

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 2020

Chapman Worth Limited
6 Newbury Street
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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 Judy 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
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SUDEP Action & linked charity Epilepsy Bereaved

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TRUSTEES' REPORT

For the year ended 31 March 2020

The trustees present their report and accounts for the year ended 31 March 2020.

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" (as amended for accounting periods commencing from 1 January 2016).

The report that follows is from the Board of Trustees of SUDEP Action for work undertaken by the charity as an unincorporated charity for the year to 31 March 2020.

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 (appointed Chair July 2018, appointment renewed as member of Board November 2019)

Professor Mike Kerr (Vice Chair)

Rachel Shah (Treasurer) (appointment renewed as member of Board July 2019)

Susan Allen (retired November 2019)

Professor Stephen Brown (appointment renewed as member of Board November 2019)

Graham Faulkner (appointment renewed as member of Board November 2019)

Simon Lees

Mark Phillips

Alex Stirling (appointment renewed as member of Board November 2019)

Judith Shakespeare (appointed November 2019)

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.

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.

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 not always followed, there are huge gaps in knowledge in this area.

Over 22,000 people are reported as having died from epilepsy in the UK since five women launched Epilepsy Bereaved at a memorial service in London in 1996. This may underestimate the true figure.

1 in 20 people will have a seizure in their life-time, whilst 600,000 in the UK live with epilepsy. 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.

Before COVID-19, deaths had fallen for all other conditions, with epilepsy and neurological conditions the only exceptions. Epilepsy as an exemplar of one of the most disadvantaged communities will be disproportionately impacted by the COVID-19 response which has increased isolation and worsened epilepsy risk at a time when risk is not understood.

Huge gaps in knowledge, commitment and ability to act persist despite national initiatives aimed at preventing deaths since 2002.

We know from nearly 900 experiences shared by the bereaved that we have already changed the culture. Half of all the bereaved in the UK were aware that epilepsy was not benign compared with just 1% in 2002. Through our work, the UK leads the world on this level of awareness and understanding of risk, but it is still staggering that over half of the bereaved experience the shock of not having been made aware that epilepsy is life-threatening. It is 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. 8% of deaths reported were in people who had not been diagnosed with epilepsy. Additionally, the reports show that the majority were unaware of epilepsy risks (including those linked to SUDEP) or how to reduce them, even though the information shared suggested the person with epilepsy faced medication and life style issues which suggested they were at risk before their death. These issues, as well as the lack of any system for doctors to be told about the death, lead to additional complexity and trauma in the aftermath of a death.

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.

They struggle to understand why avoidable deaths that occur in one place and at one time, such as an airline disaster or a fire, attracts some public attention and concern, whilst SUDEP and other epilepsy deaths, still don't. The persistence of a culture that systematically downplays risk is a major contributor to deaths.

The COVID-19 response has worsened the experience of exclusion of suddenly bereaved families as media and public attention has focused solely on bereavement from COVID-19.

How?

At SUDEP Action our focus is on changing that culture. Our Prevent21 campaign 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.

We focus our impact on:

- 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.

"The service that you, SUDEP Action offer, is worth its weight in gold. I will always be grateful that I was able to get help from you, and the fact that it can continue as long as I need it, is wonderful. Other counselling offers about six weeks, and then that's it. Grief isn't like that. Grief In various forms can last a lifetime, especially a sudden death of a young person. Just the knowledge that I can talk to someone when I need to, no matter how long has passed, is a huge comfort to me."

(bereaved parent)
- Keeping people safe:** Reaching professionals throughout the UK to enable learning from deaths, and support with education, training and safety tools such as our **standardised health check for risk**, acclaimed for Patient Safety and for innovation in tackling mortality.
- Helping 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. Using our **digital self-management tool** to encourage and support people to check their own risk and self-advocate.

- **Targeting prevention and cure:** Forging forward with our dedicated research into the cause and prevention of sudden deaths in people living with epilepsy. Including our unique reporting platform with the largest data set of lived experiences of the bereaved with them reporting therapeutic benefits on completion.
- **Increasing public awareness:** By supporting 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.

There is so much more to do. We lead this work confident of the support for our work evidenced in these national and global awards:



Our Impact this year

16,431 people were supported, over 2,500 more than in our last reporting year.

8,028 people were helped by personalised services addressing individual need.

8,403 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.

871 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 worked with research teams across the UK during the year. Our partnership working continues to strengthen with centres across the UK including Newcastle University and Plymouth University as well as with clinical research groups at Cornwall NHS Foundation Trust and the Oxford Epilepsy Research Group. Research in 2018 found a reduced risk for patients using our SUDEP and Seizure Checklist. Deaths have been observed as falling in a local population in the South-West, with no deaths reported in the learning disability community.

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

43 organisations were brought together for a Prevent21 UK Summit to tackle epilepsy deaths and SUDEP Action has led an epilepsy coalition since 2018. Our work was endorsed by the All Party Parliamentary Group on Epilepsy and the Neurological Alliance. Leading an epilepsy coalition, we brought evidence to senior level meetings and a judicial review increasing awareness and successfully influencing some positive changes in policy.

Investing in our support service for traumatised families through a new part-time case worker service has been transformative enabling us to double the number of highly complex advocacy cases we support and influencing learning from deaths and changes in clinical and organisational practice.

The success of our Prevent21 campaign has meant that we are in a position to progress the priorities identified in the Prevent 21 Summit. With additional funding we would be in a position to rapidly accelerate a roll out of learning from deaths and safety tools to speedily stop increasing unnecessary deaths from epilepsy.

Bereavement Support

Support & telephone counselling sessions – 944

Families provided with advocacy – 51

Families who have participated in research via Epilepsy Deaths Register – 871

Enabling bereaved volunteers – 38

Enabling bereaved supporters - 780

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

“All I can say is walking this journey is made a little easier when you know you're not walking it alone.”
(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 almost 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 support and comfort I got from meeting up at a Glasgow coffee morning, was amazing. I would urge everyone to try to get to one and talk about their loved one.”
(bereaved parent)

Keeping people safe

732 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)

925 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 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. 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 3,500 people with epilepsy in UK already 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)

Our formal collaboration agreements with NHS Partners, Universities and patient organisations:

SUDEP and Seizure Safety Checklist: Cornwall Partnership NHS Foundation Trust, Epilepsy Action Australia

EpSMon: Cornwall Partnership NHS Foundation Trust, Royal Cornwall Hospitals

WADD Clinical Trial: University College London (UCL) and Imperial College London

Epilepsy Deaths Register: Epilepsy Ireland

Helping people stay safe

4,918 people received our information brochures.

3,972 people 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. SUDEP Action is funding and supporting research at UCL and Imperial College to research a device that has already confirmed high sensitivity and low false alarm rates for people living with epilepsy and improve technology in this field.

The innovation has since attracted investment of 2 million euros from the European Research Council to the engineer at Imperial College enabling development of this device. SUDEP Action is the Patient and Public Involvement lead on this vitally important project which runs to 2020.

The ultimate aim is to produce a minute device which could be worn all the time by people at high risk of SUDEP. Maybe one day, it could even be implanted in children with epilepsy to keep them safe for life.

Increasing Public Awareness

Prevent21 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 global SUDEP Action Day every year.

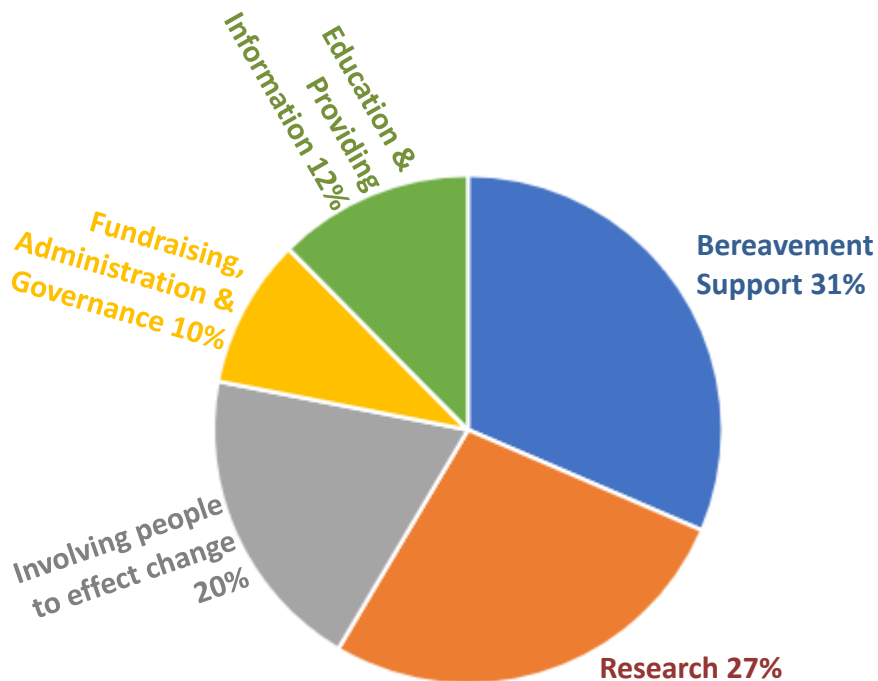
We saw an increase in page views of our website from over 147,000 to nearly 190,000 this reporting year.

We also work with umbrella organisations to strengthen our influence. We are active members of the Neurological Alliance and provide the Secretariat for the All Party Parliamentary Group on Epilepsy. 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 £479,588 was apportioned as follows:



Income and reserves

The charity's income was £483,995 (compared with £480,224 during 2018/2019, £443,143 during 2017/18, £431,122 during 2016/17 and £395,413 during 2015/16). £2,000 of income during 2019/2020 was restricted funding with the balance of all restricted funds held, including those funds from income received before this reporting year, totalling £21,993.

Thanks also to the grant giving trusts that have supported us: **Alison Hillman Charitable Trust; Adrian Swire Charitable Trust.**

Since our WADD appeal project the researcher at Imperial College London has received a grant of €2 million to develop a wearable device by 2020. The WADD restricted fund has been used this reporting year by the researcher at Imperial College to collaborate with UCL on the clinical trial on WADD. The research team at UCL and Imperial College London requested a no cost 9 month extension of the project to July 2020 because of the opportunity to increase the power of the clinical trial and facilitate further technical improvements involving a further 50 to 75 patients. The remaining WADD reserves should be fully or substantially paid out to University College London and Imperial College London by March 2021 under the conditions of the research grants agreed with these universities and in accordance with the WADD appeal.

Restricted funds totalling £6,858 to support projects working with researchers and UK clinicians will be fully paid out during 2020/21.

Our uncommitted funds or general funds stood at £310,065 at year end or just under 7 months of general fund expenditure. The Board of Trustees agreed the Board reserve policy of between 3 to 6 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.

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, but the Chair of the Board and Treasurer receive at least monthly reports and are engaged more regularly.

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. 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.

Securing and supporting the SUDEP Action team and the sustainability and growth of the charity became the most urgent objective for 2020/2021. The COVID-19 pandemic response arrived early for the SUDEP Action team as we moved swiftly some weeks before lockdown

to enable all but one of the staff team to work remotely and to make the office base COVID-19 secure. As the charity witnessed the collapse in face to face events and funding fell by half, we were also at the coal face of supporting bereaved families and clinical teams. This was as epilepsy risk escalated and bereaved families faced the most devastating of experiences without normal traditions to respond to sudden unexpected death and when public attention was focused on bereavement through COVID-19.

Strong relationships across everyone in the charity and with our supporters enabled the charity to quickly mobilise and innovate further through the crisis. Using the power of the diverse communities we serve, SUDEP Action was able to ensure we remained alongside the most vulnerable and innovate using digital means to offer meaningful connection in coffee clubs and in online remembrance; to transform a local epilepsy risk project into a local, national and international research project on epilepsy and risk during COVID-19; to increase visibility to epilepsy deaths and escalating risk with policy makers during a time when COVID-19 was likely to dominate; and most importantly to make progress in rolling out digital safety solutions to support clinical practice as much of this activity moved online.

During a year where we have seen a 50% reduction in our usual source of income, because of our strong relationships and the evidence to support our services and safety tools, the charity has been able to diversify our funding base. Whilst it remains extremely challenging times as need continues to rapidly escalate, SUDEP Action plan to thrive as well as survive.

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 2020/21 we will:

- ❖ **Maximise our potential for diversification of funding streams using our connections and our positioning after 25 years to support digital enablement and change**
- ❖ **Continue to support suddenly bereaved families and UK clinical teams**
- ❖ **Innovate to develop a programme embracing digital, written correspondence and phone to maximise connection across the most vulnerable**
- ❖ **Innovate to develop online small and large memorial and engagement events**
- ❖ **Co-produce research on the impact of the COVID-19 response on people with epilepsy, health workers and the bereaved on a national as well as international research study with University partners**

- ❖ **Lead a Lives Cut Short report to bring the evidence and 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**
- ❖ **Develop our co-production work in local sites, but also in learning disability and women with epilepsy as communities with tailored needs at high risk**
- ❖ **Review external collaborations to take account of a highly dynamic policy and third sector nationally and globally and realign to match our priorities**
- ❖ **Provide ongoing patient and public involvement for research projects including a NIHR clinical trial and development of a wearable device on people with epilepsy, to alert to an acute episode that could kill**

Signed for and on behalf of the Board of Trustees



J Hirst CBE Chair of Trustees

Summary of the Year – Message from the CEO

2019/2020 was a year of growth as our team grew from 11 to 13 (8.2FTE); a year when we moved to larger premises to facilitate further growth; and a year when we attracted increasing local, national and international recognition. In February 2020 an international medical journal published a series of papers evidencing the overwhelming case for change against a backdrop of policy decisions being made nationally without regard to epilepsy risk, including the cut in funding of the annual health check. SUDEP Action led an epilepsy coalition to improve safety on access to medicines and brought wider evidence to bear as part of our Prevent21 campaign. SUDEP Action has contributed to two national initiatives following our Prevent 21 Summit in 2018, and in February 2020 NHS England published the NHS RightCare initiative which included recognition of the SUDEP Action safety tools and the Epilepsy Deaths Register as good practice in learning from deaths and patient safety necessary to tackle epilepsy deaths.

By March 31st SUDEP Action had increased our impact in helping over 16,000 people, with person-centred support to 8,000, and we had invested in the future recruiting three new members of the team across research, project management and partnerships. The charity had strengthened its relationships with UK clinical, research and family networks and had nurtured relationships with corporate organisations through our family supporter network. Internationally we had succeeded in building the power of SUDEP Action Day and had rolled-out our SUDEP and Seizure Safety tools in Australia working with our partner Epilepsy

Action Australia and had expressions of interest from other national organisations across the world. We had also strengthened our Board with the recruitment of a recently retired GP with a special interest in epilepsy and women, who contributed to the national inquiry into maternal deaths in pregnant women with epilepsy as well as being a stakeholder on national policy work on medicines for women of child-bearing age.

I would like to thank all those who volunteer for SUDEP Action and all our community fundraisers and generous individuals who support us through legacies and donations. We have also enjoyed amazing support this year from our UK-wide clinical and cross-party political network.

It has been a tremendous privilege to work alongside dedicated colleagues across our Board and staff team.

Jane Hanna OBE
CEO, SUDEP Action

SUDEP Action & linked charity Epilepsy Bereaved

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

For the year ended 31 March 2020

I report on the accounts of the Trust for the year ended 31 March 2020, which are set out on the pages 19 to 24.

Respective responsibilities of the trustees and examiner

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

It is my responsibility to:

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

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

Independent examiner's statement

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

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



Anna Chapman FCA
Chapman Worth Limited
6 Newbury Street
Wantage
Oxfordshire
OX12 8BS
Dated.....

28/1/2021

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 2020

		SUDEP Action Unrestricted Funds 2020	SUDEP Action Designated Funds 2020	SUDEP Action Restricted Funds 2020	SUDEP Action Total Funds 2020	SUDEP Action Total Funds 2019
	Note	£	£	£	£	£
Income from						
Donations and legacies	2	456,205	-	2,000	458,205	456,403
Charitable activities	3	7,071	-	-	7,071	3,317
Other trading activities	4	17,407	-	-	17,407	19,376
Investments	5	1,312	-	-	1,312	1,128
Total incoming resources		481,995	-	2,000	483,995	480,224
Resources Expended						
Raising funds	6	70,411	-	-	70,411	51,516
Charitable activities	7-8	340,742	11,100	57,335	409,177	376,363
Total resources expended		411,153	11,100	57,335	479,588	427,879
Net income/(expenditure)		70,842	(11,100)	(55,335)	4,407	52,345
Transfers between funds	12	-	-	-	-	-
Net movement in funds		70,842	(11,100)	(55,335)	4,407	52,345
Total funds brought forward 1 April 2019 (2018)		162,823	87,500	77,328	327,651	275,306
Total funds carried forward 31 March 2020 (2019)		233,665	76,400	21,993	332,058	327,651

The notes on pages 19 to 24 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 2020 SUDEP Action Unrestricted Funds	31 March 2020 SUDEP Action Designated funds	31 March 2020 SUDEP Action Restricted Funds	31 March 2020 SUDEP Action TOTAL	31 March 2019 SUDEP Action TOTAL
		£	£	£	£	£
Current Assets						
Prepayments		10,409	-	-	10,409	3,044
Debtors		-	-	-	-	-
Accrued Gift Aid		2,895	-	-	2,895	3,523
Cash at bank and in hand		247,100	76,400	21,993	345,493	340,610
		260,404	76,400	21,993	358,797	347,177
Creditors: amounts falling due within one year	11	(26,739)	-	-	(26,739)	(19,526)
Net Assets		233,665	76,400	21,993	332,058	327,651
Funds						
Unrestricted Funds	12	233,665	-	-	233,665	162,823
Designated Funds	12	-	76,400	-	76,400	87,500
Restricted Funds	12-13	-	-	21,993	21,993	77,328
		233,665	76,400	21,993	332,058	327,651

The financial statements were approved by the Board of Trustees on 27th January 2021 and signed on its behalf by:



John Hirst
Chair of Trustees

The notes on pages 19 to 24 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 2020

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

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 2020**

1 Accounting policies, continued**f) Non-exchange transactions and foreign currency conversions.**

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

g) Allocation of support costs

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

h) Research grants

A grant of £12,500 was made to the Royal College of Paediatrics and Child Health for the "Suveillance of Deaths in children with epilepsy on the BPSU reporting scheme Nov 2016-Nov 2017.

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 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 2020**

	Unrestricted Funds £	Designated Funds £	Restricted Funds £	TOTAL 2020 £	TOTAL 2019 £
2 Donations and legacies					
Donations	70,972	-	2,000	72,972	70,361
Grants	30,000	-	-	30,000	30,250
Non-Exchange Grants	-	-	-	-	-
Gift Aid	2,920	-	-	2,920	3,941
Legacies	-	-	-	-	4,614
Fundraising donations	351,974	-	-	351,974	346,375
Collecting boxes	339	-	-	339	862
	456,205	-	2,000	458,205	456,403
3 Charitable activities					
Annual charity conference	5,597	-	-	5,597	3,037
Fees receivable	215	-	-	215	280
Contractual income *	1,259	-	-	1,259	-
	7,071	-	-	7,071	3,317
* Contractual income relates to the EpSMon project (see note 12a, Cornwall Fund)					
4 Other trading activities					
Fundraising sales	14,500	-	-	14,500	15,922
Sale of goods	2,907	-	-	2,907	3,454
	17,407	-	-	17,407	19,376
5 Investments					
Interest Receivable	1,312	-	-	1,312	1,128
	1,312	-	-	1,312	1,128

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 2020							
			Unrestricted	Designated	Restricted	TOTAL	TOTAL
			Funds	Funds	Funds	2020	2019
			£		£	£	£
6	Raising funds						
	Fundraising Expenses	30,303	-	-	30,303	35,695	
	Support costs	40,108	-	-	40,108	13,174	
		70,411	-	-	70,411	48,869	
7	Charitable activities						
	Direct charitable expenditure	300,612	11,100	57,335	369,047	346,258	
	Governance costs	1,380	-	-	1,380	1,559	
	Support costs	38,750	-	-	38,750	28,546	
		340,742	11,100	57,335	409,177	376,363	
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	5,142	-	-	5,142	3,998	
	Telecommunications	5,061	-	-	5,061	2,991	
	Printing & Publicity	14,407	-	510	14,917	8,665	
	Salaries & National Insurance	227,648	-	12,825	240,473	209,266	
	Pension Scheme Contributions	4,449	-	-	4,449	4,256	
	Consultancy & other staff costs	9,579	-	-	9,579	1,950	
	Travel, Accomodation & Subsistence	6,314	-	-	6,314	6,733	
	Research grants	-	-	44,000	44,000	40,620	
	Affiliations to Other Groups	1,268	-	-	1,268	1,061	
	Development of Web Site	4,170	-	-	4,170	9,541	
	Cost of Support Group Meetings	-	-	-	-	287	
	Bank Charges	65	-	-	65	108	
	Training	540	-	-	540	174	
	Office Costs, including Insurance	25,100	-	-	25,100	17,749	
	Conferences & Seminars	12,641	-	-	12,641	20,796	
	Sundry Expenses	1,119	-	-	1,119	660	
	Legal Costs	-	-	-	-	327	
	IT Costs	10,835	-	-	10,835	10,204	
	Equipment Purchases	11,024	-	-	11,024	9,971	
	Independent Examiner's Fee	890	-	-	890	835	
	Cost of Trustees' meetings	490	-	-	490	724	
	Office Move	-	-	-	-	25,447	
	Epsmon Maintenance***	-	11,100	-	11,100	-	
		340,742	11,100	57,335	409,177	376,363	

9	Staff Costs including Pension Scheme Contributions						
	Salaries & National Insurance	266,683		12,825	279,508	222,392	
	Pension Scheme Contributions	5,522		-	5,522	4,256	
		272,205		12,825	285,030	226,648	
There was an average of 8.3 employees (FTE) during the year (2019: 8.9)							
No employee earned over £60,000 in the year (2019: 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)

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**Notes to the Financial Statements
for the Year Ended 31 March 2020****10 Trustee expenses**

The Trustees received no remuneration during the year (2019: nil).

1 Trustee was reimbursed a total of £210 (2019: 1 trustees £307) for travel expenses.

11 CREDITORS: amounts falling due within one year

	Unrestricted Funds £	Restricted Funds £	TOTAL 2020 £	TOTAL 2019 £
Trade Creditors	10,683	-	10,683	6,380
Sundry Creditors	-	-	-	-
Credit Card	-	-	-	-
Receipts in Advance	-	-	-	-
HMRC-PAYE/NI	7,065	-	7,065	4,692
Pension	827	-	827	854
Accrued Expenditure	8,164	-	8,164	7,600
	26,739	-	26,739	15,967

12 Statement of funds

	Note	Brought Forward £ Surplus/ (Deficit)	Incoming Resources £	Resources Expended £	Transfers In/(Out) £	Carried Forward £ Surplus/ (Deficit)
Unrestricted funds						
General fund		162,823	481,995	(411,153)	-	233,665
Designated funds						
Prevent21 projects		87,500	-	(11,100)	-	76,400
Restricted funds						
WADD		50,632	2,000	(44,510)	-	8,122
Research		6,858	-	-	-	6,858
Epilepsy Death Register		16,354	-	(12,341)	-	4,013
Case Worker Project		484	-	(484)	-	-
Oxon Pilot Project		3,000	-	-	-	3,000
Total		77,328	2,000	(57,335)	-	21,993

**Notes to the Financial Statements
for the Year Ended 31 March 2020**

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.

14 Analysis of net assets between charities

	SUDEP Action	Epilepsy Bereaved	Total
Debtors	13,304	-	13,304
Cash at bank and in hand	345,493	-	345,493
Creditors	(26,739)	-	(26,739)
Total net assets	<u>332,058</u>	<u>-</u>	<u>332,058</u>

Epilepsy Bereaved had no activity during the year ended 31 March 20 or the comparative year.