

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 2015

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 (except from May 14 to Sep 14 whilst employed by the charity) Roger Scrivens Graham Faulkner
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 2015

The trustees present their report and accounts for the year ended 31 March 2015.

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", issued in March 2005.

Structure, governance and management

SUDEP Action was adopted by the trustees as the new working name of Epilepsy Bereaved on 11 January 2013. The Charity Registration number 1050459 was constituted under a Declaration of Trust dated 14 October 1995.

Board members

The trustees who served during the year were:

Professor 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

Scientific Advisory Committee

Dr Richard Appleton
Professor Stephen Brown
Professor Helen Cross
Professor David Fish
Professor Mike Kerr
Dr Lina Nashef
Professor Mark Richardson
Dr Greg Rogers
Professor Phil Smith
Professor Ley Sander
Dr Henry Smithson
Dr Marjorie Turner

SUDEP Action has a formal collaboration with Kings Health Partners, known as the SUDEP Research Initiative. The Steering Group is as follows:

Professor Stephen Brown
Dr Shane Delamont
Dr Robert Elwes
Ms Jane Hanna OBE
Mr John Lipetz
Dr Lina Nashef
Professor Mark Richardson
Professor Leone Ridsdale

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 Director. New appointments are reported at the Annual Meeting.

SUDEP Action has a policy that 50% of the trustees have direct experience of Sudden Unexpected Death in Epilepsy (SUDEP) and use their experience and knowledge to benefit the charity. The charity has around ten employees, some of whom work part-time, which equates to approximately seven full-time equivalents. The office is situated in Wantage, Oxfordshire.

There are 3 epilepsy-related deaths a day in the UK and many young and healthy people have lost their lives.

Epilepsy, like heart disease and stroke, ranks in the top ten causes of premature deaths and these deaths are potentially avoidable. Sudden Unexpected Death in Epilepsy (SUDEP) is the cause of a high proportion of these deaths. Lack of public awareness of epilepsy mortality has meant research and treatment has lagged behind. SUDEP Action recognises that while initiatives are underway in research to reduce these deaths, awareness and support for families affected is needed now. SUDEP Action currently provides information and support at the point of immediate need, but funding is urgently required in this area.

Our Mission

At SUDEP Action we focus our efforts on the priorities that bereaved families tell us are important:

- Supporting the bereaved
- Influencing policy makers
- Driving the research agenda

SUDEP Action's mission is to prevent unnecessary deaths from epilepsy. We do this by campaigning for improvement in services, highlighting the need for better understanding of the risks associated with the condition, by raising awareness and providing information and tools that help keep people with epilepsy safe.

As a charity we support the bereaved and work to raise awareness of risks associated with epilepsy. Through this awareness we aim to reduce deaths associated with the condition. If people are to make the right lifestyle choices then they need to be made aware of the risks associated with their condition, including the risk of SUDEP. This information needs to be given appropriately and sensitively at, or soon after, diagnosis.

Without this information we believe that people with epilepsy, their families, or carers are unable to make informed lifestyle choices. Such uninformed choices can lead to increased risks, including the risk of dying.

What we do

We are enormously grateful to our supporters who raise the funds that enable us to carry out our work, which includes funding and conducting research into SUDEP and other epilepsy related deaths. We support national clinical guidelines that recognise the risks associated with epilepsy including that the risk of SUDEP is essential information. SUDEP Action is supported by a scientific advisory group of experts in the field of epilepsy and epilepsy mortality.

Our services are available to all people bereaved through epilepsy and increasingly to all people with epilepsy and their parents or carers.

We are successful at influencing the NHS and government in our campaign for change and improvements in epilepsy care. We continue to work in direct liaison with health professionals, pathologists and coroners in our aim to prevent unnecessary deaths from epilepsy.

The charity has developed over the years and the service we provide today is still underpinned by the needs and views of the bereaved. For 20 years we have listened to and worked with the

bereaved to develop a service that is second to none. We pride ourselves in our work and our understanding of the vast range of emotions, needs and complexities that this type of bereavement brings.

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.

We are the only charity providing a specialist support service to people bereaved by epilepsy. 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.

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

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

Support for our work:

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. The supporters provide much needed funds for our work and allow 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.

In setting our priorities each year the trustees have regard to the Charity Commission's general guidance on public benefit and the advancement of health and saving lives.

Achievements during the year:

With the help of our supporters we have achieved so much this year. During this, our 20th year we launched tools which are the first of their kind, designed to help keep people with epilepsy safe.

The SUDEP and Seizure Safety Checklist:

The SUDEP and Seizure Safety Checklist 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 will be reviewed and updated regularly by a team of specialist medical advisors.

"Doctors and patients alike have welcomed these communication tools. Clinicians in the South-West found that using the Checklist raised discussions from 10% to 80% of all people within epilepsy services over 2 years. This compares with a recent audit from a Scottish epilepsy clinic which found that communication about risk increased from 4% to 34%. The App and Checklist are easy to use and although it is early days we are not seeing the numbers of deaths that we would have expected in this local population."

Dr Rohit Shankar, Consultant in Adult Developmental Neuropsychiatry at Cornwall Partnership NHS Foundation Trust.

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.

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 & 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.epsmon.com has been created as a platform in its own right.

"I think EpSMon is a brilliant, friendly and nicely-designed app. It is a positive tool and I feel empowered in the way it encourages me to be active in self-monitoring. It asks direct questions which really help me consider how well I am looking after myself in order to avoid risks of seizures. It reminds you to do a three monthly check-up and to make appointments with your doctor or neurologist when you don't want to face up to how your epilepsy is affecting you."

Jane South

The charity is recognised as a world leader in epilepsy mortality and works with national and international specialists in their field, many of whom have endorsed this innovative work. 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.

SUDEP Action, Cornwall Partnership NHS Foundation Trust and Royal Cornwall Hospitals NHS Trust were the original partners in the project. In 2013 Plymouth University (NeuroCoRe) were invited to partner in the development of a digital version of the Checklist (EpSMon).

"People with epilepsy are often not accurately informed about the risks of epilepsy, in particular sudden unexpected death in epilepsy. This device not only informs people about those risks but also gives information about how to modify them, so empowering patients and carers. Moreover, it provides an invaluable summary for GPs and hospital specialists involved in their care."

Professor Matthew Walker
University College, London

The Checklist Project was principally funded by Kt's Fund, following the sudden death of a young nurse.

"The conversation about risk between doctor and patients with epilepsy needs to be accepted as routine just as it is with other chronic conditions. I wish that the new safety app had been available to Katie; this would have allowed Katie to record important information on her mobile which could have been stored and then used to see if there were any triggers leading up to her seizures."

Liz Hollingdale, Kt's Fund

Further achievements during the year:

The WADD Project (Wearable Apnoea Detection Device for people with epilepsy)

During the year SUDEP Action agreed to launch a major fundraising appeal to support this potentially life-saving device to its next stage, by raising the £165k needed to test it on people with epilepsy.

Samantha Cameron hosted the launch reception for SUDEP Action at 10 Downing Street on 10 June 2014. The launch of this appeal for research into a sleep monitoring device that could improve prevention of SUDEP was also a fantastic opportunity for the charity to thank some of its dedicated supporters at this iconic location. Mrs Cameron met with charity supporters and staff at the event which brought together some 120 people including professionals, policy makers and families bereaved by epilepsy.

The research team:

Professor John Duncan: An academic clinical neurologist specialising in epilepsy at the UCL Institute of Neurology and the clinical director of the National Hospital for Neurology & Neurosurgery.

Dr. Esther Rodrigues-Villegas: An electronics engineer with a specialism in wearable sensors based at Imperial College London.

The team had developed a small wearable apnoea detection device that raises an alarm when someone stops breathing. The device has been tested on 10 sleep apnoea patients and 20 controls, which confirmed high sensitivity and low false alarm rates. This project will further test the device by monitoring the breathing patterns of 50 people with epilepsy. Such a programme is required to test how accurate and reliable it is on people having seizures. The patients will be recruited via the National Hospital for Neurology and Neurosurgery EEG unit where they are already undergoing tests and observation for their epilepsy.

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.

The Epilepsy Deaths Register for Ireland

Following the success of our register launched in 2013. We partnered with Epilepsy Ireland to launch the Epilepsy Deaths Register for Ireland in April 2015. The register will provide vital information to researchers and will help further understand epilepsy mortality, with the ability to compare regional and country differences.

"Registers of epilepsy death are a vital new development in work on prevention across the world. SUDEP Action and Epilepsy Ireland have worked together on SUDEP Awareness since the 1990's and the Epilepsy Deaths Register for Ireland partnership is a major landmark on this journey"

Jane Hanna OBE, CEO SUDEP Action

SUDEP Action Scotland

As part of our commitment to provide more local support to people, we registered as a charity in Scotland and launched our office in Livingston. Our Scotland Development Officer has already made an impact and engaged with professionals and other epilepsy organisations. Through this post we are able to influence decision makers within Scotland and highlight the need for improved care for people with epilepsy and support for those who are bereaved.

Core Work

While moving forward with these important expansions of our work and new incentives that provide a platform that encourages discussion about risk between health professionals and people with epilepsy for the first time, we pledge to maintain our core work of caring for and working with the bereaved.

Our core work is delivered through the five key strands of our charitable activities which are:

Providing information on SUDEP and risk in epilepsy:

- ❖ 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.

New during 2014/15:

- ✓ The SUDEP and Seizure Safety Checklist
- ✓ EpSMon
- ✓ The Global Conversation – edition 3
- ✓ Epilepsy – make your risks smaller - easy read information leaflet for people with epilepsy
- ✓ Epilepsy – make your risks smaller – a support guide for parents and carers

New leaflets

Our 'Make your risks smaller' leaflets raise awareness of epilepsy risks and are aimed at people with learning disabilities and their Parents and Carers. These take the form of an Easy Read booklet and an accompanying companion guide for Parents and Carers which enables them to go through the information with the person with epilepsy, providing additional information to suit their needs and ability.

Offering support when someone has died

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

New during 2014/15:

- ✓ SUDEP Action Scotland, to provide tailored information and more local support to people in Scotland
- ✓ Local Coffee Clubs to offer peer support and local access to people, especially in hard to reach areas

Coffee clubs

“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”

A bereaved father

Involving people to help effect change

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

New during 2014/15:

- ✓ Launch of SUDEP Awareness Day (23 October)
- ✓ Westminster event
- ✓ EpSMon
- ✓ WADD
- ✓ Peer Support

EpSMon

Many thanks for allowing me to be involved in a project that I feel sure will revolutionize patient-centred care for people living with epilepsy.”

Nathan Travener - Cornwall

SUDEP Awareness Day 2014

- Supported or linked to 45 epilepsy organisations worldwide.
- Our information was shared 747 times on Facebook and 345 times on Twitter.
- 330 people downloaded our leaflets
- 13145 website views on the day
- Reached a readership of 4 million through newspapers, radio and digital news outlets

The day was launched with a reception in the House of Commons, hosted by SUDEP Action President Ed Vaizey MP

Sponsoring research and education to prevent future deaths

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

New during 2014/15:

- ✓ Wearable Apnoea Detection Device (WADD)

WADD donations from supporters:

"In memory of our beautiful daughter Nik...our angel, our inspiration.
May our SUDEP angels save many. Love and miss you Nik."

Caron Robinson

Capturing data through the Epilepsy Deaths register

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

New during 2014/15:

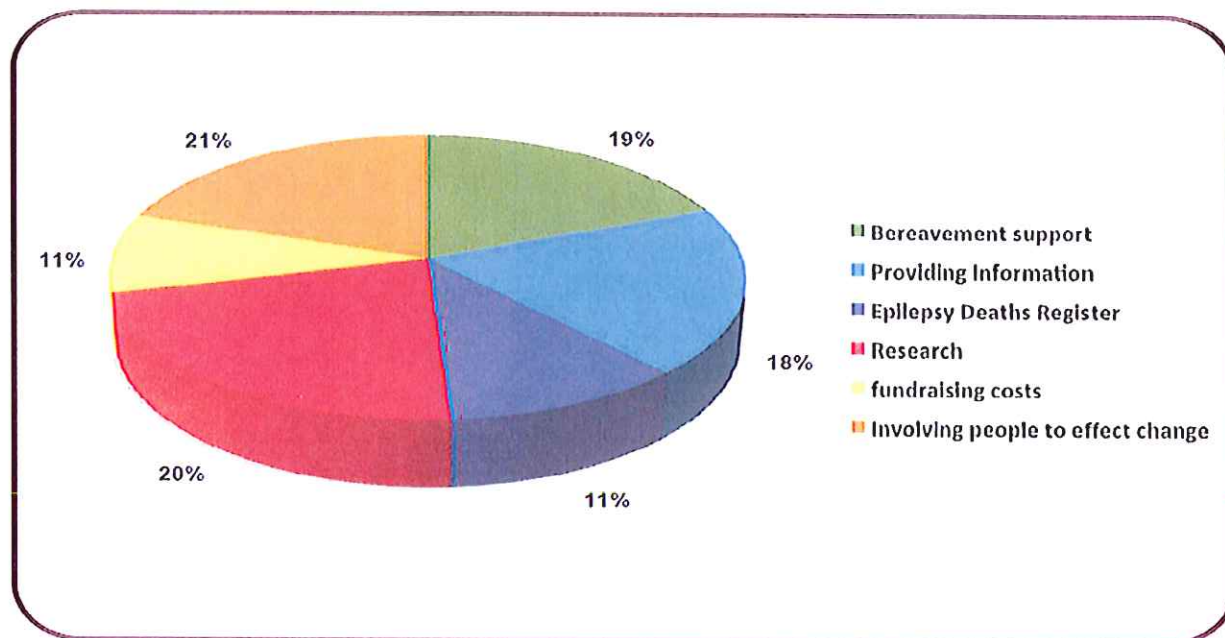
- ✓ The Epilepsy Deaths Register for Ireland

"The register will provide a place where bereaved families can register an epilepsy-related death. This information will be used for medical research, in the hope that it will one day help towards finding a cure and prevent more unnecessary loss of life"

Mike Glynn CEO Epilepsy Ireland

Financial Matters:

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



Epilepsy Deaths Register:

During the year the trustees agreed that the Epilepsy Deaths Register had become integral to our work. At the end of this financial year there were almost 400 registrations and while a full report will be published later in 2015, early analysis endorses our knowledge that epilepsy deaths are in the young. It was agreed that our work in this area should be recognised as core work and that during 2015/16 the fund be de-restricted. In light of this, the deficit balance within restricted funds was written off by a transfer from general funds.

Reserves policy:

Reserves are maintained within our general fund in order to meet the ongoing day-to-day expenditure of the charity for 12 months. Excluding funds committed to on-going and future projects, we have increased our reserves slightly, which at the end of the year reached 6 months of operating costs.

Risk management policy:

The trustees continue to assess the risks faced by the charity and to propose actions to mitigate these risks. The organisation has responded to the need to diversify and develop new revenue streams, increasing the capacity of the charity to support community fundraising and develop marketing as well as other sources of funding. The finance manager provides timely management information and trustee reports to ensure that the Board of Trustees is fully aware of the need to take action if required. In spite of recent difficult economic times, the charity's financial position has continued to be strong and has even improved.

The Future:

The current year has been one of our most exciting yet. Over the past 20 years there have been many milestones, most notably being appointed as the lead for the national audit into epilepsy related deaths in 2002.

Encouraged by our work this year and backed by professionals who are experts in the field of epilepsy and epilepsy mortality, we pledge to continue in our aim to reduce unnecessary deaths from epilepsy. 2015/2016 promises to be an equally good year for the charity with the aim of expanding our services both nationally and internationally as the main focus.

During 2015/16 we will:

- Continue to care for the bereaved and review our practice in line with our learning
- Look at on-line platforms that allow us to diversify in our delivery of care in safe and secure ways
- Launch the android version of EpSMon
- Collaborate internationally to promote EpSMon worldwide
- Develop information resources aimed at keeping children with epilepsy safe
- Work with partners to develop best practice guides for people with epilepsy in a looked after setting
- Launch our e-learning for professionals, carers and people with epilepsy
- Provide an information resource for GPs in the form of a video on epilepsy-related death
- Look to further expand the Epilepsy Deaths Register
- Collaborate with epilepsy organisations to increase the reach of SUDEP Awareness Day
- Expand our work with hard to reach groups
- Continue to highlight research that looks to reduce deaths
- Work with researchers and organisations that endorse and help further our aims

Collaboration

SUDEP Action will continue with and enhance its collaborations both nationally and internationally.

We will continue to support and secure funding for research into epilepsy mortality and will actively look for opportunities to partner in this area. We maintain our membership and working relationships with medical and epilepsy organisations in areas of common interest that will benefit people with epilepsy. Our current or recent memberships and collaborations are as follows:

- The Neurological Alliance
- The All Wales Epilepsy Forum
- The Royal College of General Practitioners
- Kings Health Partners
- Epilepsy Action
- Epilepsy Ireland
- Epilepsy Society
- Epilepsy Wales
- Epilepsy Society Brain and Tissue Bank
- Cornwall Partnership NHS Trust
- Royal Cornwall Hospital NHS Trust
- Plymouth University (NeuroCoRe)
- University College Cork
- Sheffield University Primary Care Academic Medical Unit
- Leicestershire Partnership NHS Trust: Learning Disability Service

International:

- CSR (The Center for SUDEP Research)
- SUDEP - The Global Conversation (SUDEP Action; Epilepsy Australia; and SUDEP Aware)
- PAME (Partners Against Mortality in Epilepsy)
- IBE (International Bureau for Epilepsy)

Signed for and on behalf of the Board of Trustees

A handwritten signature in black ink, consisting of a stylized 'S' followed by a long horizontal line.

**S Brown
Chair of Trustees
17 October 2015**

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF EPILEPSY BEREAVED

For the year ended 31 March 2015

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



6 Newbury Street
Wantage
Oxfordshire
OX12 8BS

Epilepsy Bereaved (SUDEP Action & SUDEP Action Scotland)

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

Statement of Financial Activities For the year ended 31 March 2015

		Unrestricted Funds 2015	Restricted Funds 2015	Total Funds 2015	Total Funds 2014
	Note	£	£	£	£
Incoming resources					
Voluntary Income	2	85,177	70,811	155,988	147,530
Activities for generating funds	3	177,025	16,203	193,228	137,742
Investment Income	4	538	-	538	503
Incoming resources from charitable activities	5	2,850	14,454	17,304	4,143
Total Incoming Resources		265,590	101,468	367,058	289,918
Resources Expended					
Cost of generating funds	6	30,981	839	31,820	20,215
Charitable activities	7	211,499	42,890	254,389	214,541
Governance Costs	8	5,700	-	5,700	4,676
Total Resources Expended		248,180	43,729	291,909	239,432
Net Incoming/(Outgoing) Resources Before Transfers		17,410	57,739	75,149	50,486
Gross Transfers between Funds	12	(4,439)	4,439	-	-
Net Movement In Funds		12,971	62,178	75,149	50,486
Funds brought forward at 1 April 2014 (2013)		110,668	30,322	140,990	90,504
Funds carried forward at 31 March 2015 (2014)		123,639	92,500	216,139	140,990

The notes on pages 17 to 21 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 2015	31 March 2015	31 March 2015	31 March 2014
	Note	Unrestricted Funds	Restricted Funds	TOTAL	TOTAL
		£	£	£	£
Fixed Assets	1f	-	-	-	-
Current Assets					
Prepayments		5,179	96	5,275	5,061
Debtors		7,032	395	7,427	13,472
Accrued Gift Aid		5,287	3,621	8,908	3,665
Cash at bank and in hand:					
Funds in credit		124,455	92,233	216,688	134,917
Fund in deficit	12	-	-	-	(6,032)
		<u>141,953</u>	<u>96,345</u>	<u>238,298</u>	<u>151,083</u>
Creditors: amounts falling due within one year	11	(18,314)	(3,845)	(22,159)	(10,093)
Net Assets		<u><u>123,639</u></u>	<u><u>92,500</u></u>	<u><u>216,139</u></u>	<u><u>140,990</u></u>
Funds					
Unrestricted Funds	12	123,639		123,639	110,668
Restricted Funds:					
Funds in credit	12		92,500	92,500	36,354
Fund in deficit	12		-	-	(6,032)
		<u><u>123,639</u></u>	<u><u>92,500</u></u>	<u><u>216,139</u></u>	<u><u>140,990</u></u>

The financial statements were approved by the Board of Trustees on 17/10/2015 and signed on its behalf by:



Stephen Brown
Chair of Trustees

The notes on pages 17 to 21 form part of these financial statements.

**Notes to the Financial Statements
for the Year Ended 31 March 2015**

1 Accounting policies

a) Basis of preparation

The financial statements have been prepared under the historical cost convention in accordance with the Statement of Recommended Practice 'Accounting and Reporting by Charities' (SORP 2005), and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008) and the Charities Act 2011 and applicable accounting standards.

b) Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity.

Designated funds are unrestricted funds earmarked by the Trustees for particular purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in note 12 to the financial statements.

c) Incoming resources

All incoming resources are included in the statement of financial activities when the charity is legally entitled to the income and the amount can be quantified with reasonable accuracy. For legacies, entitlement is the earlier of the charity being notified of an impending distribution or the legacy being received.

Other voluntary income and donations are taken into 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. Wherever possible, costs are allocated directly to the appropriate category; staff costs are apportioned on the basis of staff time spent during the year on that activity.

Fundraising costs are those incurred in seeking and acquiring voluntary contributions as well as the costs relating to the small scale sales of branded goods.

Expenditure incurred in connection with the specific objects of the charity is included under the heading Charitable Activities.

Governance costs are those incurred in connection with the administration of the charity and compliance with constitutional and statutory requirements.

e) 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 2015: nil (2014: 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.

f) 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.

Epilepsy Bereaved (SUDEP Action & SUDEP Action Scotland)

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

Notes to the Financial Statements
for the Year Ended 31 March 2015

	Unrestricted Funds £	Restricted Funds £	TOTAL 2015 £	TOTAL 2014 £
2 Voluntary Income				
Donations	46,618	25,197	71,815	53,013
Grants	8,816	35,000	43,816	53,022
Gift Aid *	27,743	5,614	33,357	40,669
Legacies	2,000	5,000	7,000	55
Sundry income	-	-	-	771
	<u>85,177</u>	<u>70,811</u>	<u>155,988</u>	<u>147,530</u>
* Gift Aid for 2014 included arrears of £20,531				
3 Activities for generating funds				
General fundraising	173,126	16,203	189,329	135,897
Collecting boxes	1,147	-	1,147	278
Sale of goods	2,752	-	2,752	1,207
Letting office space	-	-	-	360
	<u>177,025</u>	<u>16,203</u>	<u>193,228</u>	<u>137,742</u>
4 Investment Income				
Interest Receivable	538	-	538	503
	<u>538</u>	<u>-</u>	<u>538</u>	<u>503</u>
5 Incoming resources from charitable activities				
Dunchurch conference	2,850	-	2,850	3,643
Fees receivable *	-	14,454	14,454	500
	<u>2,850</u>	<u>14,454</u>	<u>17,304</u>	<u>4,143</u>

Epilepsy Bereaved (SUDEP Action & SUDEP Action Scotland)

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

Notes to the Financial Statements
for the Year Ended 31 March 2015

	Unrestricted Funds £	Restricted Funds £	TOTAL 2015 £	TOTAL 2014 £
6 Cost of Generating Funds				
Fundraising Expenses	20,981	839	21,820	10,214
Salaries and National Insurance	10,000	-	10,000	10,001
	<u>30,981</u>	<u>839</u>	<u>31,820</u>	<u>20,215</u>
7 Cost of Charitable activities				
Postage and Stationery	4,816	9	4,825	3,760
Telecommunications	3,138	40	3,178	3,416
Printing & Publicity	8,180	1,201	9,381	7,344
Salaries & National Insurance	144,977	20,479	165,456	133,563
Pension Scheme Contributions	1,079	90	1,169	736
Consultancy & other staff costs	359	-	359	690
Travel, Accommodation & Subsistence	9,660	471	10,131	7,813
Research grants	-	11,348	11,348	24,748
Affiliations to Other Groups	347	-	347	196
Development of Web Site	1,733	8,703	10,436	6,095
Cost of Support Group Meetings	16,985	435	17,420	8,490
Bank Charges	34	6	40	-
Training	644	-	644	30
Office Costs, including Insurance	18,513	108	18,621	15,084
Conferences & Seminars	845	-	845	2,395
Sundry Expenses	189	-	189	181
	<u>211,499</u>	<u>42,890</u>	<u>254,389</u>	<u>214,541</u>
8 Governance Costs				
Staff Costs	2,500	-	2,500	2,500
Cost of Trustees' meetings	2,420	-	2,420	1,414
Independent Examiner's Fee	780	-	780	762
	<u>5,700</u>	<u>-</u>	<u>5,700</u>	<u>4,676</u>
9 Staff Costs Including Pension Scheme Contributions				
Salaries & National Insurance	157,477	20,479	177,956	146,064
Pension Scheme Contributions	1,079	90	1,169	736
	<u>158,556</u>	<u>20,569</u>	<u>179,125</u>	<u>146,800</u>

There was an average of 6.3 employees (FTE) during the year (2014: 5.4)

No employee earned over £60,000 in the year (2014: 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.

Epilepsy Bereaved (SUDEP Action & SUDEP Action Scotland)

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

Notes to the Financial Statements
for the Year Ended 31 March 2015

10 Trustee expenses

The trustees received no remuneration during the year (2014: nil).
4 trustees were reimbursed a total of £1,244 (2014: 2 trustees £626) for expenses.

11 CREDITORS: amounts falling due within one year

	Unrestricted Funds £	Restricted Funds £	TOTAL 2015 £	TOTAL 2014 £
Trade Creditors	11,489	145	11,634	4,889
Sundry Creditors	-	3,197	3,197	-
Receipts in Advance	805	-	805	350
HMRC-PAYE/NI	4,611	453	5,064	2,684
Pension	264	50	314	118
Accrued Expenditure	1,145	-	1,145	2,052
	<u>18,314</u>	<u>3,845</u>	<u>22,159</u>	<u>10,093</u>

12 Statement of funds

	Brought Forward £ Surplus/ (Deficit)	Incoming Resources £	Resources Expended £	Transfers In/(Out) £	Carried Forward £ Surplus/ (Deficit)
Unrestricted funds					
General fund	110,668	256,700	248,003	(4,439)	114,926
Designated funds					
WADD	-	8,890	177	-	8,713
Total	<u>110,668</u>	<u>265,590</u>	<u>248,180</u>	<u>(4,439)</u>	<u>123,639</u>
Restricted funds					
WADD	-	63,719	784	-	62,935
Cornwall	32,617	5,000	17,122	-	20,495
Devon	2,277	-	-	-	2,277
EDR	(6,032)	25,704	24,111	4,439	-
LDA	500	5,000	1,117	-	4,383
Counselling	760	40	340	-	460
Memorial	200	-	200	-	-
Research	-	2,005	55	-	1,950
Total	<u>30,322</u>	<u>101,468</u>	<u>43,729</u>	<u>4,439</u>	<u>92,500</u>

Notes to the Financial Statements
for the Year Ended 31 March 2015

12 Statement of funds (continued)

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.

Devon Expansion of the Cornwall Life Project.

EDR Epilepsy Deaths Register - setting up a global resource for research into the causes and prevention of any epilepsy-related death. The fund was derestricted from 01/04/2015 in recognition of the completion of the setting up phase of the operation and the closing deficit made good from general funds.

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.

Memorial To provide a Remembrance Book for the triennial Memorial Service.