

## SUDEP Action

Registered Charity No.  
1164250 (England & Wales)  
SC047223 (Scotland)  
[www.sudep.org](http://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 2017

Chapman Worth Limited  
6 Newbury Street  
Wantage  
Oxfordshire  
OX12 8BS

# SUDEP Action & linked charity Epilepsy Bereaved

## CHARITY INFORMATION

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<b>Director</b>	Jane Hanna OBE
<b>Trustees</b>	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 Malisa Pierri Rachel Shah (appointed 15 July 2016)
<b>Charity No.</b>	1164250 (England & Wales) SC047223 (Scotland)
<b>Website</b>	<a href="http://www.sudep.org">www.sudep.org</a>
<b>Address for correspondence</b>	SUDEP Action 12a Mill Street Wantage Oxfordshire OX12 9AQ
<b>Accountants</b>	Chapman Worth Limited 6 Newbury Street Wantage Oxfordshire OX12 8BS
<b>Bankers</b>	HSBC Plc 24 Market Square Witney Oxfordshire OX28 6BG

# SUDEP Action & linked charity Epilepsy Bereaved

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# **SUDEP Action**

## **TRUSTEES' REPORT**

**For the year ended 31 March 2017**

The trustees present their report and accounts for the year ended 31 March 2017.

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 Memorandum and Articles of Association, the Charities Act 2011 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)" (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 March 31<sup>st</sup> 2017 and before the transfer of assets to SUDEP Action as a charitable incorporated organisation (CIO) on April 1<sup>st</sup> 2017. The trustees of the unincorporated charity and the incorporated charity are the same.

### **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.

During 2016 the Charity Commission agreed to link SUDEP Action with the Registered Charity Epilepsy Bereaved. Epilepsy Bereaved (Charity Registration number 1050459 in England and Wales and SC045208) was constituted under a Declaration of Trust dated 14 October 1995. Epilepsy Bereaved was re-numbered 1164250-1 by the Charity Commission in March 2017 following their linking of the 2 charities and the Board of Trustees resolved in May 2017 to have SC045208 removed from the Scottish Register.

Epilepsy Bereaved, an unincorporated charity adopted SUDEP Action as a working name in January 2013 and registered as a charitable incorporated organisation (CIO) in the name of SUDEP Action (1164250) in 2015. Administering the charity as 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. The linking of the two charities protects SUDEP Action from loss of legacy income in the future.

During 2016 the charity undertook a review of all significant activities and policies to ensure a smooth transition to the new charity SUDEP Action CIO.

The Charity Commission approved the transfer of assets and ongoing liabilities of Epilepsy Bereaved to the new CIO to take effect on April 1<sup>st</sup> 2017.

### **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  
Simon Lees  
John Lipetz  
Mark Phillips  
Malissa Pierri  
Roger Scrivens  
Rachel Shah (appointed July 2016)  
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 normally 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 eight employees including some who are part-time and equating to 7.4 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 which underpins all our educational materials.

## **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.

## **Why ?**

To gain recognition of SUDEP (Sudden Unexpected Death in Epilepsy) and other epilepsy-related deaths and to work towards prevention strategies.

Over 21,000 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. 600,000 live with epilepsy, usually diagnosed after 2 seizures.**

**There are 21 deaths a week. The majority are young people who are otherwise in good health.**

**9 a week could be unnecessary if SUDEP and seizure risk was taken seriously.**

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

**There is no requirement for a health check for people with epilepsy.**

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.

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.

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 the risks involved. 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 ignored by professionals.

Many deaths, up to 42%, might be avoided if there was a common awareness among doctors, 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**

**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

**Over 11,000 people have used our services with just over 16,000 uses of SUDEP Action resources and services during this reporting year. 278 advocacy and medical organisations have benefited from our services.**

## 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. 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 SUDEP experts and ask questions
- ❖ Counselling

Our specialist service dealt with 927 support communications through open ended support and telephone counselling during the reporting year from people at different stages in their journey after a death. Many newly bereaved ask the question why their loved one has died and our service was able to provide highly specialist information to help. A further 13 families with highly complex medico-legal cases were also supported. Bereaved families report the highest levels of satisfaction with our service in comparison with all professional or other general support services that they used after a death.

*"I found it so easy to cry about my loss with Tracy".*

*"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.

We recruited a new role in the charity to reach out to the bereaved in the local and online community.

During the reporting year we supported volunteers to run coffee clubs bringing 40 people together for peer support in 7 local areas. We successfully launched an online Epilepsy Memorial Day which brought 4080 connections on the day. The day runs every year alongside our memorial service in London that will be held next in 2017.

*"It felt like a risk for us to go for the first time to the coffee club yesterday. It was the unknown, and we found ourselves speaking with and listening to more people than we had ever talked to before about our loss through epilepsy. It was also helpful to learn from those who attended, about their different ways of coping and coming to terms with what has happened."*

**Source: Coffee Club evaluation 2017**

## **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.

644 families have now participated in the Epilepsy Deaths Register (EDR) - our online research platform. SUDEP Action now has the largest data set of experiences of families anywhere in the world. Our service supported 108 people during 2017 to report their experiences.

This 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.

Over 1000 supporters were involved in a range of activities whether fundraising, raising awareness or campaigning.

We involve doctors and nurses across community and acute care and involve people living with epilepsy in the development of our safety tools. 1126 clinicians were engaged with us during the reporting year.

## Providing Information and Education

- ❖ 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 9,000 people with epilepsy including 6,000 who received our leaflets and just over 3,000 people with epilepsy with our EpSMon epilepsy self-monitor App.

In total there were 1,126 uses of SUDEP Action resources by front-line NHS professionals with the charity extending our reach for the first time to ambulance crews.

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

The Royal College of General Practitioners 2017 report found that 430 GPs accessed our SUDEP and Seizure Safety e-learning with those completing a test increasing their knowledge by over 20%.

### GP e-learning

*"Very useful in trying to deliver safe care to our patients with epilepsy"*

*"An action changing short course. Several key points to take away"*

**177 GPs tested before and after our RCGP SUDEP and Seizure safety e-learning course increased their knowledge by over 20%.**



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.

Our two global online awareness platforms SUDEP Awareness Day and SUDEP Global Conversation attracted 18,000 visitors. Our social media posts alone reached 2 million on SUDEP Awareness Day.

People visiting our main site increased by 34% with over 100,000 visitors by the end of the reporting year.

### **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 can be 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, it has brought families, the local community and professional champions together. 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 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 and developed 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.epsmon.com](http://www.epsmon.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 our safety 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 have raised a remarkable £131,015 since our appeal was launched including £7,247 during this reporting year. This was enough funds for a clinical research trial on people with epilepsy. Patients are being recruited this year and next 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 – the Epilepsy Deaths Register (EDR)**

- ❖ 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 Epilepsy Deaths Register (EDR) which offers people an online research platform to share their experiences, strengthens 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 260 advocacy organisations across 99 countries on our SUDEP Awareness Day on 23<sup>rd</sup> October in a united global effort to raise awareness using common statistics and common positive messages about risk reduction. 14,000 people visited our special site on this day.

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 Clinical Trial:** University College London and Imperial College London

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

**Global Conversation:** SUDEP Aware, Epilepsy Australia

During the year we added a new collaboration with emergency service professionals who initiated contact with us to develop a training package to educate ambulance crews about SUDEP and seizure risk which will be launched next year.

*The '**Charlie Burns – Simple Steps**' Training Package was developed during the year through collaboration between SUDEP Action and the **South West Ambulance Service Foundation Trust**. Following the death of Charlie in 2011, **Jan, Baz and Izzie Burns** fought to make sure lessons were learnt from his death.*

*The training tool has been requested by at least 8 Ambulance Trusts with a potential reach of 28,000 crew.*

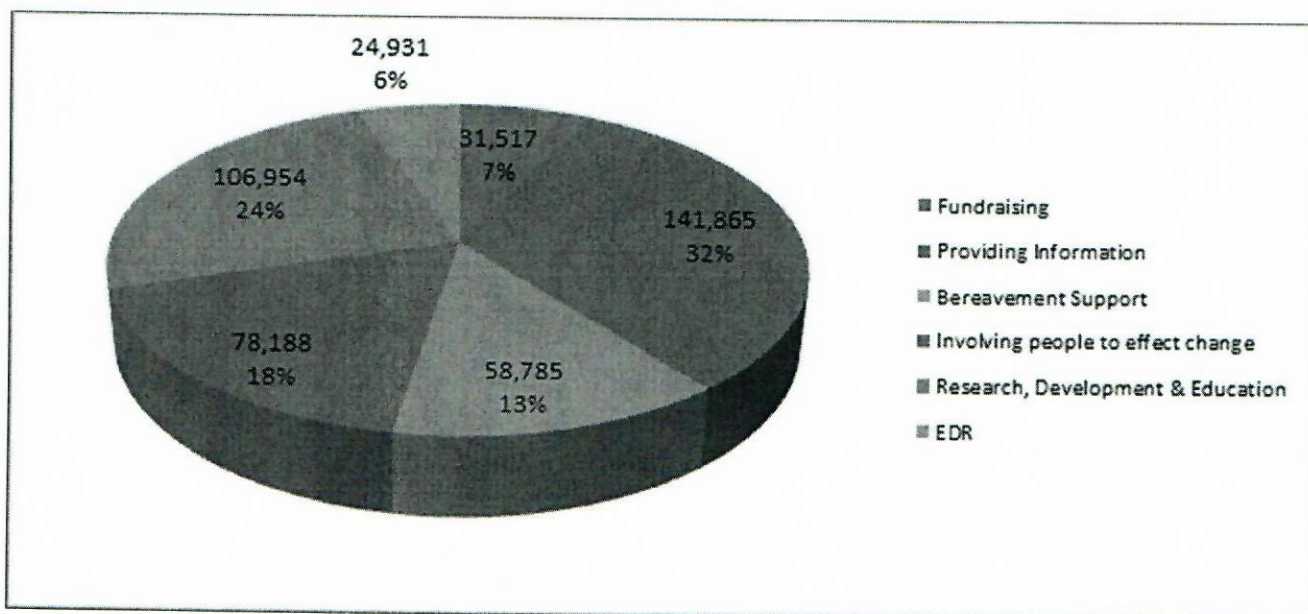
We work hard to participate in other initiatives where possible and collaborate with the Epilepsy Society Brain and Tissue Bank at UCL; the Partners Against Mortality in Epilepsy (US) and we are the UK advocacy partner for the Centre for SUDEP Research (US).

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 £442,240 was apportioned as follows, in line with what is important to our supporters:



## Income and reserves

The charity's income was £395,413 (compared with £431,122 during 2015/16 and 367,058 during 2014/15). £34,681 of income during 2016/17 was restricted funding with the balance of all restricted funds held during the reporting year totalling £107,436.

Since the WADD appeal project (Clinical trial on a wearable apnoea device to detect potentially fatal seizures) inception in June 2014, £131,015 had been raised by supporters. A payment of £55,000 was made to Imperial College, London this year and it is expected that the remaining £76,015 WADD reserves will be fully or substantially paid out to University College, London and Imperial College, London during the year 2017/2018 under conditions of research grants agreed with these universities and in accordance with the WADD appeal.

Restricted funds totalling £31,331 to support projects working with researchers and UK clinicians will be fully or substantially paid out during 2017/2018 as we launch our new appeal #PREVENT21 for the next four years.

Our uncommitted funds or general funds stood at £89,284 at year end or just under 4 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 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.

The Board has three clinicians with skill sets to strengthen the Board in line with the charity strategy of even closer working with clinical teams across the UK.

The business case for the charity 2016/2018 developed with the staff and the Board during 2016 sets out changes to the demands on the charity, how we have responded to these demands; our strengths and weaknesses and our goals ahead and how we seek to achieve them.

The main challenge is to manage transformation and growth of SUDEP Action whilst ensuring sustainability of services and development of projects. We need to grow and have a good base to do this having developed solutions that are scaleable to meet urgent needs. Our investment internally including converting to a Charitable Incorporated Organisation (CIO) means we are in readiness for this growth.

During 2016 the charity also undertook a review of all significant activities and policies to ensure a smooth transition to the new charity SUDEP Action CIO.

## **Our Position in 2017**

**With over 2,000 connections during the reporting year with bereaved families over the year families tell us these services are a life-line for them.**

**In total over 11,000 people have used our services with just over 16,000 uses of SUDEP Action resources and services by professionals and families during this reporting year. 278 advocacy and medical organisations have benefited from our services.**

**Over 100,000 in addition also visited site and 2 million were reached by social media on SUDEP Awareness Day alone.**



SUDEP Action is recognised as the organisation that first broke a global taboo that blocked any work in this field for many years and the charity has led innovation in the field of tackling epilepsy mortality.

Embracing the power of communities and innovating with technology has enabled SUDEP Action to serve the cause of preventing deaths and rebuilding lives.

The following is a list of world-firsts developed over 20 years that are today promoted as a model of good practice:

- ❖ **Research programme** pump-priming SUDEP research on risk factors, life-saving devices, and research with families driving and leading to just under 3 million pounds investment in research on epilepsy mortality in the UK.
- ❖ **Specialist service for families:** SUDEP Action leads the world as a gold standard service to support the journey of families whilst working with researchers and clinicians to tackle epilepsy deaths.
- ❖ **Unique on-line research platform:** We have developed a sustainable reporting platform with the largest data set of experiences of families and have developed a service that is able to turn private pain into public purpose.
- ❖ **Standardised health check for risk** acclaimed for Patient Safety and for innovation in tackling mortality.
- ❖ **Digital self-management tool** to encourage and support people to check their own risk
- ❖ **SUDEP and Seizure Safety training tools for GPs and Ambulance crews**
- ❖ **Global awareness day and platform universally supported showing unity of cause**

Our innovative safety tools are widely recognised in the medical literature as helpful in tackling identified barriers, so that doctors and patients are able to talk about ways of reducing individual risk.

EpsMon App has been chosen as one of eight innovations for the NHS Innovation Accelerator Programme. The validation of the safety tools represents a seismic shift in support for our strategy which is attracting interest from around the world.

This track of achievement is evidenced in these national and global awards over the last 7 years.

#### **Awards**

- ❖ **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 Global Innovation Award 2016 for best solution to tackle seizures aimed at preventing deaths
- ❖ Chief Executive Awarded Social Impact Award ILEA/IBE 2013
- ❖ Chief Executive awarded OBE for Services to Families in 2010

*"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.**

We are well positioned at a time when risk and keeping patients safe is highlighted in the media and by the NHS.

## 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 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.

Our solutions are easily scaleable so our aspirations are without local, national or global boundaries. Our priority is rolling out our projects and services in the UK to as many people as possible who need these. Where partners outside of the UK wish to contribute, we are keen to collaborate and help internationally.

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 2017/18 we will:**

- ❖ **Launch a new campaign prioritising prevention now**
- ❖ **Raise the profile of 21 sudden deaths a week and give voice to the priorities of over 600 suddenly bereaved families to speed up change**
- ❖ **Promote our service and care pathway to increase our reach to traumatised families**
- ❖ **Fund and support research aimed at embedding safety tools in front-line clinical practice with a view to preventing deaths**
- ❖ **Provide ongoing patient and public involvement for a clinical trial and development of a wearable device on people with epilepsy, to alert to an acute episode that could kill**
- ❖ **Develop our collaborations with researchers and organisations that endorse and help further our aims**
- ❖ **Launch new resources aimed at keeping children with epilepsy safe**

**Signed for and on behalf of the Board of Trustees**



**S Brown  
Chair of Trustees**

## INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

**For the year ended 31 March 2017**

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I report on the accounts of the Trust for the year ended 31 March 2017, which are set out on the pages 16 to 23

### 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.

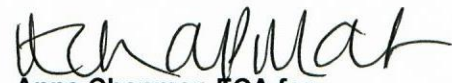
### Basis of independent examiner's statement

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 for  
Chapman Worth Limited**

6 Newbury Street

Wantage

Oxfordshire

OX12 8BS

Dated.....





## Statement of Financial Activities

### For the year ended 31 March 2017

		Epilepsy Bereaved Unrestricted Funds 2017	Epilepsy Bereaved Restricted Funds 2017	Epilepsy Bereaved Total Funds 2017	Epilepsy Bereaved Total Funds 2016
	Note	£	£	£	£
<b>Income from</b>					
Donations and legacies	2	335,898	27,156	363,054	372,510
Charitable activities	3	4,295	5,502	9,797	28,927
Other trading activities	4	19,960	2,023	21,983	28,936
Investments	5	579	-	579	749
<b>Total incoming resources</b>		<b>360,732</b>	<b>34,681</b>	<b>395,413</b>	<b>431,122</b>
<b>Resources Expended</b>					
Raising funds	6	30,723	794	31,517	42,233
Charitable activities	7-8	349,918	60,805	410,723	339,908
<b>Total resources expended</b>		<b>380,641</b>	<b>61,599</b>	<b>442,240</b>	<b>382,141</b>
<b>Net income/(expenditure)</b>		<b>(19,909)</b>	<b>(26,918)</b>	<b>(46,827)</b>	<b>48,981</b>
<b>Transfers between funds</b>	12	-	-	-	-
<b>Net movement in funds</b>		<b>(19,909)</b>	<b>(26,918)</b>	<b>(46,827)</b>	<b>48,981</b>
Total funds brought forward 1 April 2016 (2015)		130,766	134,354	265,120	216,139
<b>Total funds carried forward 31 March 2017 (2016)</b>		<b>110,857</b>	<b>107,436</b>	<b>218,293</b>	<b>265,120</b>

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

## Balance Sheet as at

	Note	31 March 2017 Epilepsy Bereaved Unrestricted Funds £	31 March 2017 Epilepsy Bereaved Restricted Funds £	31 March 2017 Epilepsy Bereaved TOTAL £	31 March 2016 Epilepsy Bereaved TOTAL £
<b>Fixed Assets</b>	1g	-	-	-	-
<b>Current Assets</b>					
Prepayments		4,144	-	4,144	4,778
Debtors		8,012	5,702	13,714	18,491
Accrued Gift Aid		6,997	51	7,048	4,575
Cash at bank and in hand		99,424	101,683	201,107	269,093
		<b>118,577</b>	<b>107,436</b>	<b>226,013</b>	<b>296,937</b>
<b>Creditors: amounts falling due within one year</b>	11	(7,720)	-	(7,720)	(31,817)
<b>Net Assets</b>		<b>110,857</b>	<b>107,436</b>	<b>218,293</b>	<b>265,120</b>
<b>Funds</b>					
Unrestricted Funds	12	110,857	-	110,857	130,766
Restricted Funds	12-13	-	107,436	107,436	134,354
		<b>110,857</b>	<b>107,436</b>	<b>218,293</b>	<b>265,120</b>

The financial statements were approved by the Board of Trustees on 02/11/2017 and signed on its behalf by:



Stephen Brown  
 Chair of Trustees

The notes on pages 21 to 26 form part of these financial statements.



**Notes to the Financial Statements  
for the Year Ended 31 March 2017**

**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). SUDEP Action is a linked charity with Epilepsy Bereaved which 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. These financial statements for the year ended 31 March 2017 are the first accounts of SUDEP Action prepared in accordance with FRS 102.

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; however the CIO remained inactive until 1 April 2017.

**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 2017. The assets of Epilepsy Bereaved will be transferred to SUDEP Action before being closed.

**c) Charitable funds**

Unrestricted funds are available to spend on activities that further any of the purposes of the charity. Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose. Restricted funds are donations which the donor has specified are to be solely used for particular areas of the charities work or for specific projects being undertaken by the charity. The aim and use of each restricted fund is set out in note 12 to the financial statements.

**d) Incoming resources**

Items of income are recognised and included in the accounts when all of the following are met:

- the charity has entitlement to the funds;
- any performance conditions attached to the item(s) of income have been met or are fully within the control of the charity;
- there is sufficient certainty that receipt of the income is considered probable; and
- the amount can be measured reliably.

For legacies, entitlement is taken the earlier of:

- the charity being notified of an impending distribution; or
- the legacy being received.

Other voluntary income and donations are included in the accounts when received.

Fundraising income is generated by the charity's supporters mainly through sponsored events.

**e) Resources expended**

All expenditure is included on an accruals basis. Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is classed under the following headings:

- Costs of raising funds comprise those incurred in seeking and acquiring voluntary contributions as well as the costs relating to the small scale sales of branded goods.
- Expenditure on charitable activities includes the Costs of activities undertaken to further the purpose of the charity and their associated support Costs



**Notes to the Financial Statements  
for the Year Ended 31 March 2017**

**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 for £55,000 was made to Imperial College London to conduct the WADD clinical trial. A similar grant is yet to be made to University College London for research into the results of the trial. A net grant for £3,906 was made to Sheffield University for EDR research (2016: £4,000); (2016 other grants (Cornwall fund): Exeter University £1,500 (CELP); Plymouth University £14,500 (EpSMon)). Note 8 refers.

**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 2017: nil (2016: 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.



**Notes to the Financial Statements  
for the Year Ended 31 March 2017**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>TOTAL 2017 £</b>	<b>TOTAL 2016 £</b>
<b>2 Donations and legacies</b>				
Donations	54,756	320	55,076	51,410
Grants	22,687	7,500	30,187	30,200
Non-Exchange Grants	72,290	-	72,290	5,338
Gift Aid	25,050	1,127	26,177	39,072
Legacies	2,000	-	2,000	11,109
Fundraising donations	157,977	18,209	176,186	232,790
Collecting boxes	1,138	-	1,138	2,591
	<b>335,898</b>	<b>27,156</b>	<b>363,054</b>	<b>372,510</b>
<b>3 Charitable activities</b>				
Annual charity conference	-	-	-	7,077
Fees receivable	4,295	-	4,295	661
Contractual income *	-	5,502	5,502	21,189
	<b>4,295</b>	<b>5,502</b>	<b>9,797</b>	<b>28,927</b>
* Contractual income relates to the EpSMon project (see note 12a, Cornwall Fund)				
<b>4 Other trading activities</b>				
Fundraising sales	17,553	2,023	19,576	25,866
Sale of goods	2,407	-	2,407	3,070
	<b>19,960</b>	<b>2,023</b>	<b>21,983</b>	<b>28,936</b>
<b>5 Investments</b>				
Interest Receivable	579	-	579	749
	<b>579</b>	<b>-</b>	<b>579</b>	<b>749</b>

**Notes to the Financial Statements  
for the Year Ended 31 March 2017**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>TOTAL 2017 £</b>	<b>TOTAL 2016 £</b>
<b>6 Raising funds</b>				
Fundraising Expenses	18,736	794	19,530	25,756
Support costs	11,987	-	11,987	16,477
	<u>30,723</u>	<u>794</u>	<u>31,517</u>	<u>42,233</u>
<b>7 Charitable activities</b>				
Direct charitable expenditure	328,275	60,805	389,080	320,392
Governance costs	4,229	-	4,229	3,508
Support costs	17,414	-	17,414	16,008
	<u>349,918</u>	<u>60,805</u>	<u>410,723</u>	<u>339,908</u>

Governance costs consist of the independent examiner's fee, costs of trustees' meetings, and reconstitution costs, all as set out in Note 8 below.

Support costs consist of staff costs not directly attributable to charitable expenditure and related office overheads, and are apportioned on the basis of staff resources committed to fundraising and charitable activities proportionately.

**8 Charitable activities**

Postage and Stationery	3,708	2	3,710	5,156
Telecommunications	2,429	36	2,465	3,221
Printing & Publicity	7,370	1,585	8,955	22,659
Non-Exchange Publicity	72,290		72,290	5,338
Salaries & National Insurance	213,970	3,312	217,282	222,066
Pension Scheme Contributions	830	87	917	1,457
Consultancy & other staff costs	4,000	-	4,000	175
Travel, Accommodation & Subsistence	7,549	410	7,959	10,358
Research grants	3,906	55,000	58,906	20,000
Affiliations to Other Groups	1,012	-	1,012	916
Development of Web Site	3,430	160	3,590	3,223
Cost of Support Group Meetings	143	-	143	17,997
Bank Charges	48	-	48	9
Training	2,042	-	2,042	177
Office Costs, including Insurance	18,155		18,155	18,039
Conferences & Seminars	4,597	213	4,810	5,362
Sundry Expenses	210	-	210	247
Independent Examiner's Fee	1,020	-	1,020	780
Cost of Trustees' meetings	2,009	-	2,009	1,828
Reconstitution Costs	1,200	-	1,200	900
	<u>349,918</u>	<u>60,805</u>	<u>410,723</u>	<u>339,908</u>

**9 Staff Costs including Pension Scheme Contributions**

Salaries & National Insurance	224,663	3,312	227,975	238,543
Pension Scheme Contributions	850	87	937	1,457
	<u>225,513</u>	<u>3,399</u>	<u>228,912</u>	<u>240,000</u>

There was an average of 7.4 employees (FTE) during the year (2016: 8.0)

No employee earned over £60,000 in the year (2016: 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.



**Notes to the Financial Statements  
for the Year Ended 31 March 2017**

**10 Trustee expenses**

The trustees received no remuneration during the year (2016: nil).  
4 trustees were reimbursed a total of £731 (2016: 4 trustees £774) for expenses.

**11 CREDITORS: amounts falling due within one year**

	Unrestricted Funds £	Restricted Funds £	TOTAL 2017 £	TOTAL 2016 £
Trade Creditors	993	-	993	20,196
Sundry Creditors	-	-	-	3,197
Receipts in Advance	35	-	35	525
HMRC-PAYE/NI	5,051	-	5,051	5,887
Pension	327	-	327	613
Accrued Expenditure	1,314	-	1,314	1,399
	<u>7,720</u>	<u>-</u>	<u>7,720</u>	<u>31,817</u>

**12 Statement of funds**

	Note	Brought Forward £ Surplus/ (Deficit)	Incoming Resources £	Resources Expended £	Transfers In/(Out) £	Carried Forward £ Surplus/ (Deficit)
<b>Unrestricted funds</b>						
General fund	12a	120,626	360,732	380,641	-	100,717
<b>Designated funds</b>						
WADD		10,140	-	-	-	10,140
<b>Total</b>		<u>130,766</u>	<u>360,732</u>	<u>380,641</u>	<u>-</u>	<u>110,857</u>
<b>Restricted funds</b>						
WADD		113,628	7,247	58,437	-	62,438
Cornwall	12a	-	13,002	2,435	-	10,567
Devon		-	-	-	-	-
LDA		3,590	-	-	-	3,590
Counselling		-	-	-	-	-
Research		17,136	14,432	727	-	30,841
<b>Total</b>		<u>134,354</u>	<u>34,681</u>	<u>61,599</u>	<u>-</u>	<u>107,436</u>

**12a Special Projects**

**Cornwall Fund:**

CELP	-	2,500	135	-	2,365
EpSMon	-	10,502	2,300	-	8,202
	<u>-</u>	<u>13,002</u>	<u>2,435</u>	<u>-</u>	<u>10,567</u>

**General Fund:**

Included in the general fund is the Scotland Development project:					
Scotland Development	(9,795)	6,250	11,150	-	(14,695)

**Notes to the Financial Statements  
for the Year Ended 31 March 2017**

**13 Details of restricted funds and special projects**

<b>WADD</b>	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.
<b>Cornwall</b>	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).
<b>Devon</b>	Expansion of the Cornwall Life Project.
<b>Research</b>	General research into the causes & prevention of epilepsy deaths.
<b>LDA</b>	Learning Disabled Adults - to provide appropriate epilepsy risk information for individuals, carers and professionals.
<b>Counselling</b>	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).

**14 Analysis of net assets between charities**

	<b>SUDEP Action</b>	<b>Epilepsy Bereaved</b>	<b>Total</b>
Fixed assets	-	-	-
Debtors	-	24,906	24,906
Cash at bank and in hand	-	201,107	201,107
Creditors	-	(7,720)	(7,720)
Total net assets	-	218,293	218,293