

## **SUDEP Action**

Registered Charity No.  
1164250 (England & Wales)  
SC047223 (Scotland)  
[www.sudep.org](http://www.sudep.org)

## **Linked with Epilepsy Bereaved**

(working names SUDEP Action  
& SUDEP Action Scotland)

## **Annual report and financial statements**

For the year ended 31 March 2023

# SUDEP Action & linked charity Epilepsy Bereaved

## CHARITY INFORMATION

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**Director** Jane Hanna OBE

**Trustees** John Hirst (Chair)  
Simon Lees  
Mark Phillips  
Alex Stirling  
Graham Faulkner  
Mike Kerr  
Rachel Shah  
Stephen Brown  
David Sibree  
Judith Shakespeare

**Charity No.** 1164250 (England & Wales)  
SC047223 (Scotland)

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

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# SUDEP Action & linked charity Epilepsy Bereaved

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## TRUSTEES' REPORT

### For the year ended 31 March 2023

The trustees present their report and accounts for the year ended 31 March 2023.

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 report that follows is from the Board of Trustees of SUDEP Action for work undertaken by the charity for the year to 31 March 2023.

### Structure, Governance and Management

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 14 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 14 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.

### Board of 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

**SUDEP Action has a policy that 50% of the trustees should have direct experience of Sudden Unexpected Death in Epilepsy (SUDEP) and use their experience and knowledge to benefit the charity.** In practice all of our trustees have experience of bereavement following a SUDEP, live with epilepsy or are clinical and research champions and it is this leadership of lived experience as well as expertise that drives the work of the charity.

The trustees also serve as part of a core group of 50 active volunteers in roles that support all aspects of SUDEP Action's work. They operate within a volunteering model that has been designed by the volunteers to meet their diverse needs including the suddenly bereaved



and clinicians. Volunteer roles include representing the charity at national cross-party groups, national policy committees and at local events.

SUDEP Action recruits for trustee positions using a variety of methods, including internet recruitment sites, recommendation, and occasionally press. Appointments are recommended to the trustees and agreed by resolution at a special meeting normally after interview with two trustees and the CEO.

The projects of the charity are, where appropriate, supported by scientific advisory committees including a UK development group of doctors, nurses and people with epilepsy who support the SUDEP and Seizure Safety Checklist, an expert panel which provides advice to our support team for families after a death, and a policy panel that helps with influencing change.

A highly specialist staff team of 11 includes specialist support and enablement, case work, research, digital projects to support improvements in care of people with epilepsy and policy. At least four of the team have lived experience.

91p of every £1 raised is spent directly on our research and services which benefit families and clinicians.

We pay tribute to veteran campaigner, co-founder, Vice-President and former Vice-Chair of the charity, Jennifer Preston, who died this reporting year. Jennifer worked tirelessly after the sudden death of her son William to educate and bring awareness of SUDEP in the UK and in Australia. Her first project 'Epilepsy and the Young Adult' in 1994 was the first booklet in the world to bring information and advice on how to reduce the risks of Sudden Unexpected Death in Epilepsy and her international work alongside four women who founded the charity brought SUDEP to world attention for the first time in the UK and globally in 1996.

The report that follows covers our mission, why we exist, a summary of our achievements during the reporting year and the full report of how we spend our funds to tackle deaths and support families.



'Education Team  
of the Year'



'Neurology Team  
of the Year'



'Healthcare  
IT'



'Education  
& Training'



## Our Mission

SUDEP Action exists to prevent deaths from epilepsy. Changing and saving lives through research and enabling people with person-centred life-saving knowledge is our priority. Supporting the suddenly bereaved and involving people with lived experience in all we do is central to our mission.

## Why?

Epilepsy, a mostly invisible disability, impacts every classroom and all communities.

**1 in 20 people will experience a seizure in their lifetime and will need to seek help. There are over 100,000 emergency visits a year in the UK because of epilepsy.**

**At least 21 people die from an epilepsy death each week with most deaths happening at home.** Up to half of deaths are Sudden Unexpected Deaths in Epilepsy with many dying suddenly in their sleep. These deaths peak in young adults with research also indicating that the incidence of SUDEP in children is the same as adults.

**The latest population research (part funded by SUDEP Action) between 2004 and 2014 showed deaths in people with epilepsy rising by 69%.** For the younger group use of A and E, injury and prescription of more than one anti-seizure medicine increased risk. Across all ages, seizure freedom was linked to lower risk of death. The latest Public Health England Report in 2018 using national official data found a similar rise and found that 49% of people with epilepsy died prematurely, with deaths three times more likely in deprived communities.

**It has been known for two decades that at least 4 out of 10 deaths could be avoided.** At that time the National Audit - Epilepsy Deaths in the Shadows was the sixth national report evidencing epilepsy as a poorly served community.

SUDEP Action has worked on all the national and regional reports that have exposed major public health inequalities experienced by families – starkly revealing that people in deprived communities are three times more likely to die; that deaths in pregnant women and their unborn have nearly doubled since 2016; and that people with epilepsy and a learning disability are dying ten years younger than people with a learning disability who do not have epilepsy (but who have other conditions).

**Epilepsy is today prioritised globally by the World Health Organisation and the UK Epilepsy Research Priorities Partnership has made epilepsy mortality the first priority for research.**

The rising harms to families and to communities from inaction are hugely out of proportion to the small commitment and investment recommended for levelling up epilepsy by every national report.



What perhaps is even more shocking is that our Epilepsy Deaths Register found that only 50% of bereaved people reporting to the register were aware that their loved one could die suddenly from SUDEP. In 2002 the National Audit found less than 1 per cent were aware, but the persistence of a culture that systematically downplays epilepsy risk is an important contributory context highlighted by the bereaved and national surveillance reports today, some two decades later.

We also know over half of the bereaved are still not being helped with explanations after a death, with many waiting many months for an inquest to report, and most are left with inadequate answers. These issues, including the lack of any standard that helps ensure people suddenly bereaved are supported quickly, lead to additional complexity and trauma in the aftermath of any sudden unexpected death, but especially during a pandemic.

Families and friends of those who have died suddenly are often left searching for answers and will turn private pain into public purpose as a tribute to the life of the person who died. SUDEP Action works alongside the families forging strong relationships with many that may be reactivated over a lifetime and bring wide communities of people who were left shocked by SUDEP or affected by it including the second generation together.

### How?

At SUDEP Action our focus is on changing the culture. Our campaigning shines a light on this shocking disaster bringing it out of the shadows and to the public's attention. With a significant change of attitude, culture, and action towards epilepsy, a huge number of lives CAN be saved.

**Turning pain to public purpose is at the heart of SUDEP Action.** The charity's values that were created by families and clinical champions, which underpin what we try to do in our daily work, are Courage; Pioneering; Impactful, Collaborative and Compassionate.

The recent pandemic and cost-of-living crisis created huge challenges as we saw the income stream for the charity fall immediately after we had invested in growth.

The legacy of the research and campaigns over two decades, including our dedicated work programme on SUDEP and epilepsy risk and our investment in digital empowerment projects was a clear contribution to tackle escalating risks and increasing need and complexity.

The team was able to deliver impact well 'above the group's weight'.

## **Our Impact this year**

**16,558 people were supported.**

**10,268 people were helped by services addressing individual need.**

**1,998 support/counselling calls and contacts with the suddenly bereaved** during the year was a 25% increase from the previous reporting year. Our published research, involving 228 suddenly bereaved people, uniquely showed profound life-long impacts and mental health burden on our community during the pandemic. Our confidential and supported research environment creates an increasingly powerful data set for learning from deaths in the UK and around the world - not just about epilepsy deaths but of relevance to other suddenly bereaved communities in the UK.

**We have experienced case work with multiple complexities, involving helping 58 families before, through and after inquests in the aftermath of a sudden death.**

**5,043 people are registered with our EpSMon epilepsy self-monitor App**, which is proven to reach people at known risk with personalised reports and encouragement to present to GPs when their epilepsy and risk is not well controlled.

**1,543 clinicians were engaged with the SUDEP and Seizure Safety Checklist alone.**

We involve doctors and nurses across community and acute care and involve people living with epilepsy in the development of our safety tools.

**3,798 people participated in SUDEP Action research and influencing change.** 2,834 people (including people with epilepsy, carers, bereaved and health workers) participated in SUDEP Action research this reporting year made possible by collaborations with 6 UK universities and research teams in Australia, India, North and South America. Research also included 2,606 experiences from women with epilepsy and their risk because of our EpSMon app. This vital evidence of women's experience of communication of risk will be crucial in helping to understand how interventions to support women can be included in decision-making about their care at a time of a doubling of maternal deaths.

**We continued our collaborations working with six research teams across the UK during the year.** Our partnership working in the UK continues to strengthen with centres across the UK including the University of Oxford, Newcastle University, Plymouth University, Exeter University, University College London and Imperial College London. Our research on epilepsy and risk during COVID-19 involved collaborations world-wide with research teams in Australia, India, North and South America.

**We continued our long-standing collaborations with Epilepsy Action Australia and Epilepsy Ireland.**

**60 organisations supported across the UK and in other countries** with agreed messages and visuals to raise awareness on SUDEP Action Day.



**During 2022-23 we focused on:**

- ❖ **Maximising our potential for diversification of funding streams to be in a position to strongly build back from the pandemic and cost of living crisis:**

We were successful in building back our funding streams to just above our strongest pre-pandemic funding income level. With the knowledge of funding expected during 2023-2024 we were also able to plan necessary investments in our services and our projects. This will enable us to meet rising demand and move forward confidently with our work to prevent future avoidable deaths.

- ❖ **Bringing back face-to-face events for our supporters, alongside our online and telephone support, and thanking all our supporters:**

We held 8 face to face events for the bereaved to meet their different needs. These were in different regional locations across England and Scotland and with other regions planned for in the future.

- ❖ **Raising awareness of deaths contributed to by systemic inequalities, with influencers and government:**

SUDEP Action worked on a national confidential report on Accident and Emergencies and a report on maternal deaths. This brought new evidence of the widening of very stark inequalities as well as recommendations for change to the attention of government. Alongside this SUDEP Action has worked to ensure positive learnings from local areas, where the charity has been successful in getting recognition of local systems to the need for action plans to tackle health inequalities. This includes working to bring in safety tools to support clinicians and families. The charity met with the UK Patient Safety Commissioner, the NHS Director of Patient Safety and the Medicines Health Regulator and corresponded with ministers. We worked with umbrella organisations to support campaigns to raise awareness of the needs of 1 in 6 people with neurological conditions, as well as supporting campaigns for improvements to patient care by National Voices.

- ❖ **Delivering systemic change with our safety tools and communication projects with University partners and local systems:**

Despite the most challenging environment, we worked in co-production with people with learning disability/carers to produce and disseminate new NHS commissioned videos and information brochures to help enable families to communicate to improve their care. In the Midlands we led a project bringing NHS and Care stakeholders together to inform a practical tool to guide the NHS and Social Care Commission to provide safe and good care for people with epilepsy and learning disability. We have developed a strong relationship and have been asked to support work in Lincolnshire to tackle epilepsy as a health inequality through the use of our safety tools across community settings.

We have been able to show through our research work with university partners that women have not received vital information on risk at a time of rising deaths and through a NIHR research grant we have built further critical knowledge on barriers that can prevent life-saving conversations about SUDEP taking place.

❖ **Influencing systemic change nationally and locally through case work and advocacy, and through our expert contributions to national and local surveillance of epilepsy-related deaths:**

Many people's lives can be saved each year if existing research and learnings from harms were used and included in the priorities of commissioners, providers of epilepsy services, national research organisations and the daily practice of health and care professionals.

During the year we provided expert assistance at all levels of surveillance on epilepsy deaths and care of people presenting at A&E, leading to two very stark national reports by MBRRACE and NCEPOD revealing disorganised care and strengthening further that it is vital that national and local systems listen to the evidence and to the families that are fighting for change.

We sadly continue to experience that families are not listened to about major patient safety issues at a national level. SUDEP Action led action aimed at getting a suspension of a new national policy that would restrict access to life-saving medication for people with epilepsy. We succeeded in bringing together 11 clinical and patient organisations, meeting intensively with national policy makers and getting the help of the Parliamentary Health Scrutiny committee. This led to a 12 month delay of the policy being implemented, the recognition that the medicine was the most effective for people at risk of SUDEP and that decisions would need to be individualised as well as a phased introduction of new restrictions. SUDEP Action is leading on work to seek major improvements to the policy going forward through helping bereaved families in our case work and through our research and policy work programme.

Our experience over decades is that improvements are made in local areas where we are able to be alongside a bereaved family who are advocating for change following an avoidable death, which acts as a catalyst for an invitation to SUDEP Action to contribute our research evidence and our epilepsy networks. Our case work service of intensive support is vital in helping enable families get answers to their questions and secure learnings to prevent future deaths.

This happened this year in the Midlands region who have mobilised by one sister's four-year campaign to get an inquiry into his death and the subsequent independent report and action plan to make change. It also happened in Surrey where a family campaign and subsequent report by the Care Quality Commission has led to SUDEP Action being invited to lead national training of the CQC on SUDEP and epilepsy safety. In Wales, the sudden death of a young pregnant woman and her unborn child has led to an independent report which will feed into a public investigation through an inquest next year.



## Bereavement Support

Support & telephone counselling sessions – 1998

Families provided with advocacy – 58

Bereaved people who have participated in research via Epilepsy Deaths Register – 1082

Enabling bereaved volunteers – 50

We listen and work with the bereaved to co-produce our service with families. The support team run a specialised service around epilepsy related deaths; they have an in-depth knowledge and years of experience working in this complex field. We are a gold standard service nationally and internationally. With input from our panel of SUDEP experts and with our advocacy and support service working closely together, we can help people bereaved by epilepsy to understand and support their grief journey. Traumatic grief has severe impacts. It will affect a person over their lifetime and affect multiple generations. SUDEP Action is there for all those bereaved by epilepsy and offers continuous support when it is needed.

We know from our research that specialist advocacy, integrated with specialist bereavement support, can help. SUDEP Action aims to provide this using a holistic approach that uniquely provides what a generic service is unable to do.

*"Thank you for all your help, support and friendship over the last 3 years. We would have been lost without your help and advice, you have helped us in ways you can't imagine"*  
(Bereaved Parent)

### What is helpful to the bereaved after an epilepsy death?

(Source: Data from the Epilepsy Deaths Register, in order of importance)

- Finding Answers
- Someone to talk to
- Help in understanding the investigation
- Learning about epilepsy related deaths
- Contact with others bereaved by epilepsy
- Getting involved with work of the charity
- Counselling
- Meeting experts

Many families want to get involved. This can be by becoming a dedicated volunteer who regularly helps, including hosting SUDEP Action coffee clubs and engaging local GPs. Whatever the reason for engaging, the aim is for them to know that they are not alone, that others have been there too.

*"I left feeling less isolated, less alone, more supported and more understood....We cried at times, but it didn't matter, the warmth and compassion in the group was palpable. Thank you"*

(Coffee Club attendee)

It is shocking that over half of the bereaved are still not being helped with explanations after a death, with many waiting many months for an inquest to report, and most are left with inadequate answers. These issues, including the lack of any standard that helps ensure families suddenly bereaved are supported quickly, lead to additional complexity and trauma in the aftermath of any sudden unexpected death, but especially during a pandemic.


SUDEP Action is able to be alongside the suddenly bereaved for every step they need us. We also help the bereaved families have visibility and validation to their experiences as risk across the whole NHS, social care and services investigating deaths has worsened. We were able to share the learnings from their experiences with the COVID Inquiry and the Bereavement Commission. We reminded all MPs of their plight and the need for action with a hand-knitted purple heart on an Epilepsy global awareness day in March.



## Safety Projects




**My Life with Epilepsy** – new resources commissioned by NHS England (project ongoing in 2022-23 and launched in October 2023)

A collaboration with Speak Up, a charity empowering people with learning disability and their families, has co-designed vital new specialist resources to help. SUDEP Action was commissioned by NHS England to lead this collaboration, also involving Sheffield University and the Cornwall Partnership NHS Foundation Trust. This has involved 6 clinical/research experts, over 10 people with epilepsy and a learning disability (2 of which are part of the core project team) and engaging with a network of more than 2000 carers and people with epilepsy throughout the project.

*“Responding to the needs of people with learning disability and autistic people is an urgent post-pandemic task” Professor Dan Goodley, Sheffield University*



SUDEP Action  

**“The My Life with Epilepsy work is important as it helps people who have epilepsy, or friends and family with epilepsy, understand how to live their lives to the full. People have lost their lives to epilepsy and with this work, we can help people live healthy lives with the condition.”**

Jodie Bradley,  
Speakup  
- an expert  
by experience

@SUDEPAction  
<https://sudep.org/my-life-epilepsy>



## SUDEP and Seizure Safety Checklist

**1543 clinicians were engaged with the SUDEP and Seizure Safety Checklist alone.** Since 2015 the Checklist has been supported by a UK-wide development team of GPs, experts and people living with epilepsy. It is regularly reviewed by SUDEP Action to ensure it considers latest research and thinking on risk in epilepsy.

*"I always ask the patients consent to complete the checklist and explain what I am doing. I put emphasis on the positive results, and we discuss how they can modify factors that potentially would put them at increased risk. I have not had a negative response."*

**(Epilepsy Specialist nurse midwife)**

SUDEP Action has received funding for a Children's Checklist which will be developed during 2023, with the launch planned for 2024. The launch of the project was announced in March 2023. Two members of our Development Group of clinical experts supporting the project share why this work is needed:

*"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"* **Professor Helen Cross**

*"I am really looking forward to bringing this project to fruition, so that we can provide an evidence based and accessible tool to every healthcare professional looking after children with epilepsy, allowing them to have meaningful discussions about reducing epilepsy-related risks."* **Dr Rohini Rattihalli**

## The EpsMon App

**5,043 people are registered with our EpSMon epilepsy self-monitor App**, which is proven to reach people at known risk with personalised reports and encouragement to present to GPs when their epilepsy and risk is not well controlled.

National reporting on deaths in women in pregnancy and deaths in people with learning disability as well as investigations into individual deaths reveal serious safety concerns. In particular a near doubling of maternal deaths and in the unborn. Safety concerns that risk of SUDEP are not being recognised or attended to or discussed, first identified across a UK national audit in 2002, persist. The EpsMon App and the SUDEP and Seizure Safety Checklist are tools that are recommended by these national investigations to tackle this problem. A national enquiry into people presenting to A and E with epilepsy this year found in 13.5% risks of SUDEP were recorded, but that too few trusts were using these tools. We worked this year in the Midlands where local NHS commissioners have committed to supporting the use of our safety tools in community settings and our programme of work is to prioritise working with partners who are concerned to tackle patient safety and health inequalities in their areas.

The app was also reviewed and approved by ORCHA (the world's leading assessor of digital health products) with a score of 69% for iOS and 71% for android. The score gives the reassurance that EpSMon is a high-quality safety tool, helping people to actively monitor and take action against epilepsy risks, in between appointments.

## Training and Information

**SUDEP Action trained 580 professionals** during the year at various events. This included an increase this year of requests for training from Paediatric and Learning Disability groups.

*"I will feel more confident and informed when discussing SUDEP with service users going forward."*

**(Attendee of SUDEP Training session held in Scotland)**

835 doctors, nurses and researchers received our professional news updating them on our work.

3232 people received our printed information brochures, but also many more were downloaded rather than sent physically.

## Research Projects

We were able to significantly involve people with epilepsy, the bereaved and clinicians in vital research on risk which we have been able to share with the UK Covid Inquiry, the UK government and Health Select Committee, the Bereavement Commission, clinicians and the public.

### Impact of the Pandemic on people with epilepsy & healthcare workers (COV-E project)

SUDEP Action partnered with Oxford University to lead the largest Epilepsy survey during the pandemic and the only survey focused on epilepsy and risk.

This enabled 2497 people with epilepsy, carers, and front-line clinicians to participate with their lived experience in the survey. Taking place originally in the UK but then securing the cooperation of research teams from 53 different countries with the survey available in 10 different languages. The published research papers, featuring findings from the UK, US,



The poster features the SUDEP Action logo and the University of Oxford logo at the top. Below them is a stylized illustration of a COVID-19 virus. The text on the poster reads: "The COVID-19 pandemic is impacting us all and it can be challenging for people with health conditions like epilepsy. This project aims to better understand the impact of COVID-19 on people with epilepsy. To take part, click the link to the survey below." Below this text are three circular icons representing different groups: "Health care workers" (a person wearing a mask), "People with epilepsy" (a person with a seizure symbol), and "Carers of people with epilepsy" (two people, one standing and one sitting). Under each icon is a list of languages: English, Portuguese (Portuguese), French (French), Italian (Italian), Chinese (Chinese), Hindi (Hindi), Bengali (Bengali), and Spanish (Spanish). At the bottom, it says "Follow us on social media at @SudepAction for more updates" and "SUDEP Action, registered charity 1184250 (England) & Wales, SC547223 (Scotland). Ethics Approval Reference: REC/20/04820".



Brazil (with a worldwide comparison to be published in 2024) from this project can be found [here](#).

SUDEP Action was the charity partner in a cutting-edge national research project (NIHR) that focussed on how clinicians communicate risk. The SUDEP Action research team supported this project involving 60 people with epilepsy. This research will look to improve clinical understanding on how risk is currently communicated with people with epilepsy, what impact this has on their understanding and risk management, and what can be done to make these important conversations as impactful as possible. The focus of the work will be to analyse the language used by epilepsy clinicians and their patients during epilepsy appointments. It is led by Conversational Analysis expert Dr Cordet Smart, with the analysis of the data involving clinicians and people with epilepsy taking part in the study.

More information about this project can be found [here](#), and we hope the research findings will be published in a series of papers in 2024.



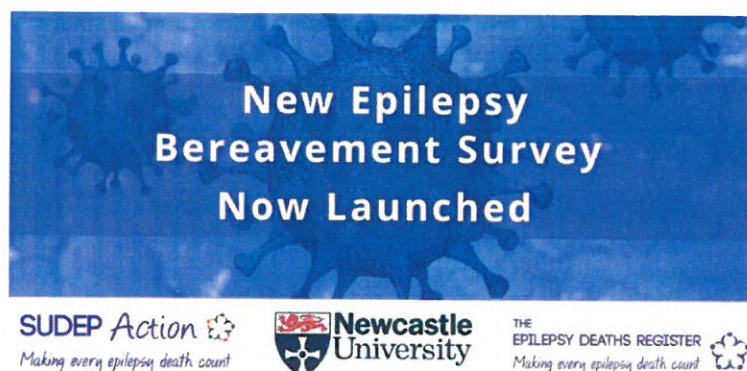
### Epilepsy Deaths Register (EDR)

Our unique Epilepsy Deaths Register (EDR) offers the bereaved an online research platform to share their experiences and strengthens the voice of the bereaved with the number of registrations currently at 1082.

The research register is the largest and most powerful collection of information on epilepsy deaths in the world designed with volunteers, involving just over 1000 families in research under the most difficult of circumstances, proving partially cathartic. The Register is vital in confirming that the experiences of the families after a death are of equal significance for learning by researchers and clinicians, as the experiences in the lead up to the death and in flagging key areas of concern. These include poor communication before and after a death; poor reporting of deaths; and learnings of factors that may have contributed to death.

The EDR enabled 228 suddenly bereaved families to participate in a COVID and Epilepsy Risk research project. We were uniquely able to involve bereaved families with Newcastle University in this new study on the impact of the pandemic on families bereaved through epilepsy. The COVID-19 response has worsened the experience of exclusion of suddenly bereaved families as media and public attention continues to focus on bereavement from

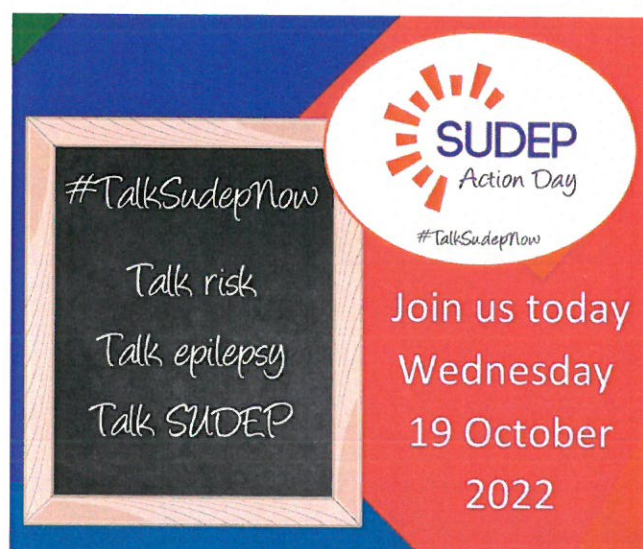
COVID-19. The research paper for this project was published in February 2023 and can be found [here](#).



## Increasing Awareness

1093 supporters received regular emails from us throughout the year keeping them up to date with news. We also produced two printed news magazines for our supporters who have told us this is their preference. On social media our followers increased by 8% across all our platforms to 20,298.

Our global event SUDEP Action Day used a Talk SUDEP Now theme with 104,000 accounts reached across the main SUDEP Action Facebook page in October 2022. Over 40 people took on a My Way to 5K walk to raise awareness and vital funds.

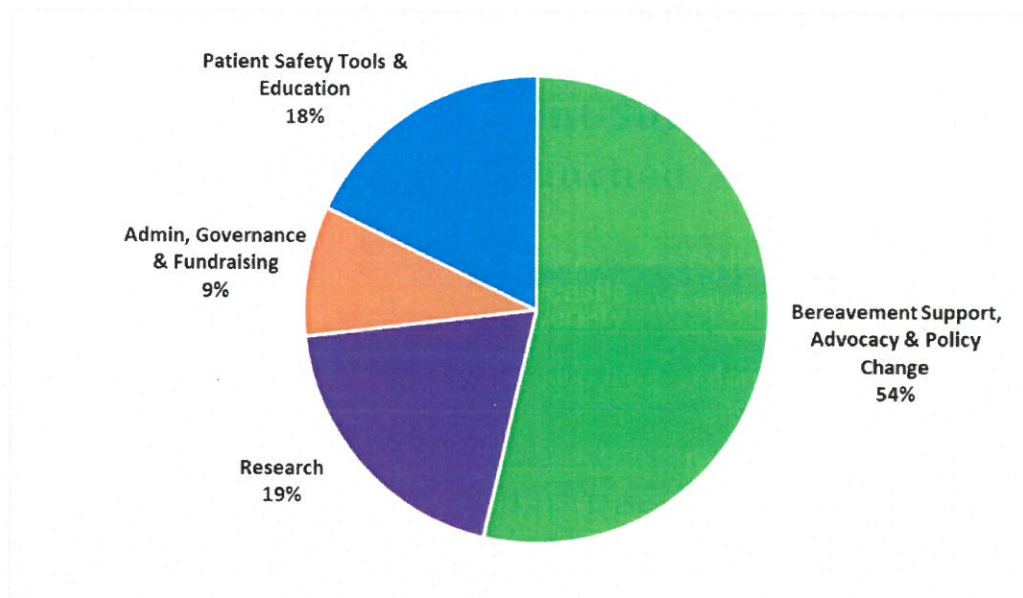


We are members of the IBE (International Bureau for Epilepsy) and ILAE (International League Against Epilepsy). We have partnerships with Epilepsy Action Australia and Epilepsy Ireland. There is increasing demand for our services and projects from other countries.



## Financial Matters

Our **expenditure** during the year of **£413,153** was apportioned as follows:



## Income and reserves

The charity's income was £505,663 (compared with £386,724 during 2021/2022, £ 501,183 during 2020/2021, £483,995 during 2019/2020, £480,224 during 2018/2019, £443,143 during 2017/2018, £395,413 during 2016/2017 and £431,122 during 2015/2016).

£36,832 of income during 2022/2023 was restricted funding with the balance of all restricted funds held, including those funds from income received before this reporting year, totalling £75,732.

Our uncommitted funds or general funds stood at £364,054 at year end or just over 11 months of general fund expenditure. The Board of Trustees agreed the Board reserve policy that the value of the reserves should be sufficient to cover between 6 to 12 months of general fund expenditure. Reserves are monitored monthly and kept under regular review at each Board meeting.

Fundraising has remained extremely challenging this year as indeed it has proved to be for most small to medium sized charities through the pandemic and cost of living crisis.

Last year the charity stated we were confident in our fundraising plan that we would build back to be in position to grow the charity. The charity did that reaching our highest level of income since the charity was founded and have strong funding projections for the next charity year. This has enabled our planning of a major charity restructure as the founder and CEO of the charity and the Chair worked with the Board and the team on a planned succession of the CEO role, internal promotions and recruitment of three new posts critical to our mission.

The charity has demonstrated financial and operational resilience through challenging times because of our Board and staff and our incredible supporters, all driven by our strong continuity of values and purpose.

## **Risk**

Financial control is through an annual budgetary process and regular reporting to management and the Board.

The trustees continue to assess the risks faced by the charity and to propose actions to mitigate these risks. The trustees review these risks on an ongoing basis and satisfy themselves that adequate systems and procedures are in place to manage, mitigate or reduce the risks identified. Where appropriate, risks are covered by insurance. The management team has a standard agenda item for reporting of significant variations and risks and the Chief Executive has regular liaison with the Chair of the charity where risks that arise in between Board meetings can be flagged and action taken.

Risk reports have included supporting safeguarding where families have been in crisis and where local services were not accessible during the pandemic. SUDEP Action has notified all relevant agencies and advocated for local services and has been the only support at times where there have been gaps. The Charity support team is supported by supervision and reporting of these complex cases to the Board on how risks are being managed.

The Board has three clinicians with skill sets to strengthen the Board in line with the charity strategy of even closer working with clinical teams across the UK.

## **The Future**

Our direction is clear. Care of people with epilepsy, their families and the bereaved is under the nature and strength of threat that we have not witnessed since the charity was founded in the 1990s.

Our priority remains to continue research and development, and the rolling out of our safety tools and services in the UK to reach as many people as we can.

Our research is focused on giving clear visibility to the experiences and challenges that families and clinicians experience at the front-line of care, and bringing the learnings from future new frontiers of research into our safety tools so that it is relevant to improvements in care.

Our own innovation work will focus next year on:

- A new Children's SUDEP and Seizure Safety Checklist ready for local systems keen to tackle epilepsy as one of the 5 nationally identified clinical areas of health inequality
- An Ireland version of our SUDEP and Seizure Safety Checklist

- Beginning our work to build EpsMon Version 2 to advance our digital safety solution and make it accessible to all

Local systems are seriously challenged but they are also looking for innovation and change. Our work in counties across the Midlands shows that systemic change across multiple organisations in a large local area is possible and we plan to identify and work in ten local areas to bring in safety solutions.

Our solutions are easily scalable, and already shared in other countries. Our aspirations are without local, national or international boundaries.

**During 2023/24 we will:**

- ❖ **Grow our team to meet demand for our services and safety solutions**
- ❖ **Bring back our National Event for the bereaved, alongside development of more local coffee clubs across the UK**
- ❖ **Accelerate our safety tools and the use and presentation of our data from our research platform with people with epilepsy and families.**
- ❖ **Develop our policy influencing work to embed our services and safety tools locally**
- ❖ **Collaborate with organisations focused on care to influence increased recognition of safety concerns and improvements to national and local policy**

Signed for and on behalf of the Board of Trustees



**John Hirst CBE**  
**Chair of Trustees**



**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES**

**For the year ended 31 March 2023**

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I report on the accounts of the Trust for the year ended 31 March 2023, which are set out on the pages 18 to 25.

**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

Oxfordshire

OX12 8JY

Dated.....

18/12/2023

## SUDEP Action

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

### Statement of Financial Activities For the year ended 31 March 2023

		SUDEP Action Unrestricted Funds 2023	SUDEP Action Designated Funds 2023	SUDEP Action Restricted Funds 2023	SUDEP Action Total Funds 2023	SUDEP Action Total Funds 2022
	Note	£	£	£	£	£
<b>Income from</b>						
Donations and legacies	2	465,521	-	36,832	502,353	382,643
Charitable activities	3	2,904	-	-	2,904	3,950
Other trading activities	4	27	-	-	27	110
Investments	5	379	-	-	379	21
<b>Total incoming resources</b>		<b>468,831</b>	<b>-</b>	<b>36,832</b>	<b>505,663</b>	<b>386,724</b>
<b>Resources Expended</b>						
Raising funds	6	45,193	-	-	45,193	87,884
Charitable activities	7-8	341,565	-	26,395	367,960	359,281
<b>Total resources expended</b>		<b>386,758</b>	<b>-</b>	<b>26,395</b>	<b>413,153</b>	<b>447,165</b>
<b>Net income/(expenditure)</b>		<b>82,073</b>	<b>-</b>	<b>10,437</b>	<b>92,510</b>	<b>(60,441)</b>
<b>Transfers between funds</b>	12	-	-	-	-	-
<b>Net movement in funds</b>		<b>82,073</b>	<b>-</b>	<b>10,437</b>	<b>92,510</b>	<b>(60,441)</b>
Total funds brought forward 1 April 2022(2021)		281,981	-	65,295	347,276	407,717
<b>Total funds carried forward 31 March 2023(2022)</b>		<b>364,054</b>	<b>-</b>	<b>75,732</b>	<b>439,786</b>	<b>347,276</b>

The notes on pages 18 to 23 form part of these financial statements.

# SUDEP Action

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

## Balance Sheet as at

	Note	31 March 2023 SUDEP Action Unrestricted Funds £	31 March 2023 SUDEP Action Designated funds £	31 March 2023 SUDEP Action Restricted Funds £	31 March 2023 SUDEP Action TOTAL £	31 March 2022 SUDEP Action TOTAL £
<b>Current Assets</b>						
Stock		1,547	-	-	1,547	1,442
Prepayments		2,098	-	-	2,098	3,837
Debtors		1,932	-	-	1,932	-
Accrued Gift Aid		-	-	-	-	1,019
Cash at bank and in hand		377,369	-	75,732	453,101	354,979
		<b>382,946</b>	<b>-</b>	<b>75,732</b>	<b>458,678</b>	<b>361,277</b>
<b>Creditors: amounts falling due within one year</b>	11	18,892	-	-	18,892	14,001
<b>Net Assets</b>		<b>364,054</b>	<b>-</b>	<b>75,732</b>	<b>439,786</b>	<b>347,276</b>
<b>Funds</b>						
Unrestricted Funds	12	364,054	-	-	364,054	281,981
Designated Funds	12	-	-	-	-	-
Restricted Funds	12-13	-	-	75,732	75,732	65,295
		<b>364,054</b>	<b>-</b>	<b>75,732</b>	<b>439,786</b>	<b>347,276</b>

The financial statements were approved by the Board of Trustees on 11/09/2023 and signed on its behalf by:



John Hirst  
Chair of Trustees

The notes on pages 20 to 25 form part of these financial statements.



**Notes to the Financial Statements**  
**for the Year Ended 31 March 2023**

**1 Accounting policies**

**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.

These accounts have been prepared using branch accounting to show the results of both SUDEP Action and Epilepsy Bereaved. CIO SUDEP Action was established in November 2015 to take forward the work of the unincorporated association Epilepsy Bereaved (formerly CCEW reg 1050459). The Charity Commission linked the two charities on 2 March 2017. Epilepsy Bereaved had no activity during the year ended 31 March 2019 and the comparative year.

**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. Epilepsy Bereaved ceased operations as of the 31 March 2023. The assets of Epilepsy Bereaved will be transferred to SUDEP Action before being closed.

**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 12 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

**SUDEP Action**

**Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)**

**Linked Charity: Epilepsy Bereaved (established 1995)**

**Notes to the Financial Statements  
for the Year Ended 31 March 2023**

**1 Accounting policies, continued****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 2023: nil (2022: 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.



**Notes to the Financial Statements  
for the Year Ended 31 March 2023**

	<b>Unrestricted Funds £</b>	<b>Designated Funds £</b>	<b>Restricted Funds £</b>	<b>TOTAL 2023 £</b>	<b>TOTAL 2022 £</b>
<b>2 Donations and legacies</b>					
Donations	44,190	-	-	44,190	97,311
Grants	32,386	-	36,832	69,218	82,588
Gift Aid	3,756	-	-	3,756	3,147
Legacies	172,500	-	-	172,500	-
Fundraising donations	212,591	-	-	212,591	199,333
Collecting boxes	97	-	-	97	263
	<b>465,521</b>	<b>-</b>	<b>36,832</b>	<b>502,353</b>	<b>382,643</b>
<b>3 Charitable activities</b>					
Annual charity conference	-	-	-	-	-
Fees receivable	2,904	-	-	2,904	2,050
Contractual income *	-	-	-	-	1,900
	<b>2,904</b>	<b>-</b>	<b>-</b>	<b>2,904</b>	<b>3,950</b>
* Contractual income relates to the EpSMon project (see note 12a, Cornwall Fund)					
<b>4 Other trading activities</b>					
Sale of goods	27	-	-	27	110
	<b>27</b>	<b>-</b>	<b>-</b>	<b>27</b>	<b>110</b>
<b>5 Investments</b>					
Interest Receivable	379	-	-	379	21
	<b>379</b>	<b>-</b>	<b>-</b>	<b>379</b>	<b>21</b>

**SUDEP Action**

Registered Charity N°: 1164250 (England &amp; Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements  
for the Year Ended 31 March 2023**

	<b>Unrestricted Funds £</b>	<b>Designated Funds</b>	<b>Restricted Funds £</b>	<b>TOTAL 2023 £</b>	<b>TOTAL 2022 £</b>
<b>6 Raising funds</b>					
Fundraising Expenses	7,523	-	-	7,523	11,620
Support costs	37,670	-	-	37,670	76,265
	<b>45,193</b>	<b>-</b>	<b>-</b>	<b>45,193</b>	<b>87,884</b>
<b>7 Charitable activities</b>					
Direct charitable expenditure	322,722	-	26,395	349,117	320,745
Governance costs	1,037	-	-	1,037	955
Support costs	17,805	-	-	17,805	37,581
	<b>341,565</b>	<b>-</b>	<b>26,395</b>	<b>367,960</b>	<b>359,281</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 and support costs**

Postage and Stationery	1,068	-	-	1,068	1,295
Telecommunications	4,472	-	-	4,472	4,563
Printing & Publicity	8,064	-	-	8,064	8,094
Salaries & National Insurance	257,851	-	19,625	277,476	269,453
Pension Scheme Contributions	6,726	-	-	6,726	5,787
Consultancy & other staff costs	-	-	4,100	4,100	8,337
Travel, Accommodation & Subsistence	512	-	-	512	-
Supporters Event	2,686	-	-	2,686	5,000
Affiliations to Other Groups	1,120	-	-	1,120	1,236
Development of Web Site	4,646	-	-	4,646	6,552
Cost of Support Group Meetings	801	-	-	801	-
Bank Charges	265	-	-	265	88
Office Costs, including Insurance	26,226	-	-	26,226	23,097
Conferences & Seminars	1,491	-	-	1,491	240
Sundry Expenses	495	-	-	495	531
IT Costs	15,872	-	-	15,872	13,846
Equipment Purchases	2,100	-	-	2,100	1,731
Independent Examiner's Fee	1,037	-	-	1,037	955
Epsmon Maintenance***	6,133	-	2,670	8,803	8,476
	<b>341,565</b>	<b>-</b>	<b>26,395</b>	<b>367,960</b>	<b>359,281</b>

\*\*\*

**9 Staff Costs including Pension Scheme Contributions**

Salaries & National Insurance	315,146	-	-	315,146	343,682
Pension Scheme Contributions	6,726	-	-	6,726	7,822
	<b>321,872</b>	<b>-</b>	<b>-</b>	<b>321,872</b>	<b>351,504</b>

There was an average of 9.20 employees (FTE) during the year (2022:10.29)

No employee earned over £60,000 in the year (2022: 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.

**SUDEP Action**

Registered Charity N°: 1164250 (England &amp; Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements  
for the Year Ended 31 March 2023****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**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>TOTAL 2023 £</b>	<b>TOTAL 2022 £</b>
Trade Creditors	2,317	-	2,317	1,397
HMRC-PAYE/NI	5,988	-	5,988	6,216
Pension	1,594	-	1,594	1,454
Accrued Expenditure	8,993	-	8,993	4,934
	<b>18,892</b>	<b>-</b>	<b>18,892</b>	<b>14,001</b>

**12 Statement of funds**

	<b>Note</b>	<b>Brought Forward £ Surplus/ (Deficit)</b>	<b>Incoming Resources £</b>	<b>Resources Expended £</b>	<b>Transfers In/(Out) £</b>	<b>Carried Forward £ Surplus/ (Deficit)</b>
<b>Unrestricted funds</b>						
General fund		281,981	468,831	386,758	-	364,054
<b>Restricted funds</b>						
Epsmon Version 2		-	-	-	7,000	7,000
EERE		-	10,392	-	-	10,392
Yorkshire		20,000	-	-	-	20,000
Learning Disability Framework		-	24,990	-	-	24,990
NHS		30,125	1,450	23,725	(7,000)	850
Childrens Checklist		12,500	-	-	-	12,500
Epsmon Development		2,670	-	2,670	-	-
<b>Total</b>		<b>65,295</b>	<b>36,832</b>	<b>26,395</b>	<b>-</b>	<b>75,732</b>

**SUDEP Action**  
**Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)**  
**Linked Charity: Epilepsy Bereaved (established 1995)**

**Notes to the Financial Statements**  
**for the Year Ended 31 March 2023**

**13 Details of restricted funds and special projects**

**Restricted Funds**

<b>Epsmon Development V2</b>	Funding to develop and improve the existing Epsmon App.
<b>EERE</b>	Testing the checklist in a Newcastle population and creating a video for different healthcare settings for example A&E, Maternity clinics.
<b>Learning Disability Framework</b>	Creating and commissioning improved guidance to improve for people with learning disabilities who have Epilepsy
<b>Childrens Checklist</b>	Creating a paediatric version of the sudep and seizure checklist.
<b>NHS</b>	My life with Epilepsy. Creating risk information for people with learning disabilities and autism with Epilepsy for families and carers.
<b>Epsmon Development V2</b>	Funding to develop and improve the Epsmon App.maintain the Epsmon App.
<b>Yorkshire Project</b>	A locally based project in Yorkshire to raise awareness and increase access to information, support and safety tools.

**14 Analysis of net assets between charities**

	<b>SUDEP Action</b>	<b>Epilepsy Bereaved</b>	<b>Total</b>
Debtors	5,577	-	5,577
Cash at bank and in hand	453,101	-	453,101
Creditors	18,892	-	18,892
Total net assets	<u>439,786</u>	<u>-</u>	<u>439,786</u>

Epilepsy Bereaved had no activity during the year ended 31 March 2023 or the comparative year.