

SUDEP Action

Registered Charity No.
1164250 (England & Wales)
SC047223 (Scotland)
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 2022

SUDEP Action & linked charity Epilepsy Bereaved

CHARITY INFORMATION

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

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SUDEP Action & linked charity Epilepsy Bereaved

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TRUSTEES' REPORT

For the year ended 31 March 2022

The trustees present their report and accounts for the year ended 31 March 2022.

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 2019).

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 2022.

During the preparation of this annual report, the epilepsy community of epilepsy and clinical organisations was taken by surprise by the publication of a new UK medicines policy that departed from other European and international countries, for which the scientific justification was entirely unclear, and which would reduce access to a key anti-seizure medication. This represented a dramatic shift in clinical practice with recognised impacts being an increase in epilepsy deaths and other harms. Our network of clinical teams around the UK invited SUDEP Action to lead the sector which we did from December 2022, without additional resources. We have unified the sector across the UK and the devolved countries and gained international support. This unexpected addition to our work programme delayed our ability to submit a timely annual report. We now have an increase in our staff team and plan an early report to be submitted to the Charity Commission for 2022/2023.

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.

85p of every £1 raised is spent directly on our research and services which benefit families and clinicians.

We pay tribute to veteran campaigners and former Vice-Presidents who died this reporting year:

Maureen Lahiff, Vice-President and former Chair of Trustees who worked tirelessly after the sudden death of her son to educate and bring awareness in the UK and in Australia.

Dr Rosie Panelli, Vice-President, clinical champion and international officer for SUDEP Action whose legacy includes her contribution to the SUDEP and Seizure Safety Checklist safety tool and making this available in Australia; SUDEP – the Global Conversation project and her huge body of work on epilepsy during her lifetime.

Our work to tackle deaths today is a tribute to all those that have died and also a tribute to the legacies of pioneering advocates who gave their life's work to the cause. These pioneer champions of SUDEP Action started their work when the world turned a blind eye to the urgent problem of sudden deaths in the young.

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 doubled; 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

16,702 people were supported.

11,973 people were helped by services addressing individual need showing a 21% increase in personalised support and involvement on our last reporting year.

1,599 support/counselling calls and contacts with the suddenly bereaved during the year was a 22% 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 experienced a 10% increase in this very intensive case work helping 77 families before, through and after inquests in the aftermath of a sudden death.

This included the reversal of a decision to a widow's pension and a finding in a regional inquiry in the Midlands into the avoidable death of Clive Treacey, that his death should have been investigated as SUDEP and there were multiple systemic failures.

4,316 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.

1379 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.

7,037 people participated in SUDEP Action research and influencing change. 4,930 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. 3 research publications have been published, with more in development. 228 bereaved people took part in

qualitative research on the impact of the pandemic on their mental health. Research also included 2,158 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 increased 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.

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

During this year we focused on:

❖ Maximising our potential for diversification of funding streams

We were commissioned by NHS England to co-produce resources with people with learning disability to empower them and their carers with understanding of risk.

We were also commissioned by NHS Midlands to develop commissioning guidance to support providers and commissioners of residential care.

We were funded by new corporate Charities of the Year and grants, alongside developing online community fundraising opportunities. This was not enough to make up for our loss of income from community fundraising events when furlough funding from the government ended but it did mean we had sufficient funding to be able to keep our team together and avoid any cuts to our services as we built back post pandemic.

❖ Delivering systemic change with our safety tools and communication projects with university partners

SUDEP Action was successful in influencing the inclusion of epilepsy as a public health inequality in NHS Midlands strategy and future planning. Despite the most challenging environment, the work in the Midlands across eleven local areas was a beacon of hope.

SUDEP Action research during this year included collaboration on an Epilepsy Research Priorities Partnership and we were delighted that after decades of bringing this urgent

problem to the fore that mortality interventions were ranked as the highest ranked priority for research in years to come.

We successfully collaborated with a new partner, Ardens, to embed our SUDEP and Seizure Safety Checklist in over 50% of GP practices in England. Following this we saw a 50% drop in GP registrations directly with the charity for the Checklist as GPs were able to access the safety tool automatically in their systems. If epilepsy is included in local NHS and care planning under the new reforms, there is a great opportunity to fully utilise the potential of the tool to tackle gaps in knowledge in local areas that are costing lives.

❖ **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 and national research organisations.

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.

This happened this year in 11 local areas across the Midlands region who have recognised epilepsy and SUDEP as a public health priority following the sudden death of Clive Treacey and a four-year campaign to get an inquiry into his death.

A complementary project 'My Life with Epilepsy', commissioned by NHS England, will focus on co-production of a new video and other information to support people with epilepsy with a learning disability and their families/carers to better understand risk and support their self-advocacy.

Nationally, we shared our vital research and policy intelligence and supported our bereaved families with lived experience to enable the UK Epilepsy Research Priorities Partnership and were delighted that epilepsy deaths were announced as the number one priority by the epilepsy community for UK epilepsy research going forward.

During the year we provided expert assistance at all levels of surveillance on epilepsy deaths and care of people presenting at A&E.

Our CEO served on national bodies tackling prevention of epilepsy deaths and emergencies including maternal deaths (MBRRACE); Accident and Emergency (NCEPOD) and on regional bodies (The Clive Treacey Independent Inquiry).

❖ **Raising awareness of deaths contributed to by systemic inequalities**

We brought the evidence and experiences of the bereaved to the attention of the National Bereavement Commission and contributed over 50 pages of evidence to the National Institute for Health and Care Excellence, taking part in their consultations, and influencing their recommendations. The charity used evidence from our substantial research throughout the pandemic and from our experience on the front line to correspond with the Secretary of State for Health, the Health Scrutiny Committee and work on a national pathology task force. There were 46 additional engagements with MPs about the impact of the Pandemic on people with epilepsy. This included alerting to the international and local calls for epilepsy to be included as an urgent public health problem. It also included, in regard to women with epilepsy, to implement the recent national MBBRACE recommendation that women and clinicians are supported with SUDEP Action Safety Tools to help reverse the trend of a doubling of maternal deaths.

❖ **Increasing our engagement with development of online community events, whilst planning for a return of face-to-face community events when we can**

Our online events for Purple Day, Online Epilepsy Memorial Day and SUDEP Action Day enabled engagement and we also held community engagement online in advance of these days. Our telephone support team supported an increasing number of families, with increasing complexity of calls.

Bereavement Support

Support & telephone counselling sessions – 1599

Families provided with advocacy – 77

Bereaved people who have participated in research via Epilepsy Deaths Register – 928

Enabling bereaved volunteers – 50

For more than 25 years we have listened to and worked 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.

"... [They are] with me every step of the way and bring me comfort that no one else is able to provide. Nothing is silly and there is no right or wrong. This support will go on as long as I need it and want it. This organisation expects nothing but give everything, a service that I will be forever grateful for."

(Bereaved Parent)

What is helpful to the bereaved after an epilepsy death?

(Source: Data from the Epilepsy Deaths Register)

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

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.

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

(Virtual 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. We were pleased that we were able to influence the National Coroner in writing to all Coroners to remind them of the underreporting of SUDEP and the importance of following the Royal College of Pathology Guidance on Epilepsy-Related Deaths.

The COVID-19 response worsened the experience of exclusion of suddenly bereaved families as national communications and the media reported on deaths and bereavement from COVID-19. SUDEP Action was able to be alongside to give visibility and validation to

the experiences of the suddenly bereaved through epilepsy as risk across the whole NHS and social care worsened. We were able to share their experiences with ministers and policy makers and were uniquely able to involve bereaved families in a new study on the impact of the pandemic on families bereaved through epilepsy.

The Charity was able to showcase progress we were making to embed our prize-winning, evidence-based safety tools in local systems, and the research we were able to do with our research partners alongside the NHS, so that what was happening at the coal-face was better understood and would contribute to learnings through the pandemic.

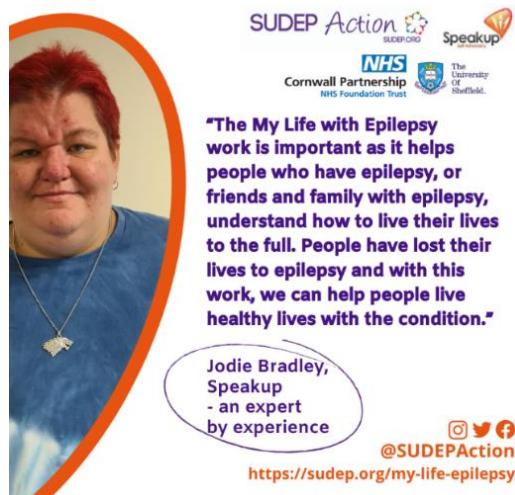


Safety Projects

My Life with Epilepsy – new resources commissioned by NHS England (ongoing, will continue in 2022-23)

We are delighted to collaborate with Speak Up, a charity empowering people with learning disability and their families, to co-design 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**



A promotional graphic for the 'My Life with Epilepsy' project. On the left is a circular portrait of Jodie Bradley, a woman with short red hair wearing a blue top. To the right of the portrait is a quote in purple text: **“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.”** Below the quote is a callout bubble containing the text: **Jodie Bradley, Speakup - an expert by experience**. At the top right are logos for SUDEP Action, Speakup, NHS Cornwall Partnership NHS Foundation Trust, and The University of Sheffield. At the bottom right are social media icons for Instagram, Twitter, and Facebook, followed by the text **@SUDEPAction** and the URL **<https://sudep.org/my-life-epilepsy>**.

SUDEP and Seizure Safety Checklist

1379 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.

Case Study – Collaboration with Ardens on SUDEP and Seizure Safety Checklist

SUDEP Action attracted 182 new individual registrations from professionals using the checklist this year, but we were able to work on an easy collaboration with Ardens to make the checklist easily available to primary care.

The SUDEP and Seizure Safety Checklist is now instantly downloadable to over 50% of GP surgeries across England, helping to give clinicians easy access to the latest evidence-based resources, and promoting best practice, medicines management and patient safety. When downloading the Checklist, clinicians also gain access to a range of free SUDEP Action resources to support both themselves and their patients, as well as having the option to hear more from SUDEP Action.

This is dramatic progress achieved in partnership with Cornwall NHS Foundation Trust since the project was initially pump-primed by Kt's Fund, a local fund set up by the parents of Katie, a young trainee nurse who died of SUDEP whilst waiting for an appointment in the South-West. Rates of communication remained as low as 4 -15% in the 12 years since UK national guidelines recommended that a discussion about SUDEP was essential in 2004. The outcome has been safety tools welcomed by clinicians and people with epilepsy and now rolled out in Australia as well as the UK. Using the Checklist has raised discussions from 10% to 80% of all people within epilepsy services and has reduced risks for patients.

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.

The EpsMon App

4,316 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.

During the year, following the MBRRACE-UK maternal deaths report finding maternal deaths had doubled, we were pleased that the EpsMon App and the SUDEP and Seizure Safety Checklist were included as vital safety tools to help inform and empower women with epilepsy and clinical teams for shared decision-making.

The app was also reviewed and approved by ORCHA (the world's leading assessor of digital health products) with a score of 74%. 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.

"EpSMon is going from strength to strength in its developing evidence. The ORCHA review adds to the app's already available expert feedback, national awards and publications. It is my hope that all this translates to continued and improved confidence in using EpSMon to keep a 'reality check' on one's epilepsy. The ORCHA review further attests that EpSMon can be a mirror to people with epilepsy to help reflect when things are going well and when things start to change, helping them to take pre-emptive action to keep themselves safe."

Professor Rohit Shankar, Consultant Neuropsychiatrist, Cornwall Partnership NHS Foundation Trust; Cornwall Intellectual Disability Equitable Research; CIDER – University of Plymouth Medical School

Training and Information

SUDEP Action trained 640 professionals at events ranging from a global event for neurologists, the Royal Society of Medicine annual meeting, as well as supporting local clinicians in the UK, for example a clinical training event for 50 clinicians in West Berkshire.

"Really informative to attend as a student nurse, especially in my first year as I haven't covered a lot of this yet".

(Attendee of Learning Disability Nurse Training course)

860 doctors, nurses and researchers received our professional news updating them on our work throughout the pandemic.

2,511 people received our printed information brochures, but also many more were downloaded rather than sent physically.

Research Projects

Throughout the pandemic 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 and the public.

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

SUDEP Action partnered with Oxford University from the first week of the lockdown 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. So far, there have been 3 research papers published and findings shared at 2 international conferences.



SUDEP Action  **UNIVERSITY OF OXFORD**
Making every epilepsy death count

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:

		
Health care workers	People with epilepsy	Carers of people with epilepsy
English	English	English
Deutsch (German)	Português (Portuguese)	Português (Portuguese)
汉语 (Chinese)	Français (French)	Français (French)
漢語 (Traditional Chinese)	Italiano (Italian)	Italiano (Italian)
हिंदी (Hindi)	汉语 (Chinese)	汉语 (Chinese)
বাংলা (Bengali)	漢語 (Traditional Chinese)	漢語 (Traditional Chinese)
	हिंदी (Hindi)	हिंदी (Hindi)
	বাংলা (Bengali)	বাংলা (Bengali)
	Español (Spanish)	

Follow us on social media at @SudepAction for more updates

SUDEP Action, registered charity 1164250 (England & Wales), SC047223 (Scotland), Ethics Approval Reference: R69353/RE001

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.



NIHR Research Study

Person Centred Risk Communication:
 What works best for people with epilepsy and their clinicians

UNIVERSITY OF EXETER **SUDEP Action**  **NIHR** **Cornwall Partnership** **UXC**
SUDEP.ORG NHS Foundation Trust

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 928.

The research register is the largest and most powerful collection of information on epilepsy deaths in the world designed with volunteers, involving just under 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.



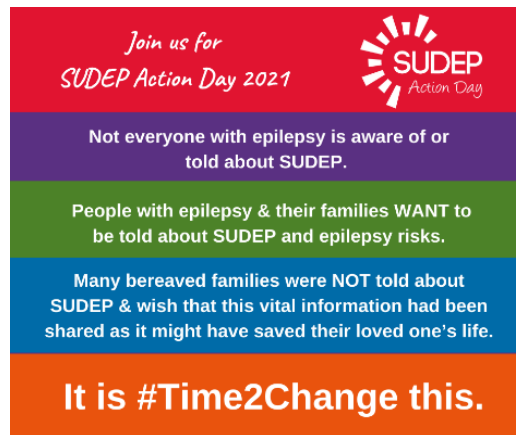
Primary Care project to embed system for GPs to use care and research pathway for the suddenly bereaved

Another major development was a collaboration with Ardens and SystmOne patient record systems which means for the first time the Epilepsy Deaths Register is accessible by GPs in situations where a patient has died.

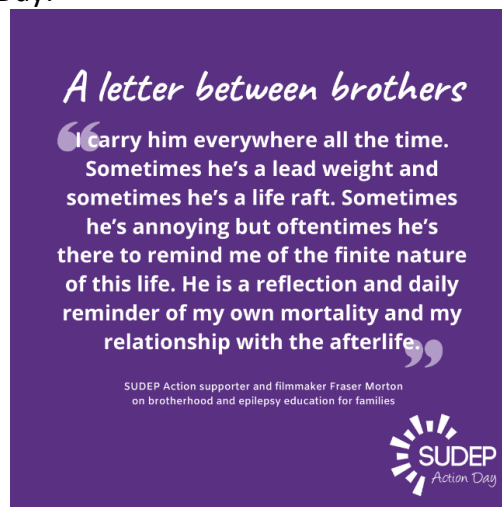
Increasing Awareness

729 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 18,794. The charity had over 58,000 engagements with our social media content. Our global event SUDEP Action Day used a Time2Change theme with nearly 60,000 people reached across the main SUDEP Action Facebook page. 150 people were involved in different events and 70 took on a My Way to 5K walk to raise awareness and vital funds.



Fraser Morton whose brother died suddenly in 1998 shared a precious letter about his feelings on SUDEP Action Day:



MPs, celebrities and even very busy local NHS organisations got involved stretching from the North of the Country to Cornwall.

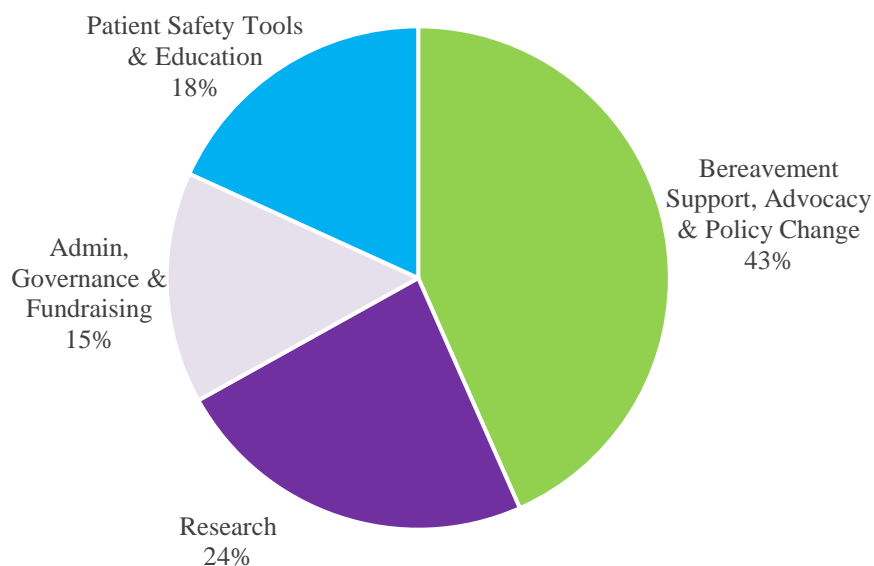




We are members of the IBE (International Bureau for Epilepsy) and ILAE (International League Against Epilepsy). We have partnerships with Epilepsy Action Australia and Epilepsy Ireland. There is increasing demand for our services and projects from other countries.

Financial Matters

Our **expenditure** during the year of **£447,165** was apportioned as follows:



Income and reserves

The charity's income was £386,724 falling back to pre-2015 levels of income (compared with £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). £61,500 of income during 2021/2022 was restricted funding with the balance of all restricted funds held, including those funds from income received before this reporting year, totalling £65,295.

Income received during the year from the Government Job Retention Scheme amounted to £21,088.

Our uncommitted funds or general funds stood at £281,981 at year end or just over 9 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.

The charity finances have not recovered yet, but SUDEP Action has demonstrated financial and operational resilience throughout the pandemic. It has been very clear that this resilience comes from a strong team of supporters, the staff and the Board driven by our values and purpose. Some long-standing relationships with charitable trusts and corporate support has been vital at a time of unprecedented challenges in fundraising, with our supporter base being incredible in helping the team to not only survive but to come through the pandemic more resilient than before.

Although there was some recovery by the time furlough support was removed, income streams were not at pre-pandemic levels. We had just recruited three new members of staff before lockdown and were able to keep this team together until this year. One of the new members of the team was made redundant as the project they had been recruited for had not been possible because of COVID-19 but we supported this staff member to work on vital new research on COVID and epilepsy risk which completed this year. The staff team as a whole was reduced during the year by not replacing a full-time member of team resigning for family reasons. We are confident with our fundraising plan, including funds due from commissioned projects with the NHS and charitable fundraising events reopening, to be in a position to build back our capacity to pre-pandemic levels in the next 18 months.

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. The COVID-19 pandemic has disproportionately impacted the most vulnerable communities as clinicians have been redeployed and services reduced. For the communities we serve, that have always faced system-wide lack of recognition and neglect and have always had to innovate solutions to tackle painful gaps, the COVID-19 response has hugely escalated the threat, whilst also highlighting our charity solutions. Our priority remains the rolling out of our projects and services in the UK to as many people as possible who need these.

Local systems are seriously challenged but they are also looking for innovation and change and our work in the Midlands shows that systemic change across multiple organisations in a large local area is possible.

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

With further development funding we can work with other centres to move quickly to meet need and deliver change.

During 2022/23 we will:

- ❖ **Continue to maximise our potential for diversification of funding streams to be in a position to strongly build back from the pandemic and cost of living crisis;**
- ❖ **Bring back face-to-face events for our supporters, alongside our online and telephone support, and thank all our supporters;**
- ❖ **Raise awareness of deaths contributed to by systemic inequalities, with influencers and government;**
- ❖ **Deliver systemic change with our safety tools and communication projects with University partners and local systems;**

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

Signed for and on behalf of the Board of Trustees



**John Hirst CBE
Chair of Trustees**

SUDEP Action & linked charity Epilepsy Bereaved

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

For the year ended 31 March 2022

I report on the accounts of the Trust for the year ended 31 March 2022, which are set out on the pages 21 to 28.

Respective responsibilities of the trustees and examiner

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
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29/06/2023

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 2022

		SUDEP Action Unrestricted 2022	SUDEP Action Designated 2022	SUDEP Action Restricted 2022	SUDEP Action Total 2022	SUDEP Action Total 2021
	Note	£	£	£	£	£
Income from						
Donations and legacies	2	321,143	-	61,500	382,643	500,788
Charitable activities	3	3,950	-	-	3,950	-
Other trading activities	4	110	-	-	110	121
Investments	5	21	-	-	21	274
Total incoming resources		325,224	-	61,500	386,724	501,183
Resources Expended						
Raising funds	6	87,884	-	-	87,884	86,225
Charitable activities	7-8	310,000	-	49,281	359,281	339,299
Total resources expended		397,884	-	49,281	447,165	425,524
Net income/(expenditure)		(72,660)	-	12,219	(60,441)	75,659
Transfers between funds	12	41,612	(41,612)	-	-	-
Net movement in funds		(31,048)	(41,612)	12,219	(60,441)	75,659
Total funds brought forward 1 April 2022(2021)		313,029	41,612	53,076	407,717	332,058
Total funds carried forward 31 March 2022(2021)		281,981	-	65,295	347,276	407,717

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 31 March 2022

		31 March 2022 SUDEP Action	31 March 2022 SUDEP Action	31 March 2022 SUDEP Action	31 March 2022 SUDEP Action	31 March 2021 SUDEP Action
		£	£	£	£	£
Current Assets						
Stock		1,442	-	-	1,442	-
Prepayments		3,837	-	-	3,837	4,508
Debtors		-	-	-	-	4,510
Accrued Gift Aid		1,019	-	-	1,019	3,195
Cash at bank and in hand		289,684	-	65,295	354,979	412,654
		295,982	-	65,295	361,277	424,867
Creditors: amounts falling due within one year						
	11	14,001	-	-	14,001	17,150
Net Assets		281,981	-	65,295	347,276	407,717
Funds						
Unrestricted Funds	12	281,981	-	-	281,981	313,029
Designated Funds	12	-	-	-	-	41,612
Restricted Funds	12-13	-	-	65,295	65,295	53,076
		281,981	-	65,295	347,276	407,717

The financial statements were approved by the Board of Trustees on 29 June 2023 and signed on its behalf by:



John Hirst
Chair of Trustees

The notes on pages 23 to 28 form part of these financial statements.

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

1 Accounting policies

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 FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS 102") and the Charities SORP "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (effective 1 January 2019). Trustee Investment (Scotland) Act 2005, Charities Accounts (Scotland) Regulations 2006. The

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 2019. 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 2022**

1 Accounting policies, continued

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) Research grants

A grant of £5,000 was made to the University College London

i) 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 2018: nil (2017: 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.

j) 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.

k) 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.

l) 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.

m) 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.

n) 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.

o) 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.

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 2022**

	Unrestricted Funds	Designated Funds	Restricted Funds	TOTAL 2022	TOTAL 2021
2 Donations and legacies					
Donations	97,311	-	-	97,311	100,870
Grants	21,088	-	61,500	82,588	132,732
Gift Aid	3,147	-	-	3,147	6,500
Legacies	-	-	-	-	36,677
Fundraising donations	199,334	-	-	199,334	223,939
Collecting boxes	263	-	-	263	70
	321,143	-	61,500	382,643	500,788
3 Charitable activities					
Fees receivable	2,050	-	-	2,050	-
Contractual income *	1,900	-	-	1,900	-
	3,950	-	-	3,950	-
* Contractual income relates to the EpSMon project (see note 12a, Cornwall Fund)					
4 Other trading activities					
Sale of goods	110	-	-	110	121
	110	-	-	110	121
5 Investments					
Interest Receivable	21	-	-	21	274
	21	-	-	21	274

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

	Unrestricted Funds	Designated Funds	Restricted Funds	TOTAL 2022	TOTAL 2021
6 Raising funds					
Fundraising Expenses	11,619	-	-	11,619	9,119
Support costs	76,265	-	-	76,265	77,106
	87,884	-	-	87,884	86,225
7 Charitable activities					
Direct charitable expenditure	271,464	-	49,281	320,745	299,599
Governance costs	955	-	-	955	950
Support costs	37,581	-	-	37,581	38,750
	310,000	-	49,281	359,281	339,299

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	1,295	-	-	1,295	940
Telecommunications	4,563	-	-	4,563	4,712
Printing & Publicity	4,394	-	3,700	8,094	9,155
Salaries & National Insurance	246,970	-	22,483	269,453	259,652
Pension Scheme Contributions	5,787	-	-	5,787	3,677
Consultancy & other staff costs	2,337	-	6,000	8,337	275
Research grants	-	-	5,000	5,000	-
Affiliations to Other Groups	1,236	-	-	1,236	982
Development of Web Site	6,552	-	-	6,552	12,462
Bank Charges	88	-	-	88	31
Office Costs, including Insurance	19,975	-	3,122	23,097	21,577
Conferences & Seminars	240	-	-	240	25
Sundry Expenses	531	-	-	531	1,234
IT Costs	13,346	-	500	13,846	12,072
Equipment Purchases	1,731	-	-	1,731	40
Independent Examiner's Fee	955	-	-	955	950
Epsmon Maintenance***	-	-	8,476	8,476	11,515
	310,000	-	49,281	359,281	339,299

9 Staff Costs including Pension Scheme Contributions

Salaries & National Insurance	343,682	-	-	343,682	333,881
Pension Scheme Contributions	7,822	-	-	7,822	6,554
	351,504	-	-	351,504	340,435

There was an average of 9.71 employees (FTE) during the year (2021:10.29)

No employee earned over £60,000 in the year (2021: 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 & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements
for the Year Ended 31 March 2022****10 Trustee expenses**

Trustees were reimbursed a total of £nil (2021: 1 trustees £210) for travel expenses.

11 CREDITORS: amounts falling due within one year

	Unrestricted Funds £	Restricted Funds £	TOTAL 2022 £	TOTAL 2021 £
Trade Creditors	1,397	-	1,397	2,920
HMRC-PAYE/NI	6,216	-	6,216	8,505
Pension	1,454	-	1,454	1,758
Accrued Expenditure	4,934	-	4,934	3,967
	14,001	-	14,001	17,150

12 Statement of funds

	Note	Brought Forward £ Surplus/ (Deficit)	Incoming Resources £	Resources Expended £	Transfers In/(Out) £	Carried Forward £ Surplus/ (Deficit)
Unrestricted funds						
General fund		313,029	325,224	397,884	41,612	281,981
Designated funds						
Prevent21 projects		41,612	-	-	(41,612)	-
Restricted funds						
WADD		8,122	-	8,122	-	-
Research		6,858	-	4,358	(2,500)	-
Oxon Pilot Project		12,950	-	12,950	-	-
Yorkshire		20,000	-	-	-	20,000
Bereavement Support		-	1,500	1,500	-	-
NHS		-	50,000	13,875	(6,000)	30,125
Childrens Checklist		-	10,000	-	2,500	12,500
Epsmon Development		5,146	-	8,476	6,000	2,670
Total		53,076	61,500	49,281	-	65,295

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

13 Details of restricted funds and special projects

Prevent 21	Funding to support the Prevent 21 campaign which aims to support our dedicated programme of research and surveillance that brings knowledge to save lives now by shining a light on key risk factors, conversations, and actions. As well as, contributing to research to help in the near future.
Restricted Funds	
WADD	Funding to trial the development of a Wearable Apnoea Detection Device, designed to trigger an alarm when breathing stops in SUDEP. Designated where there is doubt whether the specific fundraising purpose was clearly communicated.
Research	General research into the causes & prevention of epilepsy deaths.
Epilepsy Deaths Register	Funding to develop the Epilepsy Deaths Register and support collaborations to learn from epilepsy deaths. The Epilepsy Deaths Register started in 2013 is a web based data repository enabling reporting of the circumstances and impact of epilepsy deaths.
Case Worker Project	To provide support for bereaved families involved in inquests and formal enquiries into sudden deaths.
Oxon Pilot Project	To bring lifesaving solutions to local Healthcare professionals and communities in Oxfordshire.
Epsmon Development	Funding to develop and maintain the Epsmon App.
Yorkshire Project	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

	SUDEP Action	Epilepsy Bereaved	Total
Stock	1,442	-	1,442
Debtors	4,856	-	4,856
Cash at bank and in hand	354,979	-	354,979
Creditors	14,001	-	14,001
Total net assets	<u>347,276</u>	<u>-</u>	<u>347,276</u>

Epilepsy Bereaved had no activity during the year ended 31 March 2022 or the comparative year.