

Epilepsy Bereaved

(working names Sudep Action
& SUDEP Action Scotland)

Registered Charity No.
1050459 (England & Wales)
SC045208 (Scotland)
www.sudep.org

Annual report and financial statements

For the year ended 31 March 2016

Chapman Worth Limited
6 Newbury Street
Wantage
Oxfordshire
OX12 8BS

Epilepsy Bereaved

CHARITY INFORMATION

Director	Jane Hanna OBE
Trustees	Stephen Brown (Chair) Jennifer Preston (Vice Chair) Guy Neely (Treasurer) Susan Allen John Hirst Simon Lees John Lipetz Mark Phillips Alex Stirling Roger Scrivens Graham Faulkner Mike Kerr (appointed Aug 2015) Malisa Pierri (appointed Aug 2015)
Charity No.	1050459 (England & Wales) SC045208 (Scotland)
Website	www.sudep.org
Address for correspondence	Epilepsy Bereaved 12a Mill Street Wantage Oxfordshire OX12 9AQ
Accountants	Chapman Worth Limited 6 Newbury Street Wantage Oxfordshire OX12 8BS
Bankers	HSBC Plc Market Place Wantage Oxfordshire OX12 8AP

Epilepsy Bereaved

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SUDEP Action (the working name for Epilepsy Bereaved)

TRUSTEES' REPORT

For the year ended 31 March 2016

The trustees present their report and accounts for the year ended 31 March 2016.

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).

Structure, governance and management

The Registered Charity name is Epilepsy Bereaved. The Charity Registration number 1050459 was constituted under a Declaration of Trust dated 14 October 1995. In Scotland we are registered as SUDEP Action Scotland Charity number SCO45208.

SUDEP Action was adopted by the trustees as the new working name of Epilepsy Bereaved on 11 January 2013.

Chair of Board and Officers

Professor Stephen Brown
Jennifer Preston (Vice Chair)
Guy Neely (Treasurer)

Board members

The other trustees who served during the year were:

Susan Allen
Graham Faulkner
John Hirst CBE
Professor Mike Kerr (appointed July 2015)
Simon Lees
John Lipetz
Mark Phillips
Malissa Pierri (appointed July 2015)
Roger Scrivens
Alex Stirling

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 after interview with two trustees and the CEO.

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 has a Chief Executive Officer, Jane Hanna OBE, and ten employees including some who are part-time and equating to eight full-time equivalent staff members. The office is situated in Wantage, Oxfordshire. Two employees work from Wales and one in Scotland.

The projects of the charity are, where appropriate, supported by scientific advisory groups including a UK development group of doctors, nurses and people with epilepsy who support the SUDEP and Seizure Safety Checklist.

During 2016 the trustees of Epilepsy Bereaved registered a new charity which is a charitable incorporated organisation (CIO) in the name of SUDEP Action (1164250) and plan, with Charity Commission approval, to transfer the assets and ongoing liabilities of the existing unincorporated charity to the new CIO on April 1st 2017. Administering the charity through a CIO will provide benefits in relation to employing staff, leasing property and entering into contacts.

The trustees of Epilepsy Bereaved and SUDEP Action CIO are the same. Charity Commission approval has been sought to link the two charities so that Epilepsy Bereaved will be able to receive legacy income that otherwise might be lost.

Our Mission

SUDEP Action's mission is to prevent unnecessary deaths from epilepsy.

SUDEP Action is dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths including Sudden Unexpected Death in Epilepsy. We are the only UK charity specialised in supporting and involving people bereaved by epilepsy.

Our Values

Respect, determination and collaboration.

Why ?

To get recognition of SUDEP (Sudden Unexpected Death in Epilepsy) and other epilepsy-related deaths and to work towards prevention strategies. 22,366 people are reported as having died from epilepsy in the UK since the charity founded in 1995. This may underestimate the true figure.

They leave behind them loved ones; family, carers, friends: who, whilst grieving, are also looking for answers, are often angry and confused, may blame themselves but also may often be energised to become active to prevent others suffering as they did.

"My quest, when I feel more able, is to raise awareness of SUDEP"

Source: Epilepsy Deaths Register 2016

Since the 1920s with the advent of seizure preventing drugs it was widely assumed that epilepsy was not life-threatening. This led to a downplaying of the condition by everyone with fatal consequences borne by people whose lives were cut short and by their families.

1 in 20 people will have a seizure in their life-time. 600,000 live with epilepsy, usually diagnosed after 2 seizures.

There are 3 deaths a day. Most are in young people who are otherwise in good health.

Epilepsy ranks in the top ten causes of deaths from treatable conditions.

In 2013 NHS funding was cut for the annual review by GPs of people with epilepsy.

At SUDEP Action we focus our efforts on the priorities that bereaved families tell us are important. Epilepsy is not usually fatal, but it can be. The charity supports bereaved families who wish there had been a chance to try to save their loved one and who want to make sure others have this chance.

A child is found dead in their bed. Last night they were fine. The coroner is asking the mum and dad questions. The pathologist has mentioned SUDEP. The family asks what that is. Why didn't we know? Why did no one try to help? Is there anything we could have done?

Frequent scenario and questions to the charity support line.

Sadly, the many people with epilepsy are not called for a health check and are not advised of their risk. Research we commissioned found many people who died had worsening risk factors before they died, but had not been seen by an epilepsy service or GP in the year 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. Most patients say they want to be informed about risk, but either this is not discussed or positive ways to reduce their risk are not discussed.

Many deaths, up to 42%, might be avoided if there was a common awareness among doctors and people with epilepsy and the public of how risks could be reduced and if action was taken.

The problem has become more urgent since NHS funding was cut in the community. SUDEP Action has continued to respond creatively to the needs we have identified and to look for new ways to support families in the community.

By working with research and clinical champions we specialise in cutting edge innovations that can help.

Our Services

14,000 people used our services. Over 2 million people were reached through SUDEP Action awareness campaigns.

We provide our services through the five key strands of our charitable activities which are:

- ❖ **Offering support** when someone has died
- ❖ **Involving people** to help effect change
- ❖ **Providing information** on SUDEP and risk in epilepsy
- ❖ **Sponsoring research** and education to prevent future deaths
- ❖ **Capturing data** for research through the Epilepsy Deaths Register

What we do

Offering Support

SUDEP Action leads the world in the delivery of a service to support the grief journey of families after a death. For over 20 years we have listened to and worked with the bereaved to develop our service. We pride ourselves in our work and our understanding of the vast range of emotions, needs and complexities that this type of bereavement brings. This includes a strong motivation by many to turn private pain into public purpose. We provide:

- ❖ On-going emotional support
- ❖ Understanding of the investigation process and/or post-mortem
- ❖ Opportunities to be with others who have been bereaved by epilepsy
- ❖ Involvement in the cause
- ❖ Providing opportunities to meet and/or ask questions of epilepsy and SUDEP experts
- ❖ Counselling

Our specialist service dealt with 1032 calls during 2016 from people at different stages in their journey after a death. 83 newly bereaved, many with complex needs were supported. 267 were regularly involved in charity activities. Bereaved families report high levels of satisfaction (87%) in comparison with all other services they use after a death.

"Often, I would contact her, during the night via email, or if any nice things happened; the support and understanding was always there for me. The same person, so she knew all about me! I didn't need to explain, it just continued".

Source: Epilepsy Deaths Register 2016

No two losses are the same and no two people will grieve in the same way. We aim to provide services that are there when they are needed and for as long as they are needed. We regularly review our service and we remain mindful of changes in best practice and guidance for working with the bereaved, particularly those affected by the trauma of sudden death.

Our support team is uniquely staffed by qualified counsellors who are also trained in supporting people through the difficult process of death investigations. Recognising that support at the point of immediate need can be crucial for people who have experienced a sudden traumatic death we are able to support the bereaved to understand what may have happened, why it happened and to know they are not alone.

During the year we supported volunteers to run coffee clubs bringing 91 people together for peer support in 14 local areas. We successfully launched an online Epilepsy Memorial Day which will run every year alongside our memorial service in London that is organised every three years.

"It was very good to hear others' stories and to be able, safely, to describe our own reactions to trauma and tragedy. This led naturally on to how people were coping (or not) and interesting ideas on raising awareness & fundraising. Our experiences and reactions were all very different"

Source: Coffee Club evaluation 2016

We have raised funds for a new role in the charity to reach out to the bereaved in the local and online community.

Involving people

- ❖ Sharing their stories to raise awareness and achieve change
- ❖ Taking part in research projects
- ❖ Feedback on our services
- ❖ Fundraising
- ❖ Giving talks
- ❖ Peer support

Our amazing supporters and committed staff are tireless in their quest to save lives. For the bereaved, knowing that their loved ones didn't die in vain can give some comfort in what can only be described as a hugely traumatic event.

Over 500 families have now participated in our online research platform. SUDEP Action now has the largest data set of experiences of families anywhere in the world. Our service supported 93 people during 2016 to report their experiences.

The feedback from families gives us vital information to continually inform our service planning. We also involve families through national conference break-out sessions; local meetings; questionnaires and telephone debriefings. Our research and close interaction with families helps us speak for them.

The supporters we worked with regularly last year provided much needed funds for our work and allowed us to reach out to the bereaved, providing the services that they have told us are vital to them. For many of them the need to be involved is overwhelming and we provide services and support for them to do this.

During the year we increased the number of clinicians engaging with us to 1,347.

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

“Epilepsy is about managing risk and the forthcoming launch of the new safety app, EpSMon, is another step forward. It brings life-saving knowledge to the fingertips of people with epilepsy. The benefit in helping your healthcare professional keep up to speed with your condition is essential for the management of a person’s epilepsy.”

A supporter who lives with epilepsy & whose nephew died from SUDEP

Providing Information

- ❖ Evidence based tools for professionals and people with epilepsy
- ❖ Leaflets and downloads aimed at helping people reduce their risk
- ❖ Leaflets and information aimed at helping people understand more about SUDEP
- ❖ Research and lay information for professionals, people with epilepsy and the bereaved

We reached over 10,000 people with epilepsy including 8,767 who received our leaflets and downloads and just under 2,000 people with epilepsy who downloaded the EpSMon epilepsy self-monitor App.

1,347 professionals were engaged during the year through using our SUDEP and Seizure Safety Checklist in their clinics or training, by using our brochures and by receiving our professional e-news.

Visitors to our main website increased by over 25% in the year to 74,410. Our two global online platforms, SUDEP Awareness Day and SUDEP Global Conversation attracted 18,000 visitors. Our social media posts alone reached 2 million on SUDEP Awareness Day.

Our Safety tools have been recognised by numerous bodies – academic, patient representative and health – as examples of best practice that are already a front runner in an international attempt to reduce rates of SUDEP.

The SUDEP and Seizure Safety Checklist:

The SUDEP and Seizure Safety Checklist launched during 2015 is a free, practical, evidenced-based tool for professionals which is quickly completed in clinic. It encourages positive discussion of risk management with patients, offering a structured approach and supports the implementation of national guidelines and recommendations from high profile medical-legal rulings.

The Checklist is supported by a UK-wide development team of GPs, experts and people living with epilepsy. It will be regularly reviewed to ensure it considers latest research and

thinking on risk in epilepsy. This 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. The development and roll-out of the pilot is being funded through community fundraising by our supporters around the UK.

SUDEP Action partnered with Cornwall NHS Foundation Trust in 2010. Working locally bringing families, the local community and professional champions together the outcome has been safety tools welcomed by clinicians and people with epilepsy. Using the Checklist raised discussions from 10% to 80% of all people within epilepsy services over 2 years. Deaths have been observed as falling with no deaths reported in the learning disability community.

EpSMon:

In 2013 Plymouth University (NeuroCoRe) partnered with SUDEP Action, Cornwall NHS Foundation Trust and Cornwall Royal Hospital to develop a digital version of the SUDEP and Seizure Safety Checklist (EpSMon). The epilepsy self-monitor (EpSMon) is a smartphone App which helps patients to monitor risk factors from seizures and keep track of their general well-being.

EpSMon prompts users every three months to answer simple, quick questions on their condition and provides them with a summary report explaining how certain lifestyle events could impact on their epilepsy. This encourages patients, carers, and families to consider ways of improving outcomes, thereby enhancing safety and reducing the potential need for emergency care. The website www.epsmmon.com has been created as a platform in its own right.

"I'm sure Benn would have used [EpSMon]. He had no warning of his seizures & his doctors told me he took a responsible approach, looking at every option. If this app had been available, maybe the ending of this story may have been very different"

A supporter who raises awareness in memory of her son

Both tools are highlighted in the Epilepsy Commissioning Toolkit, a single access point of resources to support effective commissioning for children and adults with epilepsy, endorsed by the Royal College of General Practitioners.

"The Epilepsy Self Monitor by SUDEP Action is something that might have alerted Emily and us to the risks that she was exposed to. It is something that I, as her mother, would have encouraged her to use. It might have saved her life. So many epilepsy patients and their families are never told of Sudden Unexpected Death in Epilepsy and at the very least the app would have informed us of that risk. I am delighted that in the future people will have the chance to reduce their own risk with this brilliant app."

A supporter who raises awareness in memory of her daughter

Research

- ❖ Funding and collaborating in projects
- ❖ Disseminating new information to professionals
- ❖ Ensuring key messages are captured

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, but seizure devices are not currently recommended by clinical guidelines because evidence remains extremely thin on their effectiveness.

Teams around the world are looking at how technology needs to be researched and developed in this field.

An electronics engineer at Imperial College, London had developed a small wearable apnoea detection device that raises an alarm when someone stops breathing. The device has been tested by a research team led by the clinical director of the National Hospital for Neurology & Neurosurgery at UCL on 10 sleep apnoea patients and 20 controls, which confirmed high sensitivity and low false alarm rates.

Our supporters raised a remarkable £123,768, enough funds for a clinical research trial on people with epilepsy. Patients will be recruited next year via the National Hospital for Neurology and Neurosurgery EEG unit where they are already undergoing tests and observation for their epilepsy.

The trial will contribute to the evidence desperately needed in this field. 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.

"I really believe that the WADD has the potential to save lives. I informed all my sponsors about the project and they were even more pleased to know their money would go directly towards it"

A supporter who raises funds in memory of his father

Capturing Data for Research

- ❖ A single point for reporting all epilepsy deaths
- ❖ Providing quantitative and qualitative information

Families have suffered from the systematic denial that seizures could kill and in the past were isolated. It was not unusual for people to be told that people do not die from epilepsy or to be told it was an isolated tragic situation.

Our unique online research platform offers people a place to share their experiences and by doing this to strengthen the voice of the families.

Following the success of our register launched in 2013 we also partner with Epilepsy Ireland providing an Epilepsy Deaths Register for Ireland. The register will provide vital information to researchers and will help further understand epilepsy mortality, with the ability to compare regional and country differences.

Collaboration

We led 51 organisations across 83 countries on SUDEP Awareness Day in a united global effort to raise awareness using common statistics and common positive messages about risk reduction.

We have formal collaboration agreements with NHS Partners and Universities and patient organisations:

SUDEP and Seizure Safety Checklist: Cornwall NHS Foundation Trust

EpSMon: Plymouth University, Cornwall NHS Foundation Trust, Cornwall Royal Hospital

EpSMon US: EpSMon partners and Epilepsy Foundation of America

WADD: University College London and Imperial College London

Epilepsy Deaths Register: Epilepsy Ireland, University College Cork, Sheffield University

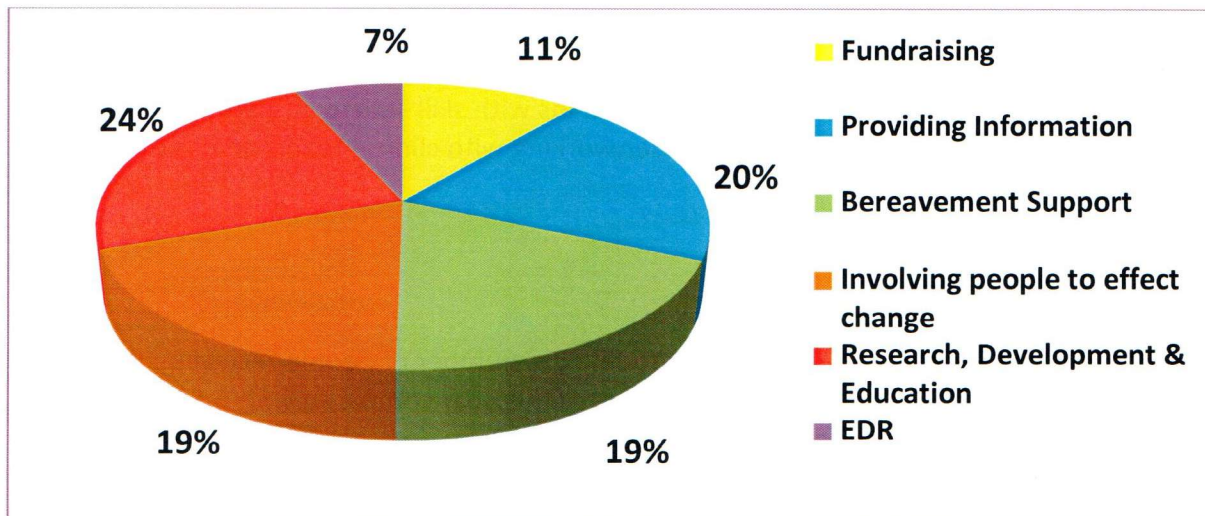
Global Conversation: SUDEP Aware, Epilepsy Australia

We work hard to participate in other initiatives where possible and collaborate with the Epilepsy Society Brain and Tissue Bank at UCL; the Partners Against Mortality in Epilepsy (US) and we are the UK advocacy partner for the Centre for SUDEP Research (US).

In the UK we are members of the Neurological Alliance and active members of the All Party Parliamentary Group on Epilepsy. We work with epilepsy organisations in Scotland and are active members of the Cross Party Group for Epilepsy and the Epilepsy Consortium. We are members of the IBE (International Bureau for Epilepsy).

Financial Matters:

Our expenditure during the year of £382,141 was apportioned as follows, in line with what is important to our supporters:



Income and reserves

The charity's income was £431,122 (compared with £367,058 in the previous year). £91,162 were restricted funds.

The balance of restricted reserves totalled £134,354. Since the WADD appeal project (Clinical trial on a wearable apnoea device to detect potentially fatal seizures) inception in June 2014, £123,768 had been raised by supporters. It is expected that the WADD reserves will be fully or substantially paid out to University College, London and Imperial College, London during the year 2016/2017 under conditions of research grants agreed with these universities.

Our general funds stood at £130,766 at year end or just over 4 months of general fund expenditure including fund transfers. The Board of Trustees agreed to this level of reserve.

Risk management

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.

During 2015-2016 the Board recruited two clinicians with skill sets to strengthen the Board in line with the charity strategy of even closer working with clinical teams across the UK.

Our Position in 2016

In the last ten years we have been able to double the number of people receiving our help. 14,000 people directly benefited from our services this year compared with 6,800 in 2006. Families tell us these services are a life-line for them.

In 2016 working with our NHS and University partners in Cornwall we shared Neurology Team of the Year 2016; a UK Patient Safety Award and a global innovation award for a solution to reduce seizures with view to preventing deaths. Our innovative safety tools are widely recognised in the medical literature as helpful in tackling identified barriers to doctors and patients being able to talk about ways to reduce individual risk. The validation of the safety tools represents a seismic shift in support for our strategy which is likely to be followed by others around the world.

Awards

- ❖ BMJ Neurology Team of the Year 2016 - BMJ (Awarded by the Association of British Neurologists)
- ❖ Patient Safety Award for Education and Training 2016 (Nursing Times and the Health Service Journal)
- ❖ Epilepsy Foundation of America global innovation award
- ❖ International League Against Epilepsy (British Branch) National Conference 1st Prize
- ❖ Also finalist for 5 Health Service Journal Awards and an EHI award

"A comprehensive and innovative approach to reduce sudden death in patients with epilepsy, and easily transferable outside the UK."

BMJ Judges Comments for UK Neurology Team of the Year 2016. Winner.

The Future

Our direction for the next 5 years is clear. Too many children are dying unnecessarily. Families and communities are left devastated by loss.

The charity has the best solutions right now to meet needs that families have so clearly identified. We have also invested in future solutions with our research grants. Our families know action is too late for them. Knowing that SUDEP Action is working to save others offers a life-line of hope.

At a time when simple health checks on people with epilepsy are no longer funded and general counselling services have long waiting lists, it is more vital than ever that we reach more people. When NHS services are under pressure it is important that we prioritise our work helping families and supporting professionals. We plan to respond creatively using technology and by developing outreach to families and professionals.

We will seek sponsorship to research and develop the SUDEP and Seizure Safety Checklist and EpSMon to make them as accessible as possible to doctors and patients.

We also need to strengthen recognition in the community of SUDEP Action as the best first point of contact for bereaved families after a death so that families can find us in a timely way. It is vital that the lessons from deaths are learnt and that families are treated fairly after a death.

We receive no government or statutory funding. We are grateful to all our supporters. Particular thanks have to go to our bereaved families and the communities that support them who raise most of the funds that enable us to carry out our work.

Our services are available to all people bereaved through epilepsy and to all people with epilepsy and their parents or carers. With development funding we can transform the charity so we can reach as many people as possible to help keep them safe.

During 2016/17 we will:

- ❖ Fund and provide patient and public involvement for a clinical trial of a wearable device on people with epilepsy to alert to an acute episode that could kill
- ❖ Involve clinicians and people with epilepsy using our safety tools in research and development to overcome any barriers to their use
- ❖ Report and promote the views of over 500 bereaved families
- ❖ Promote our service and care pathway to increase our reach to traumatised families

- ❖ Develop our services to target hard to reach groups
- ❖ Work with researchers and organisations that endorse and help further our aims
- ❖ Develop information resources aimed at keeping children with epilepsy safe
- ❖ Collaborate with other epilepsy organisations to increase the reach of SUDEP Awareness Day
- ❖ Continue to bring the latest research to those that need it
- ❖ Review all significant activities and policies and work to smooth transition and transfer of assets to the new charity SUDEP Action CIO

Signed for and on behalf of the Board of Trustees

A handwritten signature in black ink, consisting of a series of loops and a trailing line.

S Brown
Chair of Trustees
17 October 2016

Epilepsy Bereaved

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF EPILEPSY BEREAVED

For the year ended 31 March 2016

I report on the accounts of the Trust for the year ended 31 March 2015, which are set out on the pages

Respective responsibilities of 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:

- 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);
- 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
- to state whether particular matters have come to my attention.

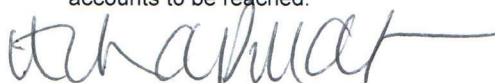
Basis of independent examiner's statement

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:

- 1) which gives me reasonable cause to believe that in any material respect, the trustees have not met the requirements to ensure that:
 - 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
 - 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
- 2) 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 for
Chapman Worth Limited
Chartered Accountants

10/11/16

6 Newbury Street
Wantage
Oxfordshire
OX12 8BS

Epilepsy Bereaved (SUDEP Action & SUDEP Action Scotland)

Registered Charity N^o: 1050459 (England & Wales), SC045208 (Scotland)

Statement of Financial Activities For the year ended 31 March 2016

		Unrestricted Funds 2016	Restricted Funds 2016	Total Funds 2016	Total Funds 2015
	Note	£	£	£	£
Income from					
Donations and legacies	2	308,487	64,023	372,510	327,531
Charitable activities	3	7,738	21,189	28,927	17,304
Other trading activities	4	22,986	5,950	28,936	21,685
Investments	5	749	-	749	538
Total incoming resources		339,960	91,162	431,122	367,058
Resources Expended					
Raising funds	6	41,067	1,166	42,233	31,820
Charitable activities	7-8	283,125	56,783	339,908	260,089
Total resources expended		324,192	57,949	382,141	291,909
Net income/(expenditure)		15,768	33,213	48,981	75,149
Transfers between funds	12	(8,641)	8,641	-	-
Net movement in funds		7,127	41,854	48,981	75,149
Total funds brought forward 1 April 2015 (2014)		123,639	92,500	216,139	140,990
Total funds carried forward 31 March 2016 (2015)		130,766	134,354	265,120	216,139

The notes on pages 17 to 22 form part of these financial statements.

Epilepsy Bereaved (SUDEP Action & SUDEP Action Scotland)

Registered Charity N°: 1050459 (England & Wales), SC045208 (Scotland)

Balance Sheet as at

		31 March 2016	31 March 2016	31 March 2016	31 March 2015
	Note	Unrestricted Funds	Restricted Funds	TOTAL	TOTAL
		£	£	£	£
Fixed Assets	1g	-	-	-	-
Current Assets					
Prepayments		4,778	-	4,778	5,275
Debtors		18,447	44	18,491	7,427
Accrued Gift Aid		4,485	90	4,575	8,908
Cash at bank and in hand		134,873	134,220	269,093	216,688
		162,583	134,354	296,937	238,298
Creditors: amounts falling due within one year	11	(31,817)	-	(31,817)	(22,159)
Net Assets		130,766	134,354	265,120	216,139
Funds					
Unrestricted Funds	12	130,766		130,766	123,639
Restricted Funds	12-13		134,354	134,354	92,500
		130,766	134,354	265,120	216,139

The financial statements were approved by the Board of Trustees on 15/10/2016 and signed on its behalf by:



Stephen Brown
Chair of Trustees

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

**Notes to the Financial Statements
for the Year Ended 31 March 2016**

1 Accounting policies

a) Basis of preparation

The financial statements have been prepared under the historical cost convention in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard for Smaller Entities (effective January 2015) and the Charities Act 2011 and applicable accounting standards.

b) Fund accounting

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.

c) 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.

d) 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

e) 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 bases on which support costs have been allocated are set out in note 7.

**Notes to the Financial Statements
for the Year Ended 31 March 2016**

1 Accounting policies, continued

f) 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 2016: nil (2015: 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.

g) 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.

h) 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.

i) 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.

j) 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.

k) Pensions

The charity operates a defined contribution pension scheme which includes both employer and employee contributions. Contributions are charged in the accounts as they become payable in accordance with the rules of the scheme.

**Notes to the Financial Statements
for the Year Ended 31 March 2016**

	Unrestricted Funds £	Restricted Funds £	TOTAL 2016 £	TOTAL 2015 £
2 Donations and legacies				
Donations	50,028	1,382	51,410	71,815
Grants	30,788	4,750	35,538	43,816
Gift Aid	35,108	3,964	39,072	33,357
Legacies	11,109	-	11,109	7,000
Fundraising donations	179,241	53,549	232,790	170,396
Collecting boxes	2,213	378	2,591	1,147
	<u>308,487</u>	<u>64,023</u>	<u>372,510</u>	<u>327,531</u>
3 Charitable activities				
Annual charity conference	7,077	-	7,077	2,850
Fees receivable	661	-	661	14,454
Contractual income *	-	21,189	21,189	-
	<u>7,738</u>	<u>21,189</u>	<u>28,927</u>	<u>17,304</u>
* Contractual income relates to the EpSMon project (see note 12a, Cornwall Fund)				
4 Other trading activities				
Fundraising sales	19,916	5,950	25,866	18,933
Sale of goods	3,070	-	3,070	2,752
	<u>22,986</u>	<u>5,950</u>	<u>28,936</u>	<u>21,685</u>
5 Investments				
Interest Receivable	749	-	749	538
	<u>749</u>	<u>-</u>	<u>749</u>	<u>538</u>

Notes to the Financial Statements
for the Year Ended 31 March 2016

	Unrestricted Funds £	Restricted Funds £	TOTAL 2016 £	TOTAL 2015 £
6 Raising funds				
Fundraising Expenses	24,590	1,166	25,756	21,820
Support costs	16,477	-	16,477	10,000
	41,067	1,166	42,233	31,820
7 Charitable activities				
Direct charitable expenditure	263,609	56,783	320,392	244,640
Governance costs	3,508	-	3,508	3,200
Support costs	16,008	-	16,008	12,249
	283,125	56,783	339,908	260,089

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				
Postage and Stationery	5,055	101	5,156	4,825
Telecommunications	3,140	81	3,221	3,178
Printing & Publicity	21,268	6,729	27,997	9,381
Salaries & National Insurance	192,826	29,240	222,066	167,956
Pension Scheme Contributions	1,457	-	1,457	1,169
Consultancy & other staff costs	175	-	175	359
Travel, Accommodation & Subsistence	8,101	2,257	10,358	10,131
Research grants	4,000	16,000	20,000	11,348
Affiliations to Other Groups	841	75	916	347
Development of Web Site	3,143	80	3,223	10,436
Cost of Support Group Meetings	17,997	-	17,997	17,420
Bank Charges	9	-	9	40
Training	177	-	177	644
Office Costs, including Insurance	17,705	334	18,039	18,621
Conferences & Seminars	3,476	1,886	5,362	845
Sundry Expenses	247	-	247	189
Independent Examiner's Fee	780	-	780	780
Cost of Trustees' meetings	1,828	-	1,828	2,420
Reconstitution Costs	900	-	900	-
	283,125	56,783	339,908	260,089

9 Staff Costs including Pension Scheme Contributions

Salaries & National Insurance	209,303	29,240	238,543	177,956
Pension Scheme Contributions	1,457	-	1,457	1,169
	210,760	29,240	240,000	179,125

There was an average of 8.0 employees (FTE) during the year (2015: 6.3)

No employee earned over £60,000 in the year (2015: nil).

The charity operates a defined contribution pension scheme. The assets of the scheme are held separately from those of the charity in an independently administered fund. Costs shown are employer contributions.

**Notes to the Financial Statements
for the Year Ended 31 March 2016**

10 Trustee expenses

The trustees received no remuneration during the year (2015: nil).

4 trustees were reimbursed a total of £774 (2015: 4 trustees £1,244) for expenses.

11 CREDITORS: amounts falling due within one year

	Unrestricted Funds £	Restricted Funds £	TOTAL 2016 £	TOTAL 2015 £
Trade Creditors	20,196	-	20,196	11,634
Sundry Creditors	3,197	-	3,197	3,197
Receipts in Advance	525	-	525	805
HMRC-PAYE/NI	5,887	-	5,887	5,064
Pension	613	-	613	314
Accrued Expenditure	1,399	-	1,399	1,145
	<u>31,817</u>	<u>-</u>	<u>31,817</u>	<u>22,159</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	12a	114,926	338,458	324,117	(8,641)	120,626
Designated funds						
WADD		8,713	1,502	75	-	10,140
Total		<u>123,639</u>	<u>339,960</u>	<u>324,192</u>	<u>(8,641)</u>	<u>130,766</u>
Restricted funds						
WADD		62,935	51,777	1,084	-	113,628
Cornwall	12a	20,495	22,075	53,388	10,818	-
Devon		2,277	-	-	(2,277)	-
LDA		4,383	2,000	2,793	-	3,590
Counselling		460	30	590	100	-
Research		1,950	15,280	94	-	17,136
Total		<u>92,500</u>	<u>91,162</u>	<u>57,949</u>	<u>8,641</u>	<u>134,354</u>

12a Special Projects**Cornwall Fund:**

CELP	3,694	886	10,886	6,306	-
EpSMon	16,801	21,189	42,502	4,512	-
	<u>20,495</u>	<u>22,075</u>	<u>53,388</u>	<u>10,818</u>	<u>-</u>

General Fund:

Included in the general fund is the Scotland Development project.

Scotland Development	(6,442)	8,020	11,373	-	(9,795)
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**Notes to the Financial Statements
for the Year Ended 31 March 2016**

13 Details of restricted funds and special projects

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. The Trustees have agreed to make available up to £50,000 from general funds for the project should the target of £165,000 not be reached, so that a viable trial may be conducted.

Cornwall Originally a community study of SUDEP deaths to identify main risk factors, funding is currently focussed on the development of an Epilepsy Self-Monitoring application in partnership with Plymouth University, Cornwall Foundation NHS Trust & the Royal Cornwall Hospital, and the maintenance and development of the underlying SUDEP and Seizure Safety Checklist (EpSMon and CELP projects resp. - see note 11a).

Devon Expansion of the Cornwall Life Project.

Research General research into the causes & prevention of epilepsy deaths.

LDA Learning Disabled Adults - to provide appropriate epilepsy risk information for individuals, carers and professionals.

Counselling To provide a professional bereavement counselling service.
Derestricted at year end, future costs to be met from general funds.

General Fund Scotland Development Project:

To extend the reach of the charity into Scotland. The costs of setting up and running an office, and providing services, are met from general funds, assisted by grants from Scottish trusts and other donations (see note 11a).