

Epilepsy Bereaved

(Sudep Action new working name)

Registered Charity No. 1050459
www.sudep.org

Annual report and financial statements

For the year ended 31 March 2014

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 Maureen Lahiff (resigned November 2013) Simon Lees John Lipetz Mark Phillips Alex Stirling Roger Scrivens Graham Faulkner (appointed October 2013)
Charity No.	1050459
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

CONTENTS

	Page
Report of the Trustees	1-11
Independent Examiner's report	12
Charity statement of financial activities	13
Charity balance sheet	14
Notes to the financial statements	15-19

SUDEP Action (the working name for Epilepsy Bereaved)

TRUSTEES' REPORT

For the year ended 31 March 2014

The trustees present their report and accounts for the year ended 31 March 2014.

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
Maureen Lahiff (resigned November 2013)
Simon Lees
John Lipetz
Mark Phillips
Alex Stirling
Roger Scrivens
Graham Faulkner (appointed October 2013)

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 eight employees, most of whom work part-time, which equates to approximately five full-time equivalents. The office is situated in Wantage, Oxfordshire.

Our Mission

Our mission as an organisation is to prevent unnecessary deaths from epilepsy, including SUDEP (Sudden Unexpected Death in Epilepsy). SUDEP occurs when a person with epilepsy, who is otherwise healthy, dies suddenly and no other cause of death is found. There are around 1200 epilepsy-related deaths each year in the UK (3 deaths every day), of which over 600 are attributed to SUDEP. Most of these deaths are in the young and are potentially avoidable.

Recently international public health experts have highlighted that the public health burden of SUDEP is substantial because the deaths are in the young. Regrettably, it continues to be underestimated by the medical profession.

What we do

SUDEP Action cares for the bereaved and works with families and professionals to bring about positive change. Through research and raising awareness, we strive to find the answers that will save lives. We provide information that helps people with epilepsy to understand the risks associated with the condition and to take steps to reduce those risks.

Whilst the causes of SUDEP remain elusive, scientific evidence supports risk reduction strategies. Minimising the number of seizures is considered the best way of reducing deaths until more evidence emerges. Epilepsy surgery may be an option for some people at high risk but many more simple interventions, such as identifying people at risk, communication of risk and elevation of care may encourage better management.

SUDEP Action supports national clinical guidelines that recognise that the risk of SUDEP, however low for some, is essential information for people with epilepsy. SUDEP Action is supported by a scientific advisory group of experts in the field of epilepsy and epilepsy mortality.

The charity continues to campaign for change and is successful at influencing the NHS and government for improvements in epilepsy care. The overarching aim is to prevent unnecessary deaths from epilepsy and our work in this area includes direct liaison with health professionals, pathologists and coroners.

Collaboration

We continue to support work, both throughout the UK and in international arenas, to secure funding for research projects into SUDEP and we promote collaboration where we can. SUDEP Action has influenced developments in the subject around the world and in 2013 the work of SUDEP Action was recognised in a prestigious international award from global medical and patient organisations following nomination by epilepsy specialists from the British branch of the International League against Epilepsy. This award is conferred once every two years in recognition of the impact in improving the lives of people with epilepsy, not only in the UK, but around the world.

SUDEP – The Global Conversation (www.sudepglobalconversation.com) is collaboration between SUDEP Action, Epilepsy Australia and SUDEP Aware (Canada), a strong partnership created and expanded since 1998. The Global Conversation enables us to spread awareness and network effectively with researchers and epilepsy organisations on a global basis.

We seek to increase and foster new working relationships as SUDEP becomes recognised as a priority for other countries.

In the UK, SUDEP Action is a member of the Neurological Alliance and the All Wales Epilepsy Forum. The charity supports work to improve neurological services, while maintaining a focus on specific changes that are necessary to address the prevention of SUDEP and other epilepsy deaths.

The charity works closely with other medical and epilepsy organisations in areas of common interest that will benefit people with epilepsy. These include the Royal College of General Practitioners, Epilepsy Action and Epilepsy Society. We influence commissioners of services for people with epilepsy and respond to consultations with NHS England.

Our priorities

Epilepsy is one of the top-ten causes of early death. More needs to be done to reduce unnecessary deaths from the condition.

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

At the heart of the charity are the bereaved and we aim to reach out to them at their point of immediate need. They inform and influence us to provide services that will help them and others, not only at a time when they struggle to understand what has happened and why, but for as long as they need us.

We continue to focus and prioritise our efforts on what the bereaved tell us is important, delivering these through the five key strands of our charitable activities. These 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** through the Epilepsy Deaths Register

During regular reviews of services we remain mindful of changes in best practice and guidance of working with the bereaved, with sudden death and with trauma.

During 2013 we met our primary objectives:

- Attracting over 300 reports to the Epilepsy Deaths Register
- Successfully working with researchers in Cornwall to develop a safety check list which is now being piloted in Cornwall with general practitioners
- Raising public awareness through our campaigns
- Providing information and advice to international agencies
- Increasing our fundraising and capacity to develop our services

This work, and also the core work of the charity, is summarised below:

Providing information:

As people with epilepsy become more aware of the risks associated with epilepsy and in particular the risk of SUDEP, they need to access information that is easy to understand, readily available and up to date. Health professionals and carers also need access to information which will inform their practice.

We actively review our information and strive to improve it when and where necessary or, produce new information when we recognise an information gap. As well as our pre-printed information, we are able to liaise with our scientific committee to provide specific answers where the information required is more complex.

During the year we provided information via our leaflets:

- Epilepsy – Be smart, be safe
- SUDEP - reducing your risk. Information for teenagers and young adults
- SUDEP – explained. A short guide for the health professional
- SUDEP – understanding the risk. Information and guidance for people with epilepsy
- SUDEP – after a death. Information for the bereaved
- How SUDEP Action helps to prevent deaths in epilepsy
- The Epilepsy Deaths Register – making every epilepsy death count

Offering support:

Sudden Unexpected Death in Epilepsy (SUDEP) can be traumatic for families and distressing for professionals. SUDEP Action provides support and information at a point of immediate need. We are the only charity in the UK providing this service. Our specialist service provides:

- A valuable listening space
- Help with understanding the post mortem
- Help with understanding the investigation of the death
- Help from our SUDEP and epilepsy experts
- On-going emotional support
- Opportunities to be with others who have been bereaved by epilepsy
- Opportunities to meet with epilepsy and SUDEP experts
- Counselling
- Training

For many who find themselves thrust into an unfamiliar world of police and coronial inquiries, finding someone who understands the procedures and can offer guidance and support is often a lifeline.

As a charity we aim to provide support for the bereaved and offer services that bring them together with like-minded professionals, to ask questions, to tell their stories and to look at ways to effect change.

For the bereaved, spending time with professionals who are prepared to share their expertise is helpful, indeed vital, to finding answers and strategies that will assist them at the most difficult time. During the financial year:

- 160 bereaved people were brought together with experts in epilepsy mortality and SUDEP
- 1500 contacts were made with bereaved people accessing support
- 60 newly bereaved families were supported at the point of immediate need
- 23 families were provided with specialist information and support relating to coronial investigations

Our service is continuous. We are there for people as long as they need us:

"I contacted the support team soon after my loss because I had to support my son and my other daughter. I was desperate for help and support. Their support line has really been my saviour.

And still, every few months I get such rewarding phone support that really lifts my spirits and moral. They remind me that I am not alone in this most shocking bereavement from SUDEP”.

A bereaved mother

Counselling:

We set up our telephone counselling service after hearing of the difficulties experienced by the bereaved in accessing suitable services. While generic bereavement support is helpful, there can be difficulties for the bereaved in establishing a relationship with the counsellor, becoming frustrated as they have to explain not only about epilepsy but about SUDEP in particular.

“The SUDEP Action counsellor was able to better relate to my situation because of my sister’s epilepsy and because of their existing knowledge of the condition. I found the counsellor very empathic”.

A bereaved sibling

We provide our SUDEP Action specialist service by telephone, as we are more easily able to reach people from remote areas, people who are not always at the same location each week and people from communities where openly accessing support after a death may not be culturally acceptable.

Our counselling service is particularly helpful to those who struggle to carry on with their day to day lives.

“As you know, I sought your help about a year after my son’s death when I felt that I could not go on without talking to someone”.

A bereaved mother

Involving people:

We support the bereaved to tell their story to help raise awareness and achieve change. For example:

It is essential that medical students learn more about epilepsy, including epilepsy deaths and the needs of the bereaved. Hearing actual stories can be more powerful than reading of the effects of SUDEP and of the devastation that such deaths bring.

Bereaved parents spoke about the effects of SUDEP at the ILAE UK Chapter Medical Students/FYI Epilepsy Teaching Weekend. Speaking at the University of Birmingham to over 70 students they told the story of their daughter Rachel, who died aged 20 and took questions from the students who found the session most informative.

“We received very positive feedback from the students and felt really glad to have done this event although it was difficult at times it is important to us to try to bring some good from the tragedy of losing our daughter to SUDEP”.

Bereaved parents

SUDEP Action supports the bereaved who want to be active in this way as many find it helpful in their grief.

People grieve differently and as a charity we recognise that, for many, being active is a way of expressing and dealing with emotion. We also understand that people often want to connect instantly, as grief can come in waves, and we offer this via different social media platforms. Our supporters are able to instantly celebrate their achievements and offer hope to others who read their stories via Facebook, Twitter and blogs.

During the year 600 people were supported to raise awareness and to generate funds for the charity.

Many supporters of the charity are university students and young adults. It is essential that awareness is raised amongst this age group as they are the most at risk.

Communications:

In the past year, SUDEP Action news items appeared in the press resulting in a total reach of around 6.2 million.

Our online reach was 671,800 supported through various online platforms including the website and social media.

We have worked hard on our social media communications and have developed a strong presence that continues to grow.

- **Twitter:**
During the year the number of SUDEP Action followers on Twitter increased to 789 and continues to grow. Of these, 147 are epilepsy organisations and professionals. SUDEP Action received 532 Twitter mentions and achieved a reach of 6,573.
- **Facebook:**
SUDEP Action followers increased to 704, the total reach being in excess of 50,000.

Sponsoring research and education:

SUDEP Action is committed to sponsoring research and providing the resources and training needed to understand the risks associated with epilepsy. The charity is proactive in highlighting gaps in research and in bringing research teams together.

Our work during the year included:

Statement of Research Need:

At a SUDEP Action research workshop held in London in January 2014, when we brought together senior UK research teams, a statement of intent was agreed setting out the principles of working to reduce unnecessary deaths from epilepsy. Following that meeting a statement of research need was agreed. The statement recognised the importance of wider awareness that urgent funds are required to answer all the research questions that make up the current UK research gap on prevention of epilepsy deaths.

“SUDEP Action has worked tirelessly to fund the research gap, but external funders do not often understand the research gap or fail to prioritise it. We will use this statement of research need to gather support and to both inform and persuade funding bodies that work on prevention of deaths should be a clearly stated priority”.

Professor Mark Richardson of Kings Health Partners

Call for openness

Jane Hanna OBE, Chief Executive of SUDEP Action and Mike Glynn, President of the International Bureau for Epilepsy (IBE) and CEO of Epilepsy Ireland, led the Call for Openness in June 2013 at the International Epilepsy Congress (IEC) in Montreal.

Working with our international partners Epilepsy Australia and SUDEP Aware in Canada we are actively promoting the call for openness at epilepsy events. To date 15 epilepsy organisations from 11 countries have signed up to support the call for openness.

Epilepsy, like heart disease and stroke, ranks in the top ten causes of premature deaths. Many of these deaths are potentially avoidable. Lack of public awareness of epilepsy mortality has meant that research and treatment has lagged behind. Three people die each day in the UK from epilepsy, including many young and otherwise healthy people.

Our Call for Openness campaign is aimed at raising awareness and saving lives. It stresses that people with epilepsy need to be fully informed if they are to make the right lifestyle choices to reduce their risk of SUDEP.

The call is for a common sense approach to alert people at risk of SUDEP of ways to reduce that risk. It aims to:

- Encourage people with epilepsy to be open about their condition
- Encourage doctors and nurses to talk about risk including the risk of SUDEP on, or soon after diagnosis
- Encourage people with epilepsy to report their seizures accurately
- Encourage people with epilepsy to take their medications regularly and as prescribed

Although there is much improved awareness around risk in epilepsy, the need for individualised communication about SUDEP is essential. Communication about risk provides an opportunity for the patient to share their thoughts and fears, which can help them to make informed decisions on medicines adherence and self-management.

Openness about SUDEP is about information being given routinely as part of general epilepsy information. Information given in a positive way early on, at or following diagnosis, can help people understand whether they are at any risk and the measures they can take to reduce and manage this.

SUDEP Action has led the development of accurate information available on the internet. We know, however, that although many people only have access to information this way, patients prefer information and discussion with their doctors and nurses. The medical team is also best placed to decide whether to withhold or delay informing someone of their risk if there is good reason to believe that information about SUDEP is likely to cause a person real harm.

International

Towards the end of the financial year we agreed to partner with Epilepsy Ireland, a charity we have worked successfully with since the 1990's, to establish The Epilepsy Deaths Register for Ireland. Funded by Epilepsy Ireland, the register will be launched in the autumn of 2014 and will use our existing systems infrastructure.

Our project, *SUDEP - The Global Conversation* website has attracted more than 300,000 hits and has disseminated 17,000 books.

During 2013 SUDEP Action gave one of three presentations at the first national workshop on SUDEP to be held in the Netherlands. The workshop led to a national action plan to raise awareness of SUDEP and undertake national research.

SUDEP Action provided speakers at an Epilepsy Research UK workshop on SUDEP in Oxford attended by international research experts, with a summary of our presentation published in a leading medical journal.

Preliminary findings of the Epilepsy Deaths Register were presented in Minneapolis at a two day conference on epilepsy mortality organised by the Partners Against Mortality in Epilepsy (PAME) in June 2014 and we provided a speaker at the meeting of regional epilepsy organisations from Australia, New Zealand and Asia at the Epilepsy Congress meeting organised by the International League Against Epilepsy and International Bureau for Epilepsy in August 2014. Raising awareness of the need and importance of registers of epilepsy deaths and highlighting the quality of data that can be obtained.

Epilepsy Life Project

Research funded in Cornwall, has produced preliminary findings which strongly indicate more awareness and better understanding of epilepsy risk is urgently needed. ([http://www.seizure-journal.com/article/S1059-1311\(14\)00056-9/abstract](http://www.seizure-journal.com/article/S1059-1311(14)00056-9/abstract))

93 records of deaths in people with epilepsy were studied, with 48 cases meeting the criteria for SUDEP. Among the 48 cases, 39 had suffered tonic-clonic seizures (the main risk factor for SUDEP). It was noted that there had been a worsening of seizures in the six months leading up to death, yet only 9 of the patients had met a specialist 1 year prior to their death and only 21 had contact with the GP for an epilepsy medication review. Night surveillance was not present in 43 cases (night seizures are a known risk factor), suggesting surveillance may be protective. Other risk factors identified in the study were non-compliance with medication and alcohol problems. Researchers concluded that many of the SUDEP deaths analysed might have been preventable.

Researchers have now developed a safety checklist which highlights 20 factors from past evidence of risk factors in people who died of SUDEP. The safety checklist is now being used routinely by general practitioners in Cornwall as part of a telemedicine outreach intervention to identify people at risk.

Capturing data:

The Epilepsy Deaths Register

The highlight of our past year was the launch of the Epilepsy Deaths Register, an easy access single point for reporting all epilepsy related deaths.

Registers of epilepsy death are an important new development in work on SUDEP prevention across the world. Reporting of all deaths will help researchers to pick up the vital details they need to fully understand why these deaths occur and how they can be prevented.

The SUDEP Action Epilepsy Deaths Register was launched at Westminster in June 2013 and proved successful receiving over 300 registrations in the first year.

This is the most significant initiative from SUDEP Action since the National Deaths Audit in 2002. I look forward to seeing what the register will show over the next few years

Professor Henry Smithson

The first year of data collection from the EDR, whilst a small sample, will be presented at an international meeting later this year and highlights a number of key points:

- young people aged 20-30 years appear to be at most risk
- parents are keen to report the death of their child
- there are still gaps in knowledge about SUDEP which need to be addressed

Future plans to expand the register into Ireland have been developed and work has already started in this area.

Finance and Service Development:

During the year SUDEP Action launched The Epilepsy Deaths Register and towards the end of 2013 agreed to work with Epilepsy Ireland to establish The Epilepsy Deaths Register for Ireland. This collaboration resulted in additional development work being carried out to our website and the deaths register infrastructure. The deficit reported in the financial figures has been recovered in the 2014/2015 financial year by way of a payment from Epilepsy Ireland

Financial Policies

Reserves policy:

Reserves are maintained in order to meet the ongoing day-to-day expenditure of the charity for 12 months. In spite of continued difficult economic times we have increased our reserves slightly, which at the end of the year reached six 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 officer provides timely management information and trustee reports to ensure that trustees are fully aware of the need to take action if required. In spite of recent difficult economic times, the charity's financial position has improved.

The Future

As a small charity receiving no government funding, we rely heavily on our supporters for financial input. Donations from bereaved families and friends are vital in helping us to deliver our aims to create change and save lives.

In little over 15 years, SUDEP Action has succeeded in raising awareness of SUDEP from near zero point to full recognition in national and international medical, legislative and political circles. Research has increased over the past few years and there continues to be more interest in this area. Whilst this is good news, we recognise that we have to focus on delivery of that research if lives are to be saved. To do this we will need to maintain funds, increase our income and choose our projects carefully.

SUDEP Action will continue to make a difference as we learn from those who have been bereaved by epilepsy and from information received via the Epilepsy Deaths Register. We believe there is an important role for us in providing accessible care for the bereaved, thus reducing potential long term problems associated with experiencing the trauma of sudden death. We recognise that, as there is now more awareness of the risks associated with epilepsy, we need to ensure that people understand ways to reduce their risk and act positively on that information.

Our network of global partners and our projects, the *Epilepsy Deaths Register* and *SUDEP – The Global Conversation*, help us to engage with initiatives around the world and to break down the taboo associated with SUDEP, which still exists in many parts of the world.

We now need to deliver this awareness and education to a wide range of professionals who are involved in treating and caring for people with epilepsy in the community, yet who remain unaware of the risk. We believe that by developing the first e-learning on SUDEP globally, we will be able to reach the UK audiences that need access to this vital information.

During 2014/15 we will:

- Provide E-Learning for professionals, carers and people with epilepsy
- Increase reporting to the Epilepsy Deaths Register
- Increase international collaboration by means of the Epilepsy Deaths Register, the Global Conversation and the Call for Openness
- Expand our work to increase our reach and provide more local access to families in rural England, Scotland and Wales
- Develop resources aimed at people with a learning disability and their parents or carers and resources aimed at discussing risk with children
- Expand the Cornwall Epilepsy Life Project
- Launch major fundraising appeals to allow us to invest in projects aimed at supporting people who are most at risk.

Signed for and on behalf of the Board of Trustees

A handwritten signature in black ink, appearing to read 'Stephen Brown', written in a cursive style.

S Brown
Chair of Trustees

10 October 2014

Epilepsy Bereaved

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF EPILEPSY BEREAVED

For the year ended 31 March 2014

I report on the accounts of the Trust for the year ended 31 March 2014, 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) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 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. 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
 - accounts are prepared which agree with the accounting records and comply with the accounting requirements of the 2011 Act; 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

Statement of Financial Activities
For the year ended 31 March 2014

		Unrestricted Funds 2014	Restricted Funds 2014	Total Funds 2014	Total Funds 2013
	Note	£	£	£	£
Incoming resources					
Voluntary Income	2	105,994	41,536	147,530	110,508
Activities for generating funds	3	136,291	1,451	137,742	103,878
Investment Income	4	503	-	503	366
Incoming resources from charitable activities	5	3,643	500	4,143	
Total Incoming Resources		246,431	43,487	289,918	214,752
Resources Expended					
Cost of generating funds	6	20,190	25	20,215	36,157
Charitable activities	7	177,032	37,509	214,541	179,960
Governance Costs	8	4,676	-	4,676	8,005
Total Resources Expended		201,898	37,534	239,432	224,122
Net Incoming/(Outgoing) Resources Before Transfers		44,533	5,953	50,486	(9,370)
Gross Transfers between Funds		(5,483)	5,483	-	-
Net Movement in Funds		39,050	11,436	50,486	(9,370)
Funds brought forward at 1 April 2013 (2012)		71,618	18,886	90,504	99,874
Funds carried forward at 31 March 2014 (2013)		110,668	30,322	140,990	90,504

The notes on pages 15 to 19 form part of these financial statements.

Balance Sheet as at

		31 March 2014	31 March 2014	31 March 2014	31 March 2013
	Note	Unrestricted Funds	Restricted Funds	TOTAL	TOTAL
		£	£	£	£
Fixed Assets	1f	-	-	-	-
Current Assets					
Prepayments		5,061	-	5,061	-
Debtors		13,442	30	13,472	-
Accrued Gift Aid		3,512	153	3,665	-
Cash at bank and in hand:					
Funds in credit		96,230	38,687	134,917	111,582
Fund in deficit	13a	-	(6,032)	(6,032)	-
		118,245	32,838	151,083	111,582
Creditors: amounts falling due within one year	11	(7,577)	(2,516)	(10,093)	(21,078)
Net Assets		110,668	30,322	140,990	90,504
Funds					
Unrestricted Funds	12	110,668		110,668	71,618
Restricted Funds:	13				
Funds in credit			36,354	36,354	18,886
Fund in deficit	13a		(6,032)	(6,032)	
		110,668	30,322	140,990	71,618

The financial statements were approved by the Board of Trustees on 10/10/2014 and signed on its behalf by:



Stephen Brown
Chair of Trustees

The notes on pages 15 to 19 form part of these financial statements.

**Notes to the Financial Statements
for the Year Ended 31 March 2014**

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 and which have not been designated for other 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 13 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 scales 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. 2014: nil (2013: 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.

**Notes to the Financial Statements
for the Year Ended 31 March 2014**

	Unrestricted Funds £	Restricted Funds £	TOTAL 2014 £	TOTAL 2013 £
2 Voluntary Income				
Donations	52,013	1,000	53,013	40,210
Grants	12,772	40,250	53,022	56,790
Gift Aid *	40,383	286	40,669	8,830
Legacies	55	-	55	-
Sundry income	771	-	771	4,678
	105,994	41,536	147,530	110,508
* Gift Aid for 2014 includes arrears of £20,531 and current year accrual of £3,665				
3 Activities for generating funds				
General fundraising	134,446	1,451	135,897	100,289
Collecting boxes	278	-	278	264
Sale of goods	1,207	-	1,207	2,461
Letting office space	360	-	360	864
	136,291	1,451	137,742	103,878
4 Investment income				
Interest Receivable	503	-	503	366
	503	-	503	366
5 Incoming resources from charitable activities				
Dunchurch conference	3,643	-	3,643	-
Fees receivable	-	500	500	-
	3,643	500	4,143	-

**Notes to the Financial Statements
for the Year Ended 31 March 2014**

	Unrestricted Funds £	Restricted Funds £	TOTAL 2014 £	TOTAL 2013 £
6 Cost of Generating Funds				
Fundraising Expenses	10,189	25	10,214	10,397
Salaries and National Insurance	10,001	-	10,001	25,760
	20,190	25	20,215	36,157
7 Cost of Charitable activities				
Postage and Stationery	3,760	-	3,760	3,940
Telecommunications	3,395	21	3,416	4,152
Printing & Publicity	7,344	-	7,344	6,842
Salaries & National Insurance	126,931	6,632	133,563	101,632
Pension Scheme Contributions	736	-	736	520
Consultancy & other staff costs	690	-	690	490
Travel, Accomodation & Subsister	6,634	1,179	7,813	5,907
Research grants	-	24,748	24,748	20,332
Affiliations to Other Groups	196	-	196	230
Development of Web Site	1,553	4,542	6,095	10,713
Cost of Support Group Meetings	8,490	-	8,490	7,540
Bank Charges	-	-	-	4
Training	30	-	30	162
Office Costs, including Insurance	15,084	-	15,084	16,771
Conferences & Seminars	2,008	387	2,395	-
Sundry Expenses	181	-	181	725
	177,032	37,509	214,541	179,960
8 Governance Costs				
Staff Costs	2,500	-	2,500	2,500
Cost of Trustees' meetings	1,414	-	1,414	4,755
Independent Examiner's Fee	762	-	762	750
	4,676	-	4,676	8,005
9 Staff Costs including Pension Scheme Contributions				
Salaries & National Insurance	139,432	6,632	146,064	129,892
Pension Scheme Contributions	736	-	736	520
	140,168	6,632	146,800	130,412

There was an average of 5.4 employees (FTE) during the year (2013: 5.0)

No employee earned over £60,000 in the year (2013: nil).

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

**Notes to the Financial Statements
for the Year Ended 31 March 2014**

10 Trustee expenses

The trustees received no remuneration during the year (2013: nil).
2 trustees were reimbursed a total of £626 (2013: 4 trustees £1,229) for expenses.

11 CREDITORS: amounts falling due within one year

	Unrestricted Funds £	Restricted Funds £	TOTAL 2014 £	TOTAL 2013 £
Trade Creditors	2,389	2,500	4,889	17,193
Receipts in Advance	350	-	350	-
HMRC-PAYE/NI	2,668	16	2,684	3,077
Pension	118	-	118	58
Accrued Expenditure	2,052	-	2,052	750
	<u>7,577</u>	<u>2,516</u>	<u>10,093</u>	<u>21,078</u>

12 UNRESTRICTED FUNDS

	2014 £	2013 £
General Fund (Unrestricted and undesignated)		
Balance at 1 April 2013 (2012)	71,618	94,374
Incoming Resources	246,431	157,594
Outgoing Resources	(201,898)	(180,350)
Transfers	(5,483)	-
Balance at 31 March 2014 (2013)	<u>110,668</u>	<u>71,618</u>

13 RESTRICTED FUNDS**a) Research Funds:****General Research** (into causes & prevention of epilepsy deaths)

	2014 £	2013 £
Balance at 1 April 2013 (2012)	-	-
Incoming Resources	4,980	5,158
Outgoing Resources	(10,463)	(5,158)
Transfers	5,483	-
Balance at 31 March 2014 (2013)	<u>-</u>	<u>-</u>

Cornwall Life Project (Community study of SUDEP deaths to identify main risk factors)

Balance at 1 April 2013 (2012)	18,886	-
Incoming Resources	17,000	40,000
Outgoing Resources	(3,269)	(21,114)
Transfers	-	-
Balance at 31 March 2014 (2013)	<u>32,617</u>	<u>18,886</u>

Devon Life Project (Expansion of Cornwall Life Project)

Balance at 1 April 2013 (2012)	-	-
Incoming Resources	2,277	-
Outgoing Resources	-	-
Transfers	-	-
Balance at 31 March 2014 (2013)	<u>2,277</u>	<u>-</u>

**Notes to the Financial Statements
for the Year Ended 31 March 2014**

13 RESTRICTED FUNDS (continued)	2014	2013
	£	£
a) Research Funds: (continued)		
Epilepsy Death Register (global resource for research into causes and prevention)		
Balance at 1 April 2013 (2012)	-	-
Incoming Resources	17,530	-
Outgoing Resources	(23,562)	-
Transfers	-	-
Balance at 31 March 2014 (2013)	<u>(6,032)</u>	<u>-</u>
b) Support Funds:		
Bereavement Counselling		
Balance at 1 April 2013 (2012)	-	5,500
Incoming Resources	1,000	12,000
Outgoing Resources	(240)	(17,500)
Transfers	-	-
Balance at 31 March 2014 (2013)	<u>760</u>	<u>-</u>
Memorial Service Book		
Balance at 1 April 2013 (2012)	-	-
Incoming Resources	200	-
Outgoing Resources	-	-
Transfers	-	-
Balance at 31 March 2014 (2013)	<u>200</u>	<u>-</u>
c) Education Funds:		
Learning Disabled Adults (to provide appropriate epilepsy risk information for individuals, carers & professionals)		
Balance at 1 April 2013 (2012)	-	-
Incoming Resources	500	-
Outgoing Resources	-	-
Transfers	-	-
Balance at 31 March 2014 (2013)	<u>500</u>	<u>-</u>