

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 2021

Chapman Worth Limited
6 Newbury Street
Wantage
Oxfordshire
OX12 8BS

SUDEP Action & linked charity Epilepsy Bereaved

CHARITY INFORMATION

Director	Jane Hanna OBE
Trustees	John Hirst (Chair) Simon Lees Mark Phillips Alexandra Stirling Graham Faulkner Michael Kerr Rachel Shah Stephen Brown Judith Shakespeare David Sibree
Charity No.	1164250 (England & Wales) SC047223 (Scotland)
Website	www.sudep.org
Address for correspondence	SUDEP Action 18 Newbury Street Wantage Oxfordshire OX12 8DA
Accountants	Chapman Worth Limited 3 The Old Estate Yard East Hendred Wantage Oxfordshire OX12 8JY
Bankers	HSBC Plc 24 Market Square Witney Oxfordshire OX28 6BG Barclays Bank PLC Marcham Road Abingdon OX14 1UB

SUDEP Action & linked charity Epilepsy Bereaved

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TRUSTEES' REPORT

For the year ended 31 March 2021

The trustees present their report and accounts for the year ended 31 March 2021.

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 2021.

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. Administering the charity as a CIO provides benefits in relation to employing staff, leasing property and entering into contracts. 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 (appointment renewed as member of Board November 2020)
Alex Stirling
Judith Shakespeare
David Sibree (appointed July 2020)

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 champions.

The trustees also serve as part of a core group of 52 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 and an expert panel which provides advice to our support team for families after a death.

A highly specialist staff team of 14 (10.8 FTE) includes specialist support and enablement, case work, research, innovation and policy. Nearly 90p of every £1 raised is spent on charity services reducing risk and the burden of tackling epilepsy deaths.

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.

Our Mission

SUDEP Action aspires to stop unnecessary deaths from epilepsy. We represent the voice of the bereaved and prioritise the acceleration of good practice as well as learning from deaths. Changing and saving lives through putting people, life-saving knowledge and support first is our priority because of the need to accelerate stopping of deaths.

Why?

At least 21 people die from an epilepsy death each week and 21 communities are suddenly bereaved; nearly half can be prevented. Good practice is too often not followed, there are huge gaps in knowledge in this area.

1 in 20 people will have a seizure in their life-time, whilst 1% of people live with epilepsy in the UK. This is an issue which, although a mostly invisible disability, is likely to touch us all during our life-time.

10 deaths each week are in the young, with epilepsy ranking in the top ten causes of deaths from treatable conditions.

Because of SUDEP Action funded research we know that epilepsy-related deaths rose by 69% in the years before the COVID-19 pandemic and doubled in pregnant women with epilepsy.

As the World Health Organisation called out epilepsy as an urgent public health issue in 2021, SUDEP Action has been able to continue to build on the substantial body of research and evidence on avoidable mortality and contribute solutions to UK national, local and other country inquiries during the pandemic. Huge gaps in knowledge, commitment and ability to act on national guidelines and national and individual prevention reports have persisted since 2002. Tackling the barriers to gaps in knowledge across community and specialist settings is one SUDEP Action has championed with university partners with evidence-based solutions that are now recognised as good practice. Our prize-winning transformational research through the pandemic, in collaboration with partners, reveals the urgency to roll-out of solutions. People with epilepsy, families, health workers and the bereaved report increasing gaps in services and rising risks against a backdrop of individual risk not understood.

We know from over 900 experiences shared by the bereaved that we have already changed the culture, but there is much more to do to ensure families are listened to.

SUDEP Action's Epilepsy Deaths Register is the largest and most powerful collection of information on epilepsy deaths in the world designed with volunteers, involving and proving partially cathartic for over 900 families in research under the most difficult of circumstances. Our research shows progress on awareness since SUDEP Action led a national report in 2002 with 5 Royal Colleges which found less than 1% of people at risk from sudden death and families knew that epilepsy could be fatal. The Epilepsy Deaths Register suggests that 80%

are aware of this today, but that only 50% were aware that their loved one could die suddenly from SUDEP. That the majority were unaware of epilepsy risks (including those linked to SUDEP) or how to reduce them, when information shared suggests the person with epilepsy faced medication and life-style issues, goes to show how much work is still needed to implement the key recommendation of the National Audit of Epilepsy Deaths of 2002. The persistence of a culture that systematically downplays epilepsy risk is a major contributor to deaths.

It is also shocking that over half 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.

Evidence through research and long experience of working with families demonstrate that the bereaved families SUDEP Action work with experience trauma including post-traumatic stress disorder. The majority of families will have struggled in accessing epilepsy services and support before the death and are often left bewildered by the investigation of death which may not recognise 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.

Families, carers and friends who whilst grieving are also looking for answers, are often angry and confused, and seek to turn private pain into public purpose as a tribute to the life of the person who died.

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.

The charity's values that underpin the work programme that have enabled the charity to bring interventions and solutions to tackle avoidable sudden death in the young:

- **Courage** is paramount as most of them are suddenly bereaved and use their voices to try to prevent this happening to other families: '**using private pain for public purpose**'.

Other descriptors include:

- **Pioneering** (bringing innovations to reduce epilepsy risk);
- **Impactful** (making a difference changing clinical practice and policy and for the bereaved);

- **Collaborative** (working ethically with others to share expertise and create change, working together to avoid duplication);
- **Compassionate** (caring, supporting and being a trusted life-line to patients, families and the bereaved)

Through these values the group has delivered impact ‘above the group’s weight’ and has contributed to seismic changes of practice and solutions to bring early interventions to tackle avoidable sudden death in the young.

During this year we delivered on:

- ❖ **Maximising diversification of funding streams:** We were commissioned by NHS England, funded by new corporate Charities of the Year and grants, alongside developing online community fundraising opportunities at pace to make up for loss of income from face to face community fundraising events.
- ❖ **Bereavement support:** SUDEP Action leads the world as a gold standard service that can be a life-line for the bereaved in trauma and can enable them to influence learning after a death.
Learnings over 25 years meant we were well placed to continue to innovate during the pandemic to embrace digital, written correspondence and phone to maximise connection across the most vulnerable. We continued to develop our online memorial event and innovated new ones.
- ❖ **Targeting prevention and cure:** Funding and conducting transformational research including the impact of the COVID-19 response on people with epilepsy, health workers and the bereaved on a national as well as an international research study with our University partners. We also provided ongoing patient and public involvement for a National Institute for Health Research (NIHR) clinical trial on communication of risk.
- ❖ **Influencing Change:** by leading a Lives Cut Short report and bringing up to date knowledge of the impact of the pandemic with the evidence and the voices of thousands of stakeholders to the attention of national policy makers and influencers to safeguard policy advances in 2020 and to build on these.
- ❖ **Developing our co-production work on solutions to help people stay safe:** Informing and empowering people to access the information and support they may not have otherwise had, to reduce risk and live well. Our digital self-management tool to encourage and support people to check their own risk and self-advocate was featured at the G7 Summit and was recognised as best practice by the NHS at a national and local level.
- ❖ **Increasing public awareness:** we continued to support organisations and communities in the UK and around the world with common messages and learning on SUDEP Action Day; and with SUDEP: the Global Conversation.

Our collaborations with seven University partners and with advocacy partners have deepened through the pandemic with our UK solutions progressed this year in both Australia and Ireland.

There is so much more to do. We lead this work confident that our work is needed more than ever through the pandemic and that our services and solutions are evidenced not just in awards but by national surveillance of untimely deaths in the young.



Our Impact this year

20,493 people were supported, a 25% increase on our last reporting year.

9,867 people were helped by personalised services addressing individual need.

10,626 people were supported by general educational material and training.

Whilst our services with the bereaved provides personal and highly specialist help for as long as needed, our innovative technology also enables personalised and meaningful engagement with people with epilepsy and participation in research by the bereaved who are difficult to reach.

928 people participated in research with the bereaved sharing their experiences through our Epilepsy Deaths Register. This confidential and supported environment creates an increasingly powerful data set for learning from deaths in the UK and around the world.

We increased our collaborations during the pandemic working with seven 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, Imperial London. Our research on epilepsy and risk during COVID-19 involved collaborations world-wide with research teams in Australia, India, North and South America.

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

70 suddenly bereaved families were supported by transformational advocacy with high impacts including national and local policy change, and for individuals helping them

influence the correct record of death as SUDEP or epilepsy. In one case this led to a reversal of a decision not to award a widow's pension.

The pandemic has created huge challenges but has also created opportunities to speed up change because of increased recognition of our unique model of support and learning from deaths.

SUDEP Action is now recognised as good practice for specialist support and prevention. With additional funding we would be in a position to rapidly accelerate a roll out of learning from deaths and safety tools to stop increasing unnecessary deaths from epilepsy.

Bereavement Support

Support & telephone counselling sessions – 1311

Families provided with advocacy – 70

Families who have participated in research via Epilepsy Deaths Register – 928

Enabling bereaved volunteers – 52

Enabling bereaved supporters - 848

The bereaved are always at the centre of what we do.

For almost 25 years we have listened to and worked with the bereaved to develop our service. 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 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.

Those bereaved by epilepsy death have many questions. One of the very difficult things that nearly every family has to face is the postmortem report. It is hard to read about the person who has died in this context, but also to understand what all the findings are (whether or not they relate to the cause of death). With input from our expert panel, and with our advocacy and support service working closely together, we can explain the findings and reassure families about elements of these reports that may have caused great anxiety.

We often support families who need answers and are concerned that an inquest might not follow an initial investigation into the death. An epilepsy death will often be categorised as by natural causes, but many deaths are avoidable. An inquest can answer important questions about how this happened, about the risk factors which apply and how epilepsy deaths might be prevented in future. Wherever needed, we work with families to advocate for inquests and to explain to coroners how vital their role can be after an epilepsy death.

Our aim is to empower the bereaved to find the answers they need. The information and advice we provide is tailored to the individual. We are led by what families and individuals want and need and we aim not to superimpose a view of what that might be.

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

“...[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 expect nothing but give everything, a service that I will be forever grateful for.”

(Bereaved Parent)

Many families want to get involved. This can involve becoming a dedicated volunteer who regularly helps including hosting coffee clubs and engaging local GPs. We have learnt over 25 years working with the bereaved that it is vital that we can offer opportunities that do not require a regular commitment but that are still incredibly powerful. This may include sharing their inspirational stories to influence change. The majority of these opportunities we are still able to provide, some we have had to put on hold due to the pandemic restrictions. Particularly the face-to-face coffee clubs. However, we have managed to adapt and to hold these virtually so the bereaved still have an opportunity to meet others who have shared a similar experience. The meetings are informal with a charity host to facilitate. They can be a way to share stories, gain support and discuss what has helped them get through this most difficult experience. Whatever the reason for meeting up, 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)

Keeping people safe

660 people receive our professional e-news updates.

We provide training for medical teams around the UK.

“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)

1156 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

The SUDEP and Seizure Safety Checklist is now instantly downloadable to over 50% of English GP surgeries across England. Ardens, who provide templates and resources for EMIS Health and SystmOne patient record systems, have included a link within their templates to enable any primary care clinician using them to download the Checklist directly. Their templates are used by over 2,800 general practices across England. Ardens also works with over 31 Clinical Commissioning Groups (CCGs), 4 Sustainability & Transformation Partnerships (STPs), 60 Primary Care Networks (PCNs) and many other groups too. Helping to give clinicians easy access to the latest evidence-based resources, and promoting best practice, medicines management and patient safety.

Updates have also been made to the templates to encourage and support clinicians to:

- upload a completed Checklist into patient records,*
- document they have had SUDEP and epilepsy risk discussions (and note what the outcomes of these discussions are),*
- encourage signposting of people with epilepsy to EpSMon, the free app, so people with epilepsy can monitor their own epilepsy risks in between appointments.*

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.

Case Study - SUDEP and Seizure Safety Checklist

The project was 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. Developed in partnership with Cornwall NHS Foundation Trust using a 9-year quality improvement drive methodology, it encourages positive discussion of risk management with patients supporting the implementation of national guidelines and recommendations, from high profile medical-legal rulings. Working locally, it has brought families, the local community and professional champions together. Research we commissioned found many people who died had worsening risk factors before they died. Rates of communication have 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 in patients. Deaths have been observed as falling, with no deaths reported in the learning disability community. A digital tool for patients has now been developed with over 4,200 people with epilepsy in UK registered users.

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 to ensure it considers latest research and thinking on risk in epilepsy.

"I have first-hand experience in losing a son to epilepsy & none of my colleagues previously realised people could die - nobody had heard of SUDEP - so now they understand the importance of using tools like the Checklist to monitor risk"
(clinician and bereaved parent)

"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)

Helping people stay safe

2,511 people received our printed information brochures, but also many more were downloaded rather than sent physically as a result of the pandemic.

4,200 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.

EpSMon is a smartphone App which helps patients to monitor risk factors from seizures and keep track of their general well-being. In 2017 it was chosen as one of eight innovations for the NHS Innovation Accelerator Programme and was used as an example of good practice in the NHS 70th year anniversary video.

EpSMon is a digital version of the SUDEP and Seizure Safety Checklist which was developed by SUDEP Action, Cornwall Partnership NHS Foundation Trust and Royal Cornwall Hospitals as a clinical tool. Our SUDEP and Seizure Safety Checklist has proved itself in reducing risk in people living with epilepsy.

Targeting prevention and cure

Epilepsy Deaths Register

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

The Epilepsy Deaths Register has proved to be therapeutic to the bereaved who are able to place their experiences in the knowledge that this will help learning for the future. 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 WADD Project (Wearable Apnoea Detection Device for people with epilepsy)

Most sudden deaths are at night when most seizures are unwitnessed. Having the ability to alert someone to come and help during a life-threatening episode may be protective. This needs to be part of a risk assessment and care plan worked up with the person with epilepsy aimed at improving safety and wellbeing. This is because it is not uncommon for bereaved families to register deaths of people who have used monitors. There are frequently many different opportunities to mitigate the risk of sudden deaths and monitors should be considered as only one part of the risk assessment and care plan for the person with epilepsy. Various devices are available commercially and it is a rapidly developing research field. SUDEP Action provides frequently asked questions to help people discuss monitors with their doctor.

SUDEP Action funded a clinical trial at University College London and Imperial College London to research a device that has already confirmed high sensitivity and low false alarm rates to test this in people living with epilepsy with a view to improving technology in this field. The results of the clinical trial are now being used as part of research and development by an engineer at Imperial College who was awarded 2 million euros from the European Research Council to develop a device.

Increasing Public Awareness

Our Prevent21 campaign throughout the year has enabled us to reach new audiences outside of the epilepsy community. This is in addition to the increased public awareness from our leadership of the global SUDEP Action Day every year.

We saw an increase in page views of our website from nearly 190,000 to over 218,000 this reporting year.

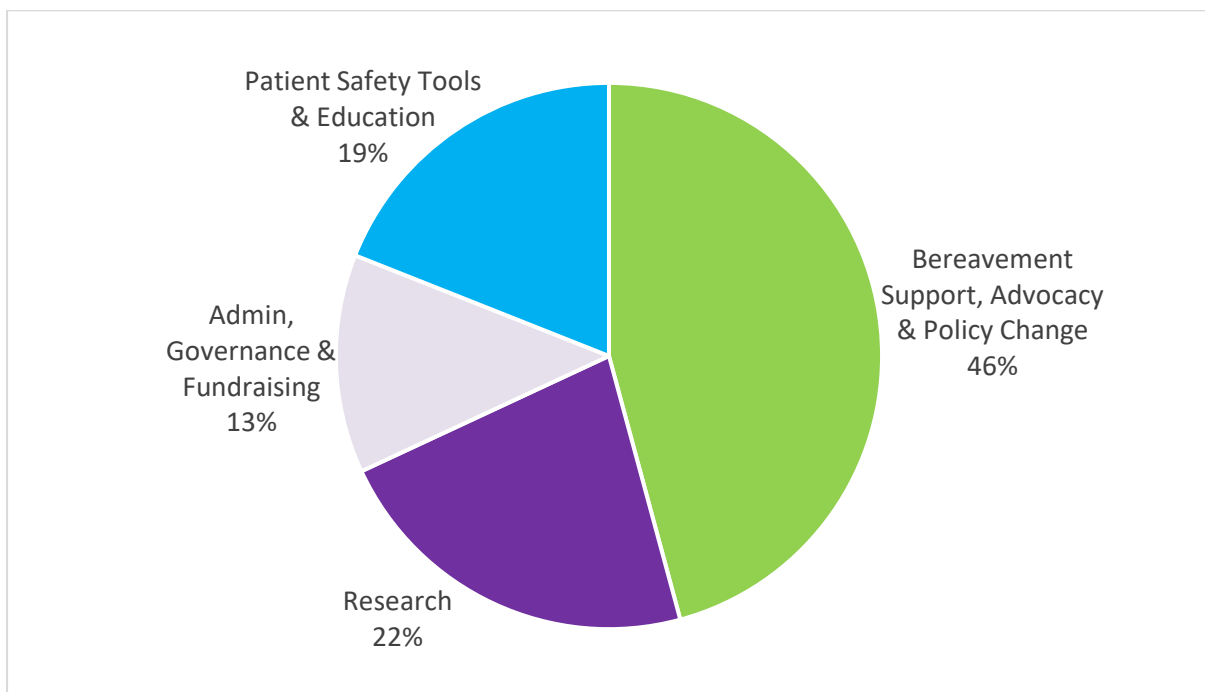
We also work with umbrella organisations to strengthen our influence. We presented on avoidable maternal deaths to the All Party Parliamentary Group on Epilepsy and to

supportive MPs. Tribute is paid to Sir David Amess MP who secured a debate on SUDEP and thanks also to Lord Vaizey who gave a speech on SUDEP and SUDEP Action to the House of Lords. We work with epilepsy organisations in Scotland and are active members of the Cross-Party Parliamentary Group for Epilepsy and the Epilepsy Consortium.

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 £425,523 was apportioned as follows:



Income and reserves

The charity's income was £501,183 (compared with £483,995 during 2019/2020, £480,224 during 2018/2019, £443,143 during 2017/18, £395,413 during 2016/17 and £431,122 during 2015/16). £46,611 of income during 2020/2021 was restricted funding with the balance of all restricted funds held, including those funds from income received before this reporting year, totalling £53,076.

Income received during the year from the Government Job Retention Scheme amounted to £47,434.

Restricted funds totalling £6,858 to support projects working with researchers and UK clinicians will be fully paid out during 2021/2022.

Our uncommitted funds or general funds stood at £313,029 at year end or just over 10 months of general fund expenditure. The Board of Trustees agreed the Board reserve policy of between 6 to 9 months income which is monitored monthly and kept under regular review at each Board meeting.

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. Charity support teams are 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.

From the beginning of the COVID-19 pandemic the Board agreed to meet each month to support the rapid transformation needed of the organisation, including to support the new funding plan in light of the fall in income from planned events. As the financial position of the charity has improved the Board has reverted to our 2020 timetable.

The charity has demonstrated financial resilience through the pandemic. We have recently experienced a 30% drop in our income and like other charities are finding that community fundraising events are slow to recover during times of uncertainty and that fundraising is extremely competitive.

The Future

Our direction is clear. Too many children of whatever age are dying unnecessarily. Parents and siblings too. Families and communities are left devastated by loss. 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.

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 2021/22 we will:

- ❖ **Maximise our potential for diversification of funding streams**
- ❖ **Increase our engagement with development of online community events whilst planning for a return of face to face community events when we can**
- ❖ **Raise awareness of deaths contributed to by systemic inequalities**
- ❖ **Deliver systemic change with our safety tools and communication projects with University partners**
- ❖ **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



J Hirst CBE Chair of Trustees

SUDEP Action & linked charity Epilepsy Bereaved

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

For the year ended 31 March 2021

I report to the charity trustees on my examination of the accounts of the Charity for the year ended 31 March 2021, which are set out on the pages 16 to 23.

Responsibilities and basis of report

The charity's trustees are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011. The charity trustees consider that the audit requirement of regulation 10(1) (a) to (c) of the 2006 Accounts Regulations does not apply. The trustees are satisfied that the Charity is not required by charity law to be audited and have chosen instead to have an independent examination.

Basis of independent examiner's statement

I report in respect of my examination of the Trust's accounts as carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act. 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 I do not express an audit opinion on the view given by the accounts.

Independent examiner's statement

Since the charity has prepared its accounts on an accruals basis and is also registered in Scotland your examiner must be a member of a body listed in Regulation (11) (2) of the Charities Accounts (Scotland) Regulations 2006 (as amended). I can confirm that I am qualified to undertake the examination because I am a registered member of ICAEW which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Charity as required by section 44 (1) (a) of the 2005 Act and Regulation 4 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and section 130 of the 2011 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements Regulations 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirements that the accounts give a 'true and fair view' which is not a matter considered as part of an independent examination.

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



Anna Chapman FCA

Chapman Worth Limited

3 The Old Estate Yard

East Hendred

Wantage

Oxfordshire

OX12 8JY

Dated.....

12 January 2022

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 2021

		SUDEP Action Unrestricted Funds 2021	SUDEP Action Designated Funds 2021	SUDEP Action Restricted Funds 2021	SUDEP Action Total Funds 2021	SUDEP Action Total Funds 2020
	Note	£	£	£	£	£
Income from						
Donations and legacies	2	454,177	-	46,611	500,788	458,205
Charitable activities	3	-	-	-	-	7,071
Other trading activities	4	121	-	-	121	17,407
Investments	5	274	-	-	274	1,312
Total incoming resources		454,572	-	46,611	501,183	483,995
Resources Expended						
Raising funds	6	86,225	-	-	86,225	70,411
Charitable activities	7-8	288,983	34,788	15,528	339,299	409,177
Total resources expended		375,208	34,788	15,528	425,524	479,588
Net income/(expenditure)		79,364	(34,788)	31,083	75,659	4,407
Transfers between funds	12	-	-	-	-	-
Net movement in funds		79,364	(34,788)	31,083	75,659	4,407
Total funds brought forward 1 April 2020 (2019)		233,665	76,400	21,993	332,058	327,651
Total funds carried forward 31 March 2021 (2020)		313,029	41,612	53,076	407,717	332,058

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 2021 SUDEP Action Unrestricted Funds £	31 March 2021 SUDEP Action Designated funds £	31 March 2021 SUDEP Action Restricted Funds £	31 March 2021 SUDEP Action TOTAL £	31 March 2020 SUDEP Action TOTAL £
Current Assets						
Prepayments		4,508	-	-	4,508	10,409
Debtors		4,510	-	-	4,510	-
Accrued Gift Aid		3,195	-	-	3,195	2,895
Cash at bank and in hand		317,966	41,612	53,076	412,654	345,493
		330,179	41,612	53,076	424,867	358,797
Creditors: amounts falling due within one year	11	17,150	-	-	17,150	26,739
Net Assets		313,029	41,612	53,076	407,717	332,058
Funds						
Unrestricted Funds	12	(313,029)	-	-	(313,029)	233,665
Designated Funds	12	-	(41,612)	-	(41,612)	76,400
Restricted Funds	12-13	-	-	(53,076)	(53,076)	21,993
		(313,029)	(41,612)	(53,076)	(407,717)	332,058

The financial statements were approved by the Board of Trustees on 06/01/2022 and signed on its behalf by:



John Hirst
Chair of Trustees

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)

Notes to the Financial Statements
for the Year Ended 31 March 2021

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 accounts have been prepared in accordance with FRS102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" ("FRS102"), "Accounting and Reporting by Charities" the Statement of Recommended Practice for charities applying FRS102, 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 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

Notes to the Financial Statements
for the Year Ended 31 March 2021

1 Accounting policies, continued

f) 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.

g) 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 2021: nil (2020: 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.

h) 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.

i) 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.

j) 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.

k) 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.

l) 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.

m) 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 ActionRegistered Charity N^o: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

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

	Unrestricted Funds £	Designated Funds £	Restricted Funds £	TOTAL 2021 £	TOTAL 2020 £
2 Donations and legacies					
Donations	100,870	-	-	100,870	72,972
Grants	86,121	-	46,611	132,732	30,000
Gift Aid	6,500	-	-	6,500	2,920
Legacies	36,677	-	-	36,677	-
Fundraising donations	223,938	-	-	223,938	351,974
Collecting boxes	70	-	-	70	339
	454,177	-	46,611	500,788	458,205
3 Charitable activities					
Annual charity conference	-	-	-	-	5,597
Fees receivable	-	-	-	-	215
Contractual income *	-	-	-	-	1,259
	-	-	-	-	7,071
4 Other trading activities					
Fundraising sales	-	-	-	-	14,500
Sale of goods	121	-	-	121	2,907
	121	-	-	121	17,407
5 Investments					
Interest Receivable	274	-	-	274	1,312
	274	-	-	274	1,312

Notes to the Financial Statements
for the Year Ended 31 March 2021

	Unrestricted Funds £	Designated Funds	Restricted Funds £	TOTAL 2021 £	TOTAL 2020 £
6 Raising funds					
Fundraising Expenses	9,119	-	-	9,119	30,303
Support costs	77,106	-	-	77,106	40,108
	<u>86,225</u>	<u>-</u>	<u>-</u>	<u>86,225</u>	<u>70,411</u>
7 Charitable activities					
Direct charitable expenditure	249,283	34,788	15,528	299,599	369,047
Governance costs	950	-	-	950	1,380
Support costs	38,750	-	-	38,750	38,750
	<u>288,983</u>	<u>34,788</u>	<u>15,528</u>	<u>339,299</u>	<u>376,363</u>

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	940	-	-	940	5,142
Telecommunications	4,712	-	-	4,712	5,061
Printing & Publicity	9,155	-	-	9,155	14,917
Salaries & National Insurance	220,851	34,788	4,013	259,652	240,473
Pension Scheme Contributions	3,677	-	-	3,677	4,449
Consultancy & other staff costs	275	-	-	275	9,579
Travel, Accommodation & Subsistence	-	-	-	-	6,314
Research grants	-	-	-	-	44,000
Affiliations to Other Groups	982	-	-	982	1,268
Development of Web Site	12,462	-	-	12,462	4,170
Bank Charges	31	-	-	31	65
Training	-	-	-	-	540
Office Costs, including Insurance	21,577	-	-	21,577	25,100
Conferences & Seminars	25	-	-	25	12,641
Sundry Expenses	1,234	-	-	1,234	1,119
IT Costs	12,072	-	-	12,072	10,835
Equipment Purchases	40	-	-	40	11,024
Independent Examiner's Fee	950	-	-	950	890
Cost of Trustees' meetings	-	-	-	-	490
Epsmon Maintenance	-	-	11,515	11,515	11,100
	<u>288,983</u>	<u>34,788</u>	<u>15,528</u>	<u>339,299</u>	<u>409,177</u>

9 Staff Costs including Pension Scheme Contributions

Salaries & National Insurance	333,881	-	-	333,881	279,508
Pension Scheme Contributions	6,553	-	-	6,553	5,522
	<u>340,435</u>	<u>-</u>	<u>-</u>	<u>340,435</u>	<u>285,030</u>

There was an average of 10.29 employees (FTE) during the year (2020:8.3)

No employee earned over £60,000 in the year (2020: 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 2021****10 Trustee expenses**

The Trustees received no remuneration during the year (2020: nil).

Trustees were reimbursed a total of £nil (2020: 1 trustees £210) for travel expenses.

11 CREDITORS: amounts falling due within one year

	Unrestricted Funds £	Restricted Funds £	TOTAL 2021 £	TOTAL 2020 £
Trade Creditors	2,920	-	2,920	10,683
HMRC-PAYE/NI	8,505	-	8,505	7,065
Pension	1,758	-	1,758	827
Accrued Expenditure	3,967	-	3,967	8,164
	<u>17,150</u>	<u>-</u>	<u>17,150</u>	<u>26,739</u>

12 Statement of funds

	Note	Brought Forward £ Surplus/ (Deficit)	Incoming Resources £	Resources Expended £	Transfers In/(Out) £	Carried Forward £ Surplus/ (Deficit)
Unrestricted funds						
General fund		<u>233,665</u>	<u>454,572</u>	<u>375,208</u>	<u>-</u>	<u>313,029</u>
Designated funds						
Prevent21 projects		<u>76,400</u>	<u>-</u>	<u>(34,788)</u>	<u>-</u>	<u>41,612</u>
Restricted funds						
WADD		8,122	-	-	-	8,122
Research		6,858	-	-	-	6,858
Epilepsy Death Register		4,013	-	(4,013)	-	-
Case Worker Project		-	-	-	-	-
Oxon Pilot Project		3,000	9,950	-	-	12,950
Yorkshire		-	20,000	-	-	20,000
Epsmon Development		-	16,661	(11,515)	-	5,146
Total		<u>21,993</u>	<u>46,611</u>	<u>(15,528)</u>	<u>-</u>	<u>53,076</u>

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

13 Details of restricted funds and special projects

Designated Funds

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
Debtors	12,212	-	12,212
Cash at bank and in hand	412,654	-	412,654
Creditors	17,150	-	17,150
Total net assets	<u>407,717</u>	<u>-</u>	<u>407,717</u>

Epilepsy Bereaved had no activity during the year ended 31 March 2021 or the comparative year.