting records are kept in accordance with section 130 of the 2011 Act and section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations; and
 - (ii) accounts are prepared which agree with the accounting records and comply with the accounting requirements of the 2011 Act and section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Accounts Regulations; or
- (b) to which in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Anna Chapman FCA
Chapman Worth Limited
2 The Old Estate Yard, High Street, East Hendred, Wantage, OX12 8JY

1 December, 2025

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH, 2025

Income from	Note	Unrestricted	Designated	Restricted	Total Funds	Total Funds
		Funds 2025	Funds 2025	Funds 2025	2025	2024
		£	£	£	£	£
Donations & legacies	2	444,358		60,000	504,358	618,187
Charitable activities	3	5,600			5,600	5,335
Other trading activities	4	(22)			(22)	27
Investments	5	7,676			7,676	10,497
Total incoming resources		457,612		60,000	517,612	634,046
Resources expended						
Raising funds	6	56,937			56,937	51,342
Charitable activities	7-8	455,384		183,665	639,049	461,752
Total resources expended		512,321		183,665	695,986	513,094
Net income (expenditure)		(54,709)		(123,665)	(178,374)	120,952
Transfers between funds	12	20,367		(20,367)		
Net movement in funds		(34,342)		(144,032)	(178,374)	120,952
Total funds brought forward 1 April 2024 (2023)		312,462		248,276	560,738	439,786
Total funds carried forward 31 March 2025 (2024)		278,120		104,244	382,364	560,738

The notes on pages 29 to 35 form part of these financial statements.

BALANCE SHEET AT 31 MARCH, 2025

	Note	31 March 2025 Unrestricted Funds	31 March 2025 Designated Funds	31 March 2025 Restricted Funds	31 March 2025 TOTAL	31 March 2024 TOTAL
		£	£	£	£	£
Current Assets						
Stock		1,988			1,988	1,725
Prepayments		3,827			3,827	5,630
Debtors		1,772			1,772	3,966
Accrued Gift Aid		2,033			2,033	813
Cash at bank and in hand		332,150		104,244	436,394	582,352
		341,770		104,244	446,014	594,486
Creditors: amounts falling due within one year	11	39,650			39,650	21,748
Net Current Assets		302,120		104,244	406,364	572,738
Creditors: amounts falling due after one year						
Provisions		24,000			24,000	12,000
Net Assets		278,120		104,244	382,364	560,738
Funds						
Unrestricted Funds	12	278,120			278,120	312,462
Designated Funds	12					
Restricted Funds	12-13			104,244	104,244	248,276
		278,120		104,244	382,364	560,738

The financial statements were approved by the Board of Trustees on 1 December, 2025 and signed on its behalf by:

John Hirst CBE
Chair of Trustees

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2025

1 ACCOUNTING POLICES

COMPANY INFORMATION

SUDEP Action is a Charitable Incorporated Organisation registered with the Charities Commission for England and Wales and with The Scottish Charities Register (OSCR). Epilepsy Bereaved is the linked charity of SUDEP Action. Epilepsy Bereaved is an unincorporated charity registered with the Charities Commission for England and Wales and The Scottish Charities Register (OSCR).

a) Basis of preparation

The financial statements have been prepared in accordance with the charity's Memorandum and Articles of Association, the Charities Act 2011 and "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)" (as amended for accounting periods commencing from 1 January 2019), Trustee Investment (Scotland) Act 2005, Charities Accounts (Scotland) Regulations 2006. The charity is a Public Benefit Entity as defined by FRS102.

The accounts are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest £1.

The financial statements have been prepared to give a 'true and fair' view and 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 Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities: Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

The financial statements have been prepared under the historic cost convention. The principle accounting policies adopted are set out below.

b) Going concern

At the time of approving these accounts, 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 accounts.

c) Charitable funds

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charities work or for specific projects being undertaken by the charity. The aim and use of each restricted fund is set out in note 13 to the financial statements.

d) Incoming resources

Items of income are recognised and included in the accounts when all of the following are met:

- the charity has entitlement to the funds;
- any performance conditions attached to the item(s) of income have been met or are fully within the control of the charity;
- there is sufficient certainty that receipt of the income is considered probable; and
- the amount can be measured reliably.

For legacies, entitlement is taken the earlier of:

- the charity being notified of an impending distribution; or
- the legacy being received.

Other voluntary income and donations are included in the accounts when received.

Fundraising income is generated by the charity's supporters mainly through sponsored events.

e) Resources expended

All expenditure is included on an accruals basis. Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classed under the following headings:

- Costs of raising funds comprise those incurred in seeking and acquiring voluntary contributions as well as the costs relating to the small scale sales of branded goods.
- Expenditure on charitable activities includes the costs of activities undertaken to further the purpose of the charity and their associated support costs.

f) Non-exchange transactions and foreign currency conversions

Monetary assets and liabilities in foreign currencies are translated into sterling at the rate of exchange ruling at the year end date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling on the date of the transaction. Exchange differences are taken into account in arriving at the net income/expenditure.

g) Allocation of support costs

Support costs are those functions that assist the work of the charity but do not directly undertake charitable activities. These costs have been allocated between costs of raising funds and expenditure on charitable activities. The basis on which support costs have been allocated are set out in note 7.

h) Taxation

The charity is an exempt approved charity under the Income and Corporation Taxes Act 1988. All its charitable trading activity is used solely for its charitable purposes and any non-charitable trading falls below the statutory thresholds. Tax payable 2025: nil (2024: nil).

Most of the charity's income is exempt from or outside the scope of VAT, and the trustees do not see any advantage to be gained by voluntary registration. Unrecoverable VAT is included in relevant costs in the statement of financial activities.

i) 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.

j) Tangible fixed assets and depreciation

The charity does not have any fixed assets. The trustees consider the provision of office equipment to be part of the running costs of the organisation and it is written off in the year of purchase.

k) Debtors

Trade and other debtors are recognised at the settlement amount. Prepayments are valued at the amount prepaid after taking account of any trade discounts due.

l) Creditors and provisions

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

m) 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 measured at their settlement value.

n) Pensions

The charity operates two defined contribution pension schemes which includes both employer and employee contributions. Contributions are charged in the accounts as they become payable in accordance with the rules of the schemes.

	Unrestricted Funds	Designated Funds	Restricted Funds	TOTAL 2025	TOTAL 2024
	£	£	£	£	£
2) DONATIONS & LEGACIES					
Donations & legacies	101,843			101,843	126,662
Grants	15,000		60,000	75,000	234,000
Gift Aid	6,516			6,516	4,226
Legacies	500			500	18,517
Fundraising donations	320,499			320,499	234,739
Collecting boxes					43
	444,358		60,000	504,358	618,187
3) CHARITABLE ACTIVITIES					
Annual charity conference					2,353
Fees receivable	5,600			5,600	2,182
Letting income					800
	5,600			5,600	5,335
4) OTHER TRADING ACTIVITIES					
Sale of goods	(22)			(22)	27
	(22)			(22)	27
5) INVESTMENTS					
Interest receivable	7,676			7,676	10,497
	7,676			7,676	10,497

517,611

	Unrestricted Funds	Designated Funds	Restricted Funds	TOTAL 2025	TOTAL 2024
	£	£	£	£	£
6) RAISING FUNDS					
Fundraising expenses	10,421			10,421	8,235
Support costs	46,516			46,516	43,107
	56,937			56,937	51,342

7) CHARITABLE ACTIVITIES

Direct charitable expenditure	414,990		183,665	598,655	421,945
Governance costs	1,508			1,508	1,190
Support costs	38,886			38,886	38,617
	455,384		183,665	639,049	461,752

Governance costs consist of the independent examiner's fee, costs of trustees' meetings, and reconstitution costs, all as set out in Note 8 below.

Support costs consist of staff costs not directly attributable to charitable expenditure and related office overheads, and are apportioned on the basis of staff resources committed to fundraising and charitable activities proportionately.

8) CHARITABLE ACTIVITIES & SUPPORT COSTS

Postage & stationery	2,752			2,752	1,428
Telecommunications	2,369			2,369	4,173
Printing & publicity	6,907			6,907	9,659
Salaries & National Insurance	305,812		99,905	405,717	338,237
Pension scheme contributions	8,721			8,721	5,998
Consultancy & other staff costs	17,718			17,718	3,319
Travel, accommodation & subsistence	3,120			3,120	2,506

	Unrestricted Funds	Designated Funds	Restricted Funds	TOTAL 2025	TOTAL 2024
	£	£	£	£	£
Annual conference					5,476
Affiliations to other groups	2,196			2,196	1,319
Development of website	6,815			6,815	15,838
Cost of support group meetings	566			566	432
Legal fees	1,110			1,110	765
Fraud investigation	23,601			23,601	
Bank charges	272			272	107
Office costs, including insurance	30,129			30,129	31,282
Dilapidations provision	12,000			12,000	12,000
Conferences & seminars	196			196	1,347
Sundry expenses	656			656	1,783
IT costs	12,611			12,611	15,768
Equipment purchases	5,334			5,334	2,569
Independent examiner's fee	1,140			1,140	1,190
EpSMon maintenance	11,359			11,359	6,556
EpSMon development			83,760	83,760	
	455,384		183,665	639,049	461,752

Fraud investigation costs consist of expenses incurred to date for an investigation, and subsequent prosecution proceedings, in relation to the alleged theft of funds collected on behalf of SUDEP Action. It is anticipated that SUDEP Action should recoup the majority of its costs, but will not account for the expected refund until it is received.

9) STAFF COSTS, INCLUDING PENSION SCHEME CONTRIBUTIONS

Salaries & National Insurance	338,696	99,905	438,601	380,145
Pension scheme contributions	9,403		9,403	7,138
	348,099	99,905	448,004	387,283

There was an average of 10.42 employees (FTE) during the year (2024: 9.80). No employee earned over £60,000 in the year (2024: nil). The charity operates two defined contribution pension schemes. The assets of the schemes are held separately from those of the charity in independently administered funds. Costs shown are employer contributions.

10) TRUSTEE EXPENSES

The Trustees received no remuneration during the year or comparative year. The Trustees were not reimbursed any expenses during the year or comparative year.

11) CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	Unrestricted Funds	Restricted Funds	TOTAL 2025	TOTAL 2024
	£	£	£	£
Trade creditors	20,515		20,515	6,847
HMRC - PAYE / NI	6,471		6,471	5,743
Pension	2,328		2,328	1,503
Accrued expenditure	10,336		10,336	7,655
	39,650		39,650	21,748

12) STATEMENT OF FUNDS

	Brought forward	Incoming resources	Resources expended	Transfers in / (out)	Carried forward
	£	£	£	£	£
	surplus / (deficit)				surplus / (deficit)
General funds	312,462	457,612	512,321	20,367	278,120
Restricted funds	248,276	60,000	183,665	(20,367)	104,244
	560,738	517,612	695,986		382,364
Restricted funds					
EpSMon Version 2	5,525		97,670	126,072	33,927
EERE	3,055		3,055		
Yorkshire	20,367			(20,367)	
Children's Checklist	2,576		2,576		
Adult Checklist (UK, Ireland, Australia)	160,072			(126,072)	34,000
NHS Lincolnshire	15,275				15,275
Bernard Lewis	41,406	60,000	80,364		21,042
Total	248,276	60,000	183,665	(20,367)	104,244

13) DETAILS OF RESTRICTED FUNDS

EpSMon V2: Funding to develop and improve the existing EpSMon App.

EERE: Testing the Checklist in a Newcastle population and creating a video for different healthcare settings, for example A&E, maternity clinics.

Yorkshire Project: A locally based project in Yorkshire to raise awareness and increase access to information, support and safety tools.

Children's Checklist: Creating a paediatric version of the SUDEP & Seizure Safety Checklist.

Adult Checklist (UK, Ireland, Australia): Development of an adult Checklist for the UK, Ireland and Australia.

NHS Lincolnshire: Find a middle-ground solution for what GPs and nurses would like from the checklist's implementation in their systems, against the limitations of the system and the demands on GP software company.

Bernard Lewis: Promote the uptake of the EpSMon App and further increase awareness of SUDEP Action. Influence official policies regarding SUDEP & epilepsy deaths.



SUDEP Action

Making every epilepsy death count

SUDEP Action

18, Newbury Street, Wantage, Oxon OX12 8DA

Tel: 01235 772850 (office) or 01235 772852 (support)

Email: info@sudep.org Website: sudep.org



Registered with
**FUNDRAISING
REGULATOR**

Registered charity 1164250 (England & Wales), SCO 47223 (Scotland).
Epilepsy Bereaved (founded 1995) is part of SUDEP Action.