

# SUDEP Action

*Making every epilepsy death count*



# ANNUAL REPORT 2023-2024

A background image of pink cherry blossoms in bloom, with soft, out-of-focus petals and green stems. The flowers are in various stages of opening, showing delicate pink petals and yellow stamens.

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This year saw a period of significant change for SUDEP Action with our founding CEO Jane Hanna OBE stepping down in August 2023.

Jane continues to work for the charity in a reduced capacity, using her significant expertise as our Director of Policy and Influencing. Sammy Ashby, who has worked at SUDEP Action since 2014, most recently acting as our Deputy CEO, has taken over the role of CEO.

[Read more about Sammy](#)



“There is no way that I can adequately put into words the extraordinary job Jane Hanna has done over so many years since she and four others founded the charity in 1996. She has built a remarkable reputation both in the UK and internationally in the fight for recognition and understanding of SUDEP and avoidable epilepsy mortality, and in supporting those of us who have suffered such bereavements.

She leaves the job of CEO with the charity in excellent shape. This means she can pass on the responsibility of leadership at a time when the charity’s work is of the highest order and impact, and it will allow her and her family a better work/life balance.”

**John Hirst CBE**  
**SUDEP Action Chair**

*“Thank you Jane for your help, care and outstanding contribution to the sadness that SUDEP brings. Without the charity I’m not sure I could have coped with losing my daughter. You gave me hope, a purpose to carry on, a little light at the end of a very dark tunnel. We will be eternally grateful to you.”*

*“Thank you so much for starting this valuable place for those affected by SUDEP. A lifeline.”*

*“Thank you for giving voice and movement to what was too often kept silent or ignored.”*

## Jane Hanna: outgoing CEO

"I am really pleased that SUDEP Action is in a strong position and it is the right time to look to the future. The last few years have been challenging, but hopeful too, because of the overwhelming support the charity has received.

For me personally, this year would have been the 60th birthday of my first partner Alan who died of SUDEP in 1990, aged 27. At a deep emotional level, I knew that this year was the right time for me and my family to look at how I could continue



to support the acceleration of change, whilst passing on the responsibility of the CEO role.

As many have said over the years, SUDEP Action is a club that no one wants to join, but it can also be a lifeline. For me, it has been a particular privilege to have made thousands of connections with suddenly bereaved families and to have had a glimpse of the love that flows through generations of families and communities. It is this which explains why SUDEP Action has always punched above its weight in impact, not just in the UK, but worldwide."

**Jane Hanna OBE**

## Sammy Ashby: CEO



"It is a real privilege to be given the opportunity to become the new CEO of SUDEP Action and to lead the charity into the future.

The mission of the charity is, and always will be, to do all we can to prevent epilepsy deaths. We want to make sure that all epilepsy deaths are acknowledged and learnt from and we also want to be there as a lifeline, a voice and an ally to anyone who is bereaved due to epilepsy.

Our fantastic SUDEP Action team have massive hearts and we are rightly seen by many as experts in what we do. It's a privilege to be able to continue working alongside them."

**Sammy Ashby**

“

*We would have been lost without the support of the charity over the last 32 months since we lost our beautiful daughter. She was 18 and our only child. Despite having epilepsy myself, I knew nothing about SUDEP until we got in touch with the charity, who are still supporting us today.*

”

At a time when charities are under increasing demands and financial pressures, SUDEP Action are thankfully going against this trend. This is vital so we can continue to be there for those who need us. However, it's important to be realistic about what we can achieve to continue sustainably into the future.

A key part of our development has been working with the staff team, Board of Trustees and our supporters to begin work on our

new strategy, which will cover 2024-2027. This work has been a collaborative effort, with the strategy reflecting who we are as an organisation, what we want to achieve, and how best we can do this with the resources available. Most importantly though, it has our supporters, particularly those bereaved by epilepsy, at its heart. There are some details about the strategy process later in this report. We hope you'll join us on this next part of our journey – we can't do this without you.



*“The SUDEP Action team is truly amazing and through you we have met so many other families who through our grief and sadness have all become friends.”*

**2,078**Communications with  
Bereavement Services**500**Health professionals  
engaged with our  
training**53**Families received  
personalised support**99**Contacts engaged  
with Bereavement  
Services for the  
first time**1,740**Health professionals  
registered to use our  
Checklist**82**My Way to  
5K sign-ups**5,236**EpSMon  
users**68**Reports to the  
EDR

No other charity in the UK, or the world, provides the level of bereavement services to those whose loved one has died because of 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 anyone who needs them. Everyone's grief experiences are different. We understand this and use nearly 30 years' experience to support people on their unwanted, devastating journeys.

“

*Thank goodness for SUDEP Action,  
an amazing charity raising  
awareness for this little known  
or understood condition. Your  
bereavement support saved me.*

”

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

In 2023-2024 there were 2,078 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 will be people engaging with the charity just once, others will be repeat users of this service, encompassing both bereaved individuals and professionals working in the field of bereavement.

Over the course of the year there were 99 new individual contacts engaging with the charity via Bereavement Services for the first time.

*“How do we support families? We want to say first of all, get to us early. We know about epilepsy deaths, including SUDEP. We support people with advocacy and advice, but we put this all together with emotional support.”*

*Julia Stirling,  
Bereavement Services  
Caseworker*



As well as providing ongoing telephone support, our BACP registered counsellor provides counselling sessions to bereaved individuals who are further along in their grief journey.

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. However, often there are other

ways to access early specialist and tailored support. Our telephone service offers similar techniques and support relating to traumatic grief, for a longer period of time.

Since the pandemic, our Bereavement Support Services team has seen an increase in demand and complexity of contact. Our casework service has been particularly affected by this, supporting 53 families in the last year with highly personalised support.

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 details of what to expect at inquests and with investigations so they are aware of the process, the people involved, and feel able to ask questions and input into these processes.
- Create evidence-based documents and identify experts to support and help the family request a proper investigation into their loved one's death and accurately record why they died.
- 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

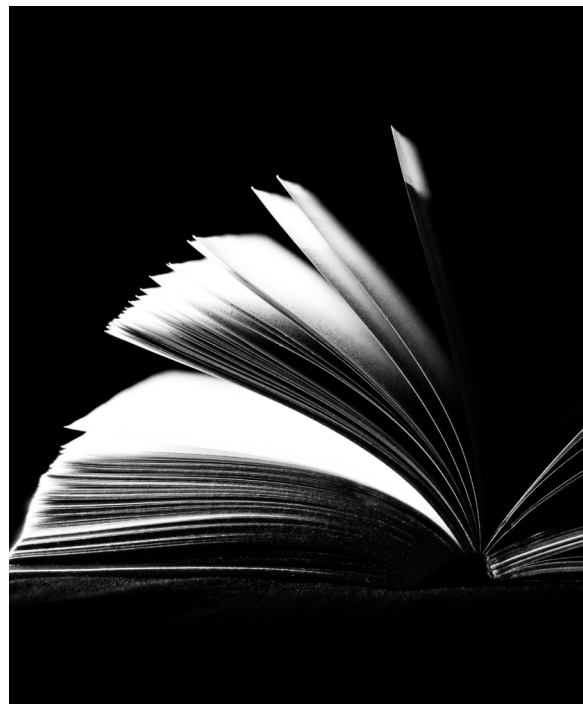
investigations, regulatory authorities, the Ombudsman and MPs, suggesting lines of questioning and strategy, liaising with Coroners and Trusts and supporting families to participate / advocating on their behalf.

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 places in private.

Many of our bereaved supporters want their loved one to be remembered and for their story to be told to help raise awareness. Their experiences are woven throughout our work and keep those who have died at the heart of all we do.

Our 'My Story' page on our website is an example of this and in 2023-24 several powerful stories were shared. Statistics don't reflect the full story of personal loss when someone dies unexpectedly due to epilepsy. These stories are precious to us and help highlight the often preventable nature of many epilepsy/ SUDEP deaths, providing learnings for the future.

We also received information relating to epilepsy deaths from 68 people via our Epilepsy Deaths Register (see our projects research and collaborations section for more details).



Across the advocacy we have provided throughout 2023-24, these themes have been prevalent:

- SUDEP risk discussions not happening between clinician and patient.
- Maternal deaths where person-centred conversations about risk and medication didn't happen.
- Failure to understand risks for people with a learning disability and epilepsy in residential care. Also, minimal investigations into deaths.
- Problems with access to specialist care for breakthrough/worsening seizures.
- Access to appropriate medications restricted or unavailable.
- Issues with accurate diagnosis (resulting in delays to treatment or no treatment at all).

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.



*One family we began supporting via our casework service this year is Alison's. Her daughter Megan died, preventably, in June 2022 and was 17 weeks' pregnant at the time. Alison shares why it is important to her to get justice and answers for her daughter in this video, and how our casework service has helped with this process. [See here](#) Megan's inquest is ongoing and we continue to support the family.*

“

*It's such an important organisation to those who are drawn into contact with it, like my family have been. It creates a focus for action to make a difference which in turn has helped me in the grieving process.*

”

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.

## Lives put at risk because of medication restrictions

A key policy campaign in 2023 involved [new restrictions being put on the use of a well-used anti-seizure medication, Sodium Valproate.](#)

We led a coalition of 11 organisations from across the epilepsy and health sector, calling on the Secretary of State for Health and Social Care and the Medicines Health Regulatory Authority (MHRA) to pause their processes until safety measures could be put in place to protect the lives of those who rely on the medication for seizure control. Concern was raised across the epilepsy community that these restrictions (affecting women, men and children) could lead to some people with epilepsy being taken off the medication. There were also fears that newly-diagnosed people with epilepsy may not be offered the medication, even if historically it would have been prescribed to them.



Click on images to access videos



During 2023-24 we produced a number of statements, letters, and communication assets to support our Sodium Valproate campaign, as well as leading on the distribution of press releases, quotes and information for interviews on this important issue.

Most notably, we were featured in a Channel 4 News interview with Victoria MacDonald (4mins+), also featuring Hannah Mulcahy and her brother Sandy.



Safety is always going to be an important topic for us. That's why we chose 'My Safety Matters' as our theme for SUDEP Action Day 2023.

[See here](#)

Journalist Caroline Scott shared publicly the challenges her son Rupert has faced since his epilepsy diagnosis.

[See here](#)

Thanks to our fantastic supporters MSPs pledged their support for Purple Day in Scotland memory of Jessica (right). Each MSP received a crocheted purple heart handmade by Jessica's family and friends – that's a

whopping 129 hearts. They even managed to get Glasgow University lit up purple to raise more local awareness.

[See here](#)



“

*This is an extraordinary charity that has provided light in the darkest of times. Your work is appreciated.*

”

Over the course of this year we supported an increasing number of people with epilepsy (or their family members), and health professionals who contacted us directly for support and information.

This included signposting to our existing freely-available resources such as the SUDEP and Seizure Safety Checklist, EpSMon app and information leaflets, as well as more personalised responses to specific questions or assurances over risk management.

Providing training on SUDEP, epilepsy risks

and how health systems can better support and engage with the bereaved after a death is an important aspect of our work. However, awareness of epilepsy deaths, and how to prevent them, remains inconsistent across the country.

We're a small team but, where possible, we provide training sessions to healthcare teams. Since the pandemic this has been digitally (cutting down cost to the charity), with some in-person sessions. In the 2023-24 charity year we engaged with almost 500 health professionals in this way.

“

*Awareness of epilepsy deaths, and how to prevent them, remains inconsistent across the country.*

”

## Online Epilepsy Memorial Day - May

**170+** tributes via our social media and dedication wall

**6.7k** tributes via our social media and 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 poem read by members of [our Bereavement Services team](#), as well as another [reading by one of our supporters Sophie](#). 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. 2023's theme was #EpilepsyMatters and was used to remind the world that epilepsy is a serious condition that deserves more attention and understanding.

## SUDEP Action Day & My Way to 5K - October

The theme of the 10th annual SUDEP Action Day was 'My Safety Matters' – building on the theme from National Epilepsy Week and our policy work around medicines safety.

This day is an opportunity for organisations and supporters around the world to share the same messages about SUDEP and epilepsy risks.

Alongside this campaign, supporters took part in our annual fundraiser My Way to 5K. Originally started during the pandemic to give people a chance to support the charity from a distance, this event saw more than 82 people complete a 5k in various ways, from runs to hill climbs, gym circuits to wheelbarrow races! Our supporters never fail to come up with creative ways to support our work.

**90+ organisations** took part in SUDEP Action Day

**4,600+** social media engagements for the day



### Light Up the Sky - December / January

*Christmas-time is challenging for many of our bereaved supporters and we often see an increase in 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 303 tributes to our dedication wall.*



### Coffee Clubs



*Sharing with others who have gone through this terrible loss felt like a safe place to talk freely.*

**Coffee Club attendee**



Our bereaved community welcomes opportunities to meet with others who are bereaved. Throughout 2023 we held five Coffee Club meetings, in four different areas of the UK, to help them make these important connections with others who 'get it'. These meetings are run by some of our fantastic volunteers who give their time freely to enable these important meet-ups to happen. We are grateful for their support. Each Coffee Club is free to attend, with SUDEP Action often covering the cost of the venue and refreshments as well as helping organise the bookings and key information for each event.

## Conferences

One important way we raise awareness among health professionals is by attending their conferences. At the 2023 ILAE British Branch Conference the SUDEP Action team had an information stand where we were able to hold valuable conversations about SUDEP, epilepsy bereavement and our free tools and services. We were also able to discuss personally with health professionals how they could improve patient safety / discussions.

More than 30 health professionals requested further information from us at this single event.

This conference also provided us with the opportunity to display two posters relating to our research work (see the research, projects and collaboration section for more details), as well as allowing us to present our policy work on Sodium Valproate to an audience of 100+ people (also see pages 11-12).

“

*There was a wonderful family atmosphere that I have not found in any other organisation, charity or group. It was such a pleasure to be together even when it's challenging at times to remember what we've been through.*

”

Our National Conference returned in November 2023 for the first time since the pandemic. This is our main event for updating supporters about the work of the charity and bringing supporters together. It's exclusively for those bereaved by epilepsy, giving them the chance to be themselves around others who understand the daily reality of grief. We had 52 attendees this year, with 25 being families

newly-bereaved since our last conference in 2019. This year's conference was a one-day event and marked the changeover of CEO from Jane Hanna to Sammy Ashby. Jane talked to people about the charity's impact since our last conference,



with Sammy sharing more about our future direction and ambitions, and how supporters can play a vital part in helping us achieving these goals.



SUDEP Action received an incredible donation of £31,000 from the Gravesend Epilepsy Network, who have ceased operations.

Recognising the great work that we do, they kindly donated their remaining charity

funds to support our much-needed research into epilepsy death prevention. Thank you so much to Lynn Savill MBE, Counsellor & founder of the Gravesend Epilepsy Network, and Fred Savill, Chairman of the Gravesend Epilepsy Network, for this generous contribution.

## 90p of every £1 is spent on research & services

We rely on our fantastic supporters getting involved as individuals, families, teams and communities. Most of our annual income is from their fabulous fundraising efforts and donations in memory of those who have died. Because of this we ensure we use funds carefully - for every £1 the charity spends, 90p goes directly on our research and services, to benefit bereaved families, people with epilepsy and clinicians.

As well as our fantastic fundraising supporters, we are also incredibly grateful to the following grants, foundations and donors whose repeated support of SUDEP Action mean we can continue to fight for a future without preventable epilepsy

deaths, and where everyone bereaved by epilepsy has ready access to specialist epilepsy bereavement support.

- Alison Hillman Trust
- Bath and North East Somerset Crematorium
- Bernard Lewis Family Charitable Trust
- Cornwall NHS
- Gallagher Insurance
- Gravesend Epilepsy Network
- Lee's Smile
- Mr & Mrs Pye Charitable Trust
- Stifel
- The Anne and John Walters Charitable Trust
- The Davies Foundation

Our fundraisers take on all sorts of challenges to raise money to support our work, often in memory of someone who has died. From bake sales, to race nights, runs to purple balls, our fundraisers are never shy when it comes to being creative. By taking part, they also help raise vital awareness of SUDEP and epilepsy deaths. Here are a selection of some of our fantastic fundraisers who took part in events between April 2023 and March 2024. Their phenomenal

efforts help us to save lives and provide our services for free to those who need them. While we can't showcase each and every single person who has fundraised for us over the last year, we recognise their fantastic involvement and contributions that enable us to continue to be there for others. Thank you to everyone who has supported us in this way, and to all their networks who helped make their fundraising possible.

Members of the Test Valley Golf Club supported SUDEP Action with a variety of fundraising events over the last year, raising a phenomenal £17,135.42. Thank you to captains Abi Lamb and Barry Higgins for their involvement, as well as Bob (former seniors' captain) and Meryl Craddock for nominating us and helping to raise this incredible amount, in memory of their granddaughter Rosie.



Brett Saunders took on the epic challenge of running from John O'Groats to Land's End in 16 days (which meant running more than 50 miles a day). He ran in memory of his friend's brother, Tom Sibree. This challenge was tough on Brett, and part way through his family and friends stepped in to help him reach the finish line in a real team effort.

You can read more about the challenge [here](#)

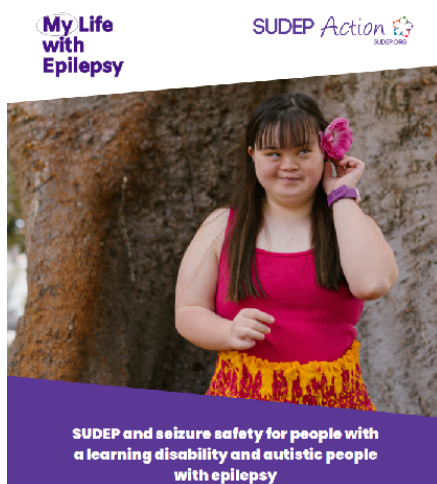




*2023-2024 was a busy year with progress in our projects, research and collaborations. By working with health professionals, researchers and other charities and organisations, across the UK and internationally, we're able to extend our reach and continue to raise vital awareness in the hope of improving safety and saving lives.*



## Resources for people with a learning disability / autistic people with epilepsy



We completed two new projects delivering key risk information.

[My Life with Epilepsy](#) resulted in the creation of free risk leaflets and videos to better support people with a learning disability and autistic people with epilepsy, as well as their families, carers and health professionals.

We also worked with NHS commissioners

and care providers on [The Clive Treacey Commissioning Guidance and Checklist](#) - to create resources to support better decision-making for NHS inpatient and care services. This guidance seeks to ensure that epilepsy risks are more understood and seriously considered as part of care plans provided. This project followed on from previous work in the NHS Midlands following the tragic death of Clive Treacey to provide a legacy in his name.



### The SUDEP and Seizure Safety Checklist, EpSMon app and Epilepsy Deaths Register

Our ongoing projects, the SUDEP and Seizure Safety Checklist, EpSMon app and Epilepsy Deaths Register (EDR) have continued to grow in reach and impact. By the end of March 2024, there were 1,740 health professionals registered to use our Checklist, 5,236 EpSMon users and 68 new reports relating to epilepsy deaths had been made to the Epilepsy Deaths Register. This represents an increase of 21% of new people engaging with these free services.

2023 saw the announcement of our plans to create a paediatric version of our Checklist – with the intention to make it available to health professionals supporting young people with epilepsy / the parents of children with epilepsy. The project will provide a structured, evidence-based tool to help discuss epilepsy risks in a personalised and empowering way.

By starting these conversations early in a person's epilepsy journey, it embeds good risk awareness and management from a young age, something many of our bereaved

community were not given the opportunity to experience before their loved one's death.

This project is a collaboration with Cornwall Partnership NHS Foundation Trust and Young Epilepsy. It is fantastic to build on our previous work with Young Epilepsy who have supported SUDEP Action Day for many years, as well as raising SUDEP and risk awareness among their young audience. Clinicians from across the UK are supporting the project. It is due to be completed in the 2024-2025 charity year.



“

*It is a group none of us wants to join, but brings so much comfort, knowing we are not alone through the most loneliest and devastating times of our lives, trying to understand why it happens. So I thank you, from the bottom of my heart for all the work you have tirelessly done.*

”

Our EpSMon project team published a new research paper looking at the data provided by women with epilepsy using the app, to understand their risk awareness and education over time.

Key findings were:

- Only 25% of women had received pre-conception counselling and knew of epilepsy risks to be aware of during pregnancy.
- 54% of women were aware of SUDEP and its risks – suggesting that efforts to communicate these risks are not always effective. More needs to be done to make this information clearly understood by all women with epilepsy.

This important paper highlighted how many women are still not being given vital risk information, particularly surrounding pre-conception counselling and pregnancy. This is deeply troubling, given maternal death inquiries continue to indicate this as a significant factor contributing to deaths of women with epilepsy during or shortly after pregnancy.

*“Although it won’t bring a loved one back, it could save someone else from suffering in the same way”*

The Epilepsy Deaths Register is now one of the largest worldwide databases of information into epilepsy-related deaths and the impact of these deaths on bereaved individuals and families. The EDR continues to show the devastation faced after an epilepsy death, with issues being flagged about getting inquests and /or investigations into a loved one’s death. This leads to many unanswered questions, complicating the trauma and grief already being faced on a daily basis. The value of providing a safe space for the bereaved community to share this information cannot be underestimated. Their motivations for doing so are often wide-ranging, from wanting to help prevent future deaths, to supporting research, to learning more about why people with epilepsy die.

The EDR data shows more people are aware that epilepsy can be a potentially fatal condition, with 71% aware of SUDEP before their loved one’s death (compared to 19% pre-2000). There is still much to do to bring this figure closer to 100%.

A National Institute of Health Research project on epilepsy risk communication wrapped up during this year. For the project, 24 epilepsy appointments in eight hospitals were recorded to understand the role language plays in promoting risk awareness and positive risk management. While the research papers from this project are yet to be published, key tips for health professionals to consider when discussing risks with their patients include:

- Be careful of testing a patient’s knowledge with exam style questions such as ‘what do you know about risk?’ as this can be stressful for them.
- Try to develop empowering conversations – have shared expectations about risks and how this relates to the patient’s own life experiences.
- Make conversations personal rather than a scripted set of facts to run through.
- Be aware of different interpretations of how things are said – what you think you’re saying isn’t always understood how you’d expect.
- Try to be honest and clear.

The upcoming charity year (2024-25) will see the start of a new strategy for the charity. Work has begun in this charity year to get input from the SUDEP Action Board of Trustees, staff team and some of our bereaved supporters about:

- How they see the work of SUDEP Action.
- What aspects of our work are important to them.
- Where they want to see the charity go in the future.

What became clear very quickly during these conversations was the ambitious future we must aim for as a charity and community, so that we:

- Stop preventable epilepsy deaths.
- Are the 'go to' bereavement service for anyone who has experienced an epilepsy death.

When speaking to some of our bereaved supporters, they shared that:

- Connection with others is key. Supporters would love easier ways to connect (virtually and in person).
- The personal connections the SUDEP Action team has with supporters is hugely valued, creating strong bonds. There is significant strength of feeling towards our bereavement support services.
- Maximum empowerment comes from clarity of messaging. Keeping information crisp, short and punchy helps supporters to feel confident in their abilities to raise awareness for the charity and avoid feeling overwhelmed with too much information. It is important to show progress and impact.

Final takeaways from supporters:

- There is power in the personal – stories continue to resonate with our bereaved supporters and many are willing to share their experiences if asked.
- More visibility is desired – a higher profile for both epilepsy and the work of the charity. Many long for a 'celeb' to associate with us, and to see more media coverage.
- More understanding of why deaths happen – this remains a key driver for supporters engaging with the charity, as does the need to stop deaths happening to others. Our research and projects are visible signs that progress is being made.

When speaking to the staff team and our Board of Trustees, it was clear that:

- Our heart is our biggest strength – We must continue to represent the bereaved community and seek their input into the charity's work.
- Getting a bigger presence is important – but we need to keep sight of who we are, what we do and why we do it.
- We must keep our work simple and make it sharper. It is a delicate balance to ensure we grow, adapt and react to the world around us, whilst staying true to our mission.

This process has helped us identify existing work that needs to remain central to what we do, and has helped us clearly identify opportunities where we can grow and have even more reach and impact. This has real potential to continue changing and saving lives.

It is set to be an exciting few years ahead for the charity, and we look forward to working with our community to make this happen.

*“We don't have to engage in grand, heroic actions to participate in the process of change. Small acts, when multiplied by millions of people, can transform the world.”*

**Howard Zinn**

# FINANCIAL STATEMENTS

## FOR THE YEAR ENDED 31 MARCH, 2024

The report that follows covers the work undertaken by SUDEP Action for the year 1st April 2023 to 31st March 2024.

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 (appointed August 2023)

Jane Hanna OBE (retired August 2023)

### TRUSTEES

John Hirst CBE (Chair)

Professor Mike Kerr (Vice Chair)

Rachel Shah (Treasurer)

Professor Stephen Brown

Graham Faulkner

Simon Lees

Mark Phillips

Alex Stirling

Judith Shakespeare

David Sibree

Currently 6/10 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](http://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, 2024

I report on the accounts of the Charity for the year ended 31 March 2024, 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**

**19 December, 2024**

## STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 MARCH, 2024

|                                                             |      | Unrestricted<br>Funds 2024 | Designated<br>Funds 2024 | Restricted<br>Funds 2024 | Total Funds<br>2024 | Total Funds<br>2023 |
|-------------------------------------------------------------|------|----------------------------|--------------------------|--------------------------|---------------------|---------------------|
| Income from                                                 | Note | £                          | £                        | £                        | £                   | £                   |
| Donations & legacies                                        | 2    | 361,687                    | —                        | 256,500                  | 618,187             | 502,353             |
| Charitable activities                                       | 3    | 5,335                      | —                        | —                        | 5,335               | 2,904               |
| Other trading activities                                    | 4    | 27                         | —                        | —                        | 27                  | 27                  |
| Investments                                                 | 5    | 5,867                      | —                        | 4,630                    | 10,497              | 379                 |
| <b>Total incoming resources</b>                             |      | <b>372,916</b>             | <b>—</b>                 | <b>261,130</b>           | <b>634,046</b>      | <b>505,663</b>      |
| <b>Resources expended</b>                                   |      |                            |                          |                          |                     |                     |
| Raising funds                                               | 6    | 51,342                     | —                        | —                        | 51,342              | 45,193              |
| Charitable activities                                       | 7-8  | 373,166                    | —                        | 88,586                   | 461,752             | 367,960             |
| <b>Total resources expended</b>                             |      | <b>424,508</b>             | <b>—</b>                 | <b>88,586</b>            | <b>513,094</b>      | <b>413,153</b>      |
| <b>Net income (expenditure)</b>                             |      | <b>(51,592)</b>            | <b>—</b>                 | <b>172,544</b>           | <b>120,952</b>      | <b>92,510</b>       |
| Transfers between funds                                     | 12   | —                          | —                        | —                        | —                   | —                   |
| <b>Net movement in funds</b>                                |      | <b>(51,592)</b>            | <b>—</b>                 | <b>172,544</b>           | <b>120,952</b>      | <b>92,510</b>       |
| <b>Total funds brought forward<br/>1 April 2023 (2022)</b>  |      | <b>364,054</b>             | <b>—</b>                 | <b>75,732</b>            | <b>439,786</b>      | <b>347,276</b>      |
| <b>Total funds carried forward<br/>31 March 2024 (2023)</b> |      | <b>312,462</b>             | <b>—</b>                 | <b>248,276</b>           | <b>560,738</b>      | <b>439,786</b>      |

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

## BALANCE SHEET AT 31 MARCH, 2024

|                                                      | Note  | 31 March 2024<br>Unrestricted<br>Funds | 31 March 2024<br>Designated<br>Funds | 31 March 2024<br>Restricted<br>Funds | 31 March 2024<br>TOTAL | 31 March 2023<br>TOTAL |
|------------------------------------------------------|-------|----------------------------------------|--------------------------------------|--------------------------------------|------------------------|------------------------|
|                                                      |       | £                                      | £                                    | £                                    | £                      | £                      |
| <b>Current Assets</b>                                |       |                                        |                                      |                                      |                        |                        |
| Stock                                                |       | 1,725                                  | —                                    | —                                    | 1,725                  | 1,547                  |
| Prepayments                                          |       | 5,630                                  | —                                    | —                                    | 5,630                  | 2,098                  |
| Debtors                                              |       | 3,966                                  | —                                    | —                                    | 3,966                  | 1,932                  |
| Accrued Gift Aid                                     |       | 813                                    | —                                    | —                                    | 813                    | —                      |
| Cash at bank and in hand                             |       | 334,075                                | —                                    | 248,276                              | 582,352                | 453,101                |
|                                                      |       | <b>346,209</b>                         | <b>—</b>                             | <b>248,276</b>                       | <b>594,486</b>         | <b>458,678</b>         |
| Creditors: amounts falling due within one year       | 11    | 21,748                                 | —                                    | —                                    | 21,748                 | 18,892                 |
| Net Current Assets                                   |       | <b>324,461</b>                         | <b>—</b>                             | <b>248,276</b>                       | <b>572,738</b>         | <b>439,786</b>         |
| <b>Creditors: amounts falling due after one year</b> |       |                                        |                                      |                                      |                        |                        |
| Provisions                                           |       | 12,000                                 | —                                    | —                                    | 12,000                 | —                      |
| Net Assets                                           |       | <b>312,461</b>                         | <b>—</b>                             | <b>248,276</b>                       | <b>560,738</b>         | <b>439,786</b>         |
| <b>Funds</b>                                         |       |                                        |                                      |                                      |                        |                        |
| Unrestricted Funds                                   | 12    | 312,462                                | —                                    | —                                    | 312,462                | 364,054                |
| Designated Funds                                     | 12    | —                                      | —                                    | —                                    | —                      | —                      |
| Restricted Funds                                     | 12-13 | —                                      | —                                    | 248,276                              | 248,276                | 75,732                 |
|                                                      |       | <b>312,462</b>                         | <b>—</b>                             | <b>248,276</b>                       | <b>560,738</b>         | <b>439,786</b>         |

The financial statements were approved by the Board of Trustees on 19 December, 2024 and signed on its behalf by:

**John Hirst CBE**  
Chair of Trustees

# NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2024

## 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

Google provide a grant to meet their associated publicity costs (see notes 2 & 8). The currency unit is US dollars, which is converted to sterling at the prevailing exchange rate at each month end.

#### 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 2024: nil (2023: 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 2024     | TOTAL 2023     |
|------------------------------------|--------------------|------------------|------------------|----------------|----------------|
|                                    | £                  | £                | £                | £              | £              |
| <b>2) DONATIONS &amp; LEGACIES</b> |                    |                  |                  |                |                |
| Donations & legacies               | 104,162            | —                | 22,500           | 126,662        | 44,190         |
| Grants                             | —                  | —                | 234,000          | 234,000        | 69,218         |
| Gift Aid                           | 4,226              | —                | —                | 4,226          | 3,756          |
| Legacies                           | 18,517             | —                | —                | 18,517         | 172,500        |
| Fundraising donations              | 234,739            | —                | —                | 234,739        | 212,592        |
| Collecting boxes                   | 43                 | —                | —                | 43             | 97             |
|                                    | <b>361,687</b>     | —                | <b>256,500</b>   | <b>618,187</b> | <b>502,353</b> |

#### 3) CHARITABLE ACTIVITIES

|                           |              |   |   |              |              |
|---------------------------|--------------|---|---|--------------|--------------|
| Annual charity conference | 2,353        | — | — | 2,353        | —            |
| Fees receivable           | 2,182        | — | — | 2,182        | 2,904        |
| Letting income            | 800          | — | — | 800          | —            |
|                           | <b>5,335</b> | — | — | <b>5,335</b> | <b>2,904</b> |

#### 4) OTHER TRADING ACTIVITIES

|               |           |   |   |           |           |
|---------------|-----------|---|---|-----------|-----------|
| Sale of goods | 27        | — | — | 27        | 27        |
|               | <b>27</b> | — | — | <b>27</b> | <b>27</b> |

#### 5) INVESTMENTS

|                     |              |   |              |               |            |
|---------------------|--------------|---|--------------|---------------|------------|
| Interest receivable | 5,867        | — | 4,630        | 10,497        | 379        |
|                     | <b>5,867</b> | — | <b>4,630</b> | <b>10,497</b> | <b>379</b> |

|                             | Unrestricted Funds | Designated Funds | Restricted Funds | TOTAL 2024    | TOTAL 2023    |
|-----------------------------|--------------------|------------------|------------------|---------------|---------------|
|                             | £                  | £                | £                | £             | £             |
| <b>6) RAISING FUNDS</b>     |                    |                  |                  |               |               |
| <b>Fundraising expenses</b> | 8,235              | —                | —                | 8,235         | 7,523         |
| <b>Support costs</b>        | 43,107             | —                | —                | 43,107        | 37,670        |
|                             | <b>51,342</b>      | —                | —                | <b>51,342</b> | <b>45,193</b> |

## 7) CHARITABLE ACTIVITIES

|                                      |                |   |               |                |                |
|--------------------------------------|----------------|---|---------------|----------------|----------------|
| <b>Direct charitable expenditure</b> | 333,359        | — | 88,586        | 421,945        | 349,118        |
| <b>Governance costs</b>              | 1,190          | — | —             | 1,190          | 1,037          |
| <b>Support costs</b>                 | 38,617         | — | —             | 38,617         | 17,805         |
|                                      | <b>373,166</b> | — | <b>88,586</b> | <b>461,752</b> | <b>367,960</b> |

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

|                                                |         |        |         |         |
|------------------------------------------------|---------|--------|---------|---------|
| <b>Postage &amp; stationery</b>                | 1,428   |        | 1,428   | 1,068   |
| <b>Telecommunications</b>                      | 4,173   |        | 4,173   | 4,472   |
| <b>Printing &amp; publicity</b>                | 3,501   | 6,158  | 9,659   | 8,064   |
| <b>Salaries &amp; National Insurance</b>       | 263,985 | 74,252 | 338,237 | 277,476 |
| <b>Pension scheme contributions</b>            | 5,998   |        | 5,998   | 6,726   |
| <b>Consultancy &amp; other staff costs</b>     | 3,319   |        | 3,319   | 4,100   |
| <b>Travel, accommodation &amp; subsistence</b> | 1,256   | 1,250  | 2,506   | 512     |

|                                   | Unrestricted Funds | Designated Funds | Restricted Funds | TOTAL 2024     | TOTAL 2023     |
|-----------------------------------|--------------------|------------------|------------------|----------------|----------------|
|                                   | £                  | £                | £                | £              | £              |
| Annual conference                 | 5,476              |                  |                  | 5,476          | 2,686          |
| Affiliations to other groups      | 949                |                  | 370              | 1,319          | 1,120          |
| Development of website            | 15,838             |                  |                  | 15,838         | 4,646          |
| Cost of support group meetings    | 432                |                  |                  | 432            | 801            |
| Legal fees                        | 765                |                  |                  | 765            | —              |
| Bank charges                      | 107                |                  |                  | 107            | 265            |
| Office costs, including insurance | 31,282             |                  |                  | 31,282         | 26,226         |
| Dilapidations provision           | 12,000             |                  |                  | 12,000         | —              |
| Conferences & seminars            | 1,347              |                  |                  | 1,347          | 1,491          |
| Sundry expenses                   | 1,783              |                  |                  | 1,783          | 495            |
| IT costs                          | 15,768             |                  |                  | 15,768         | 15,872         |
| Equipment purchases               | 2,569              |                  |                  | 2,569          | 2,100          |
| Independent examiner's fee        | 1,190              |                  |                  | 1,190          | 1,037          |
| EpSMon maintenance                | —                  |                  | 6,556            | 6,556          | 8,803          |
|                                   | <b>373,166</b>     | <b>—</b>         | <b>88,586</b>    | <b>461,752</b> | <b>367,960</b> |

## 9) STAFF COSTS, INCLUDING PENSION SCHEME CONTRIBUTIONS

|                               |                |          |          |                |                |
|-------------------------------|----------------|----------|----------|----------------|----------------|
| Salaries & National Insurance | 380,145        | —        | —        | 380,145        | 315,146        |
| Pension scheme contributions  | 7,138          | —        | —        | 7,138          | 6,726          |
|                               | <b>387,283</b> | <b>—</b> | <b>—</b> | <b>387,283</b> | <b>321,872</b> |

There was an average of 9.80 employees (FTE) during the year (2023: 9.20). No employee earned over £60,000 in the year (2023: 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<br>Funds | Restricted<br>Funds | TOTAL 2024    | TOTAL 2023    |
|---------------------|-----------------------|---------------------|---------------|---------------|
|                     | £                     | £                   | £             | £             |
| Trade creditors     | 6,847                 | —                   | 6,847         | 2,317         |
| HMRC - PAYE / NI    | 5,743                 | —                   | 5,743         | 5,988         |
| Pension             | 1,503                 | —                   | 1,503         | 1,594         |
| Accrued expenditure | 7,655                 | —                   | 7,655         | 8,993         |
|                     | <b>21,748</b>         | <b>—</b>            | <b>21,748</b> | <b>18,892</b> |

## 12) STATEMENT OF FUNDS

|                                                     | Brought forward     | Incoming<br>resources | Resources<br>expended | Transfers<br>in / (out) | Carried forward     |
|-----------------------------------------------------|---------------------|-----------------------|-----------------------|-------------------------|---------------------|
|                                                     | £                   | £                     | £                     | £                       | £                   |
|                                                     | surplus / (deficit) |                       |                       |                         | surplus / (deficit) |
| <b>Unrestricted funds</b>                           |                     |                       |                       |                         |                     |
| <b>General fund</b>                                 | 364,054             | 372,916               | 424,508               | —                       | 312,462             |
| <b>Restricted funds</b>                             |                     |                       |                       |                         |                     |
| <b>EpSMon Version 2</b>                             | 7,000               | 5,000                 | 6,556                 | 81                      | 5,525               |
| <b>EERE</b>                                         | 10,392              |                       | 7,392                 | 55                      | 3,055               |
| <b>Yorkshire</b>                                    | 20,000              |                       |                       | 367                     | 20,367              |
| <b>Learning<br/>Disability Framework</b>            | 24,990              |                       | 24,990                |                         | —                   |
| <b>NHS</b>                                          | 850                 |                       | 850                   |                         | —                   |
| <b>Children's Checklist</b>                         | 12,500              |                       | 9,970                 | 46                      | 2,576               |
| <b>Adult Checklist (UK,<br/>Ireland, Australia)</b> | —                   | 166,500               | 9,500                 | 3,072                   | 160,072             |

|                         | Brought forward     | Incoming resources | Resources expended | Transfers in / (out) | Carried forward     |
|-------------------------|---------------------|--------------------|--------------------|----------------------|---------------------|
|                         | £                   | £                  | £                  | £                    | £                   |
|                         | surplus / (deficit) |                    |                    |                      | surplus / (deficit) |
| <b>Restricted funds</b> |                     |                    |                    |                      |                     |
| EDR Learning Disability |                     | 10,000             | 10,000             |                      | —                   |
| NHS Lincolnshire        |                     | 15,000             |                    | 275                  | 15,275              |
| Bernard Lewis           |                     | 60,000             | 19,328             | 734                  | 41,406              |
|                         | <b>75,732</b>       | <b>256,500</b>     | <b>88,586</b>      | <b>4,630</b>         | <b>248,276</b>      |

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

**Learning Disability Framework:** Creating and commissioning improved guidance to improve safety for people with learning disabilities who have epilepsy.

**NHS:** My Life with Epilepsy. Creating risk information for people with learning disabilities and autism with epilepsy for families and carers.

**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.

**EDR Learning Disability:** Research & analysis of relevant EDR data and dissemination thereof.

**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.

### 14) ANALYSIS OF NET ASSETS BETWEEN CHARITIES

|                          | SUDEP ACTION   | EPILEPSY BEREAVED | TOTAL          |
|--------------------------|----------------|-------------------|----------------|
| Debtors                  | 12,134         | —                 | 12,134         |
| Cash at bank and in hand | 582,352        | —                 | 582,352        |
| Creditors                | 21,748         | —                 | 21,748         |
| Provision                | 12,000         | —                 | 12,000         |
| Total net assets         | <b>560,738</b> | <b>—</b>          | <b>560,738</b> |

Epilepsy Bereaved had no activity during the year ended 31 March 2024 or the comparative year.

# 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](mailto:info@sudep.org)

Website: [sudep.org](http://sudep.org)



Registered with  
**FUNDRAISING  
REGULATOR**

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