

Epilepsy Bereaved

Registered Charity No. 1050459
www.sudep.org

Annual report and financial statements

For the year ended 31 March 2012

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 Simon Lees John Lipetz Mark Phillips Alex Stirling Roger Scrivens
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

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TRUSTEES' REPORT

For the year ended 31 March 2012

The trustees present their report and accounts for the year ended 31 March 2012.

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

Epilepsy Bereaved, 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:

Mrs S Allen
Professor S Brown (Chair)
Mr J Hirst
Mrs M Lahiff
Mr S Lees
Mr J Lipetz
Mr G Neely (Treasurer)
Mr M Phillips
Mrs J Preston (Vice-Chair)
Mr R Scrivens
Ms A Stirling

Scientific Advisory Committee

Dr. Richard Appleton
Dr. Marjorie Turner
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

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*Epilepsy Bereaved has a formal collaboration with Kings College, London and Kings College Hospital Foundation NHS Trust, 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

Epilepsy Bereaved 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. Epilepsy Bereaved 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 eight employees, most of whom work part-time, which equates to approximately five full time equivalents. The main office is situated in Wantage, Oxfordshire. Three staff are based in Wales.

Charity Mission:

Our mission as an organisation is to prevent SUDEP and other epilepsy-related deaths. SUDEP occurs when a person with epilepsy, who is otherwise healthy dies suddenly and no other cause of death is found. There are over 1000 epilepsy-related deaths each year in the UK, of which over 500 are attributed to SUDEP.

Epilepsy deaths feature in the national top ten of all causes of mortality that ought to be avoided because most deaths occur in the young (the peak age is between 20 and 40) and there is greatest potential for prolonging life.

Epilepsy Bereaved uniquely dedicates its efforts into three key strands of work, each of which contribute to the overarching aim of prevention of deaths:

1. Funding and conducting research into the causes of SUDEP (sudden unexpected death in epilepsy) and other epilepsy-related deaths
2. Supporting bereaved families and helping them cope with their grief through involving them in our work
3. Campaigning for Change – this work involves:
 - Influencing policy makers and health professionals for improvements in epilepsy care to prevent unnecessary deaths

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- Raising awareness of SUDEP and ways to reduce the risks of epilepsy-related deaths amongst people with epilepsy

Epilepsy Bereaved is a member of the Neurological Alliance; and the Wales Epilepsy Forum. The charity supports general campaign work to improve neurological services, but maintains a focus on the specific changes that are necessary to address prevention of SUDEP and other epilepsy deaths.

Internationally we lead and actively collaborate with SUDEP campaign projects working in particular with Epilepsy Australia; SUDEP Aware (Canada) and Partners Against Mortality in Epilepsy (North America).

Background

Since founding in 1995 Epilepsy Bereaved has worked closely in collaboration with interested researchers to achieve change. Sudden deaths in epilepsy were not generally recognised in research or in clinical practice up until recently. Indeed SUDEP and bereavement from epilepsy was a taboo subject world-wide for many years.

Epilepsy Bereaved spearheaded an international SUDEP campaign from 1995, participating and speaking at epilepsy events in the UK and Ireland, Europe, Australia, North and South America. In 2004 Epilepsy Bereaved partnered with Epilepsy Australia and produced 'SUDEP - the Global Conversation'. The book, available from epilepsy.com - a major US website - as well as Epilepsy Bereaved and Epilepsy Australia has stimulated world-wide interest in SUDEP and fostered an ongoing dialogue on SUDEP between international researchers, policy makers and the voluntary sector. In 2011 a new partner, SUDEP Aware (North America) joined the collaboration and a new edition and web-based global resource was produced. Some 10,000 copies including contributions from over 60 international experts have been distributed across the world by Epilepsy Bereaved, Epilepsy Australia, SUDEP Aware and also by the Epilepsy Foundation of America.

In 2008, and again in 2012, Epilepsy Bereaved was invited to support North American action on SUDEP. In 2011 Epilepsy Mortality featured for the first time in the Presidential symposium of the Epilepsy World Congress.

The outcomes of the global campaign in 2012 are:

- A widely accepted scientific definition of SUDEP in the international scientific community
- Concerted global action by international researchers and international advocacy groups
- Identification of common risk factors especially not being seizure-free

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- Wide acceptance in the international scientific community of the priority for action on SUDEP focused on potential for avoidance of death through reduction of risk
- Wide acceptance in the international scientific community of the importance of national and international surveillance of deaths
- A research strategy focused on surveillance of deaths, clinical research improving understanding of risk and intervention as well as searching for potential preventative treatments through basic science and genetics research projects.

“Your personal efforts and those of Epilepsy Bereaved have provided inspiration for those of us in the United States and around the world. Epilepsy Bereaved has demonstrated the importance of advocacy organizations in helping to inform the lay community and professional societies. It is our hope that through future collaborations with Epilepsy Bereaved and other international advocacy groups, we will move beyond awareness of SUDEP to prevention of epilepsy related deaths.

Jeff Buchhalter, Gardiner Lapham (Partners Against Mortality in Epilepsy 2012)

Today, although many uncertainties remain, there is recognition that the research justifies a new approach to epilepsy management – recognising that epilepsy is a serious rather than benign condition and that supporting the person with epilepsy and their family to manage risks of the condition must be central to clinical practice and services. A landmark judicial determination in 2011 supported the approach of sharing information on SUDEP with patients and carers about prevention and the ways to reduce risk.

Research, education and influencing strategies will be necessary to overcome major barriers to the implementation of this radical change. Evidence from national inquiries into maternal deaths and coronial investigations suggests the main cultural barrier is an underestimation of risk by professionals in the community.

Today as a result of Epilepsy Bereaved and our partnership working with the medical profession and the voluntary sector, much of the ground work has been done and there is real hope for the future.

In North America significant advances were made during the year with announcements of \$4 million government and private sector funding for major

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For the year ended 31 March 2012

SUDEP research initiatives, as well as the first Partners Against Mortality in Epilepsy (PAME) conference bringing researchers, clinicians, lay advocacy groups and families together to advance understanding and action. The Director was invited to deliver the key note address and Epilepsy Bereaved together with our research partners at King's College, London, and Sheffield Primary Care Medical Unit were sponsored as international experts at the meeting.

In the UK, funding is urgently needed to advance preventative strategies. UK national research funds are not ring-fenced for SUDEP and indeed projects such as national surveillance of deaths are outside the remit of national research funds. Epilepsy Bereaved is dedicated to tackling the gaps in our understanding of SUDEP and can provide vital seed funding for research projects that would otherwise not get off the ground.

The last national surveillance of epilepsy deaths found that 42% of these deaths could potentially be avoided. This resulted in national clinical and pathology guidelines which are today being used as models for guidelines in other countries. Epilepsy Bereaved led this major programme, working with five medical Royal Colleges. The findings from this work programme remain core to the evidence accepted by government today which supports the case for improving the commissioning of epilepsy services. It is over ten years old now, however, leaving a very serious gap in our understanding.

Epilepsy Bereaved plans to address this gap using research funds raised by bereaved families to work with our research partners, supported by the existing infrastructure of the charity. There is interest in international collaboration to develop a standardised approach and to share findings. Funding is needed to develop the UK surveillance and to enable international collaboration going forward.

Our Work during 2011-12

1. Support for bereaved relatives

Epilepsy Bereaved meets the needs of people affected by SUDEP and other epilepsy-related deaths.

In the midst of the shock of SUDEP, many families find themselves in the totally alien world of crime scene investigations, post-mortems and the inquest process. Questions include: How could a healthy person die so suddenly? Did they suffer? Could I have saved them? It is this last question which so often torments the people who call Epilepsy Bereaved. The support the charity provides can help to break the isolation at a time of trauma when nothing seems to make sense.

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Research commissioned by Epilepsy Bereaved found that people have a deep need to understand SUDEP and to break the isolation they experience after a death. A bespoke service has been developed tailored to helping the needs of families who have experienced this very complicated grief. Epilepsy Bereaved is there to provide specialised information on SUDEP and the system for the investigation of sudden deaths.

Having built up expertise in this area, Epilepsy Bereaved is frequently called upon to provide specialist information and opinion for inquests and Fatal Accident Inquiries.

Year round services for families and carers

Uniquely staffed by bereavement counsellors who are trained in SUDEP and epilepsy mortality and supported by a panel of experts, the charity is able to answer the very individual questions that people need to begin to make sense of what has happened, as well as providing a listening service.

Research shows that sudden death with many unresolved questions can often complicate the grieving process and that early intervention can reduce associated morbidity.

"I honestly don't think I would be here today if it wasn't for the wonderful lady at Epilepsy Bereaved. I didn't have to wear my mask with her and I could finally let it all out."

During 2011 – 12, Epilepsy Bereaved managed around 1,000 calls in relation to 72 newly bereaved families as well as ongoing calls to existing families. Over 1,100 families receive ongoing information and opportunities to use the services of the charity.

Involving families in research

During 2011 a research project involving bereaved families found that the support service at Epilepsy Bereaved was able to collect high quality information and consents to research from bereaved families in a well supported environment. This unique organisation will enable Epilepsy Bereaved to establish itself as a reporting centre for epilepsy deaths as well as supporting registry developments in North America that are aiming to involve bereaved families.

Counselling

During the year Epilepsy Bereaved took forward a telephone counselling service pilot. While the contact line is available to families at any time, telephone counselling offers people a structured service of eight one-hour sessions. The service was set up in response to a demand from families who

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reported that they could not access bereavement services locally or they preferred a counselling service that had an understanding specifically related to the issues of SUDEP and epilepsy mortality.

"The counsellor at EB was better able to relate to my situation because of my sister's epilepsy; this was because of her existing knowledge of the condition. I found my counsellor very empathic."

A counselling client whose sister died from epilepsy.

Seven people have benefited from the counselling service so far and the pilot will be evaluated on completion. Once this pilot feeds back, the charity is likely to need to set up a longer-term service.

National and local conferences

The charity uniquely offers opportunities for bereaved families to meet researchers and clinicians across the UK.

A weekend event was held at Dunchurch, Rugby, involving 77 people affected by SUDEP and other epilepsy-related deaths. Researchers and clinicians presented the latest research and were able to answer questions from families. Supporters who had fundraised and raised awareness during the year were celebrated and there was plenty of social time for families to get to know each other or see old friends.

"Such a helpful experience in wonderful company and surroundings - will look forward to next year's meeting."

Janice Ackerman, newly bereaved mother.

Following feedback from its members, the charity committed to organising local one day meetings throughout the UK bringing families and researchers together in a supported environment. During the year five regional meetings took place attracting another 60 people.

"Personally, I find the group meeting brilliant. I've made friends there – and I won't be without it. It's energising. There's a feeling of kinship.

And, because people don't know much about SUDEP, they find it helpful to be able to ask a professional whatever's on their mind."

Carla Wilton, who lost her daughter, Helen, 39, three years ago sums up how many bereaved families feel.

2. Research

The SUDEP Research Initiative, a formal research collaboration with King's College Hospital NHS Foundation Trust and King's College, University of

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London has progressed well during the year. In particular, this unique partnership has enabled cutting-edge research to be undertaken with a relatively small amount of funding and support from Epilepsy Bereaved. During the year Epilepsy Bereaved has also supported other research teams across the UK working in the field of SUDEP and has been successful as a co-applicant on a major research award from CURE (US) to a research team at the National Hospital, London.

Outcomes from Epilepsy Bereaved funded research

Epilepsy mortality trends, published in the British Journal of General Practice and Pulse, identified risks for epilepsy mortality. These included: poor adherence to medication and missed prescriptions. These were cited as important new findings in the New England Journal of Medicine later in the year, as well as featuring in briefings used by the epilepsy voluntary sector to Parliament and to the Prime Minister.

Study of Anticonvulsant Drug Utilisation in Relation to Epilepsy, published in Seizure found significant discrepancies in relation to prescribing of medications in the community.

Audit of mortality post Vagal Nerve Stimulation treatment - poster presented at the International League against Epilepsy National Conference

Preliminary analysis of 472 patients with refractory epilepsy, who have had a vagal nerve stimulator inserted, was presented as showing no significant impact on mortality rates. Follow-up will take place again in five years.

A pilot register involving Bereaved Families - poster presented at the International League Against Epilepsy National Conference and the Association of British Neurologists

Current research into epilepsy deaths tends to focus on hospitalised patients with difficult to control epilepsy. Anecdotally we know there are significant numbers of people with mild, recently diagnosed and untreated epilepsy who die. It is vital, going forward, that there is national surveillance of deaths in the population as well as selected clinical cohorts. The collaboration between King's College and Epilepsy Bereaved has enabled bereaved families to report a death to the charity support team with a neurologist at King's analysing and reporting data as part of her MSc. The research found that the support team at Epilepsy Bereaved was able to collect high quality data while involving the bereaved in a highly supported environment.

Audit on mortality following epilepsy surgery (ongoing)

This research will flag up mortality rates for patients post epilepsy surgery now and in five years' time to evaluate trends in epilepsy mortality.

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3. Campaigning for change

There are two strands:

- **Influencing** policy makers and health professionals for improvements to tackle unnecessary deaths
- **Raising awareness** of ways to reduce the risks of epilepsy-related deaths among people with epilepsy through whichever channel is most appropriate

The charity campaigns with policy-makers, health managers, clinicians and coroners. Our aim is to raise awareness of the risks of SUDEP and determine how these can be reduced. This in turn is designed to ensure that people with epilepsy have a well-managed care programme. This includes publicising the risks in stopping medication, encouraging people to manage their alcohol intake and ensuring they get a proper night's sleep.

Epilepsy Bereaved and Epilepsy Society announced a strategic alliance during the year. To date this has involved Epilepsy Bereaved working closely with the Epilepsy Society and Neurological Commissioning Support to further our goals on NHS commissioning of good epilepsy services within the development of services for people with neurological conditions.

Epilepsy Bereaved's core communications work during the year included distributing copies of our publication "Be Safe – Reduce Risk" to nurses and other health professionals in the UK, and media work, including international, national, regional and local articles, letters and blogs.

Epilepsy Bereaved highlights during the year included:

- World-wide distribution of 10,000 copies of SUDEP- Continuing the Global Conversation
- The Epilepsy World Congress Presidential Symposium
- Collaboration with Partners Against Mortality in Epilepsy (North America)
- Judicial determination supporting communication of risk of SUDEP and ways to reduce risk to patients and carers (Scotland Fatal Accident Inquiry into the deaths of Erin Casey and Christina Ilia)
- UK debate in Parliament focused on epilepsy mortality
- Presentation to the cross-party group on epilepsy in Scotland and meeting with the Minister for Public Health
- Presentations during the scientific programme of the International League Against Epilepsy (UK) on emergency response to seizures and on practical advice for clinicians after a death

Involvement of the bereaved is at the core of Epilepsy Bereaved. During the year 185 people were supported to be involved. Developing these

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relationships is vital if the charity is to continue to punch above its weight and reach regional audiences as health reforms devolve power more locally.

During the year the charity was able to develop a Volunteer Ambassador Pilot.

Volunteer Ambassadors Pilot

The charity recruited a new post to work with active supporters and develop volunteering. The pilot has been taken forward with

- Six volunteers across the UK committed to working one day a month
- A volunteering policy
- Two training days
- Supported tasks and regular supervision

Main outcomes so far include

- Four coroners wanting information from the charity and keen to sign-post families to Epilepsy Bereaved
- Death investigators in Scotland (Procurator Fiscal) meeting planned
- Offer of meeting from Health Minister Norman Lamb
- MP speaking in Parliament and national media

Denise Brown. Epilepsy Bereaved Volunteer Ambassador case study

Denise's youngest daughter Eve Brown died aged 21 while studying at Staffordshire University

"On the 15th October – Eve's birthday, we attended an Epilepsy Bereaved meeting in Liverpool. It was as if fate guided us there - we could be nowhere else. We met others who knew a little of how we felt and who understood the depth of our loss. Let's face it - losing a child doesn't get much worse. Afterwards we felt a new sense of purpose....I am now six years down the line, and feel that I am ready to pass on my experience and insight to others... I see raising awareness of the risks of epilepsy as a lifelong commitment."

Denise has held a meeting with her local coroner who has offered to speak at charity meetings and is happy to encourage bereaved families to contact Epilepsy Bereaved. Her local MP is also keen to help and has written to government ministers.

Finance and Service Development:

The charity introduced Enews during the year and increased the percentage of supporters receiving e-news to over 50%. This has enabled Epilepsy

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Bereaved to reduce costs, while continuing to provide hard copy news for supporters without access to the internet.

The charity's hard copy magazine was replaced by a smaller and cheaper hard copy news.

A priority of the year ahead is to review our IT requirements and if cost-effective, transfer from server technology to cloud technology.

Reserves policy

Reserves are maintained in order to meet the ongoing day-to-day expenditure of the charity for 12 months. Difficult economic times have meant that our reserves at the end of the financial year reached seven months of operating costs. A priority of the year ahead is to build our marketing capacity with the recruitment of a communications professional and to invest in a new website.

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 by increasing the capacity of the charity to support community fundraising and develop marketing as well as other sources of funding. The finance administrator reports using a traffic light system so that trustees are fully aware of the need to take action should we need to. In spite of difficult financial times, the charity's financial position has improved and indeed quarterly reports to trustees during the year were 'green' and 'amber'.

A volunteering policy has been introduced to support the management of risks arising from involving volunteers and this will be reviewed annually.

The Future

More than 500 mostly young people die unnecessarily each year because not enough money is dedicated to tackling Sudden Unexpected Death in Epilepsy (SUDEP). The shock and devastation of losing a child or partner in the prime of their life rips at the heart of families, friends and ripples through schools, communities and workplaces. The bereavement is profound because the natural order of life has been turned upside down and those left behind find it almost impossible to move on. On top of this unbearable pain, is the knowledge their loved one died from a condition that could have been prevented, is not widely understood and is considered a taboo subject for most people. This is why the work, support, campaigns and research funded

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by Epilepsy Bereaved is more necessary than ever in the UK. EB is the only charity to have spent more than a decade investing into mortality research, which has provided clinicians, governments and policy makers with the evidence needed to drive change and save many lives. The funding is a drop in the ocean of what is needed to harness the major opportunities for international collaboration and maximise the real potential to turn SUDEP awareness into action to tackle prevention of unnecessary deaths.

In addition, EB has a unique bereavement support service that families describe as a life-line before and after inquests. Our annual weekend meeting continues to go from strength to strength and there will be a continuation of our regional support meetings, which will be tailored to people's needs and built upon from the experiences of this year. An evaluation of the pilot counselling project will feed into our future plans for the support service and there will be continued on-going support of families involved in research.

The charity has a strong campaigning arm that not only raises the profile of SUDEP and seizure-related deaths internationally, but also gives families a reason to carry on fighting to increase awareness to prevent other parents, siblings, children and partners from going through the same experience.

The success of our global campaign on SUDEP has resulted in teams across the world focusing efforts on SUDEP. This has led to a better understanding internationally that epilepsy deaths are in the top ten of all conditions with the greatest public health burden because so many of those affected are young people. It is therefore not surprising that this fact has prompted the US government to prioritise research funding into epilepsy mortality and to introduce state surveillance of SUDEP across 17 states.

Looking to the future, the following projects are vital if we are to move the prevention agenda forward:

A SUDEP and seizure deaths research register

The main challenge that lies ahead in the UK is the development of a death register. Epilepsy Bereaved successfully led the NICE National Sentinel Clinical Audit of epilepsy-related deaths in 2002. But while there is no major research funding available for a register in the UK at this time, the information it could provide is crucial. Without this research, doctors, nurses and local managers are working in the dark. Understanding the circumstances of the deaths that are reported in official statistics is necessary to plan services and understand whether any interventions that are being tried to save lives are working. Key stakeholders, including the Chief Medical Officer, have supported the importance of such an initiative.

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Working with our research partners, seed funding has been agreed to establish Epilepsy Bereaved as a reporting centre for deaths. EB is commissioning a new website that will allow for secure online registration of a death. It will also provide opportunities for researchers to report a death and for bereaved families to consent to participate in research. These consents are vital for access to medical information.

Research publicised at international conferences this year reported that Epilepsy Bereaved has the capability to coordinate the support of the bereaved and collect high quality data in a supportive environment. The National Institutes for Health (US) and other organisations planning registry development are keen to collaborate with EB on the development of surveillance of deaths. Working with our academic partners, we plan to both coordinate and provide supported involvement of bereaved families in giving the necessary consents and information to support research, but also access to counselling and other EB services.

Epilepsy Life Project

Epilepsy Bereaved plans to commission research for a "safety check list" to support professionals advising people with epilepsy about risk. Many doctors report that they do not discuss the risk of SUDEP with epilepsy patients, yet communication of risk is fundamental. Information leaflets are available to support this communication, but are not enough to help professionals tailor discussion of risk with their patients. The support tool will use the evidence available in the scientific literature, but will be developed following research on the last 50 deaths in Cornwall.

Responding to the challenge of the NHS reforms and therefore to local rather than national decision-making in the NHS, Epilepsy Bereaved will establish a local pilot aimed at developing the evidence at a local level of modifiable risk factors for both sudden death and emergency admission so that local managers can make informed decisions about the planning of services.

Cornwall is the chosen locality because of the strength of collaboration between key partners in this area and the availability of funding. The charity has brought together local researchers and clinicians, SUDEP experts and the local coroner and aims to seek early interest and engagement by those responsible for purchasing and delivering epilepsy services in the local area. With improved understanding of the evidence, the charity hopes that this pilot will deliver change on the ground and will be part of our plan of action across the rest of the UK.

The project will be reported to the Epilepsy Commissioning Group, led by the Epilepsy Society, and made up of epilepsy organisations and Neurological

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Commissioning Support who are working together to share information and work collaboratively to tackle the challenge of the new NHS reforms.


International collaboration

Prevention of SUDEP and epilepsy mortality needs to be tackled globally as well as nationally and locally. The National Institutes for Health (US) and other organisations planning registry development are keen to collaborate with Epilepsy Bereaved on the development of surveillance of deaths. Epilepsy Bereaved has been asked and has agreed to share our expertise and experience with SUDEP Aware to support the development of an enhanced support service for families affected by SUDEP in North America who need support or who are interested in reporting a death to a research registry. We will also be working on agreeing other projects which mutually benefit the two organisations, thereby reducing duplication of effort where appropriate.

Communications

There are some major opportunities for Epilepsy Bereaved and the SUDEP cause. A new website is being commissioned and our branding reviewed and developed as part of a communication plan aimed at raising the necessary awareness and funding needed to tackle prevention; to offer our bereavement support service to even more families; to provide a platform for campaigns and a source of authoritative information for families, epilepsy patients, researchers and medical professionals.

Signed for on behalf of the Board of Trustees



S Brown
Chair of Trustees

Signed for on behalf of the Board of Trustees

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INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF EPILEPSY BEREAVED

For the year ended 31 March 2012

I report on the accounts of the Trust for the year ended 31 March 2012, 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

30/11/12

6 Newbury Street
Wantage
Oxfordshire
OX12 8BS

EPILEPSY BEREAVED**STATEMENT OF FINANCIAL ACTIVITIES**

		Year ended 31 March 2012 £	Year ended 31 March 2012 £	Year ended 31 March 2012 £	Year ended 31 March 2011 £
	Notes	Restricted	Unrestricted	Total	Total
Incoming resources from generated funds					
Voluntary Income					
Donations	2	4,305	44,945	49,250	36,487
Grants	3	5,500	12,550	18,050	6,750
Gift Aid Tax Relief		-	21,167	21,167	10,642
Legacies		-	-	-	6,200
Sundry Income		-	405	405	760
Activities for generating funds					
Fund raising	4	2,842	106,334	109,176	115,432
Letting Office Space		-	864	864	864
Investment Income					
Bank Interest		-	355	355	335
Total Incoming Resources		<u>12,647</u>	<u>186,620</u>	<u>199,267</u>	<u>177,470</u>
Resources Expended					
Cost of generating funds					
Fundraising	5	-	25,870	25,870	10,118
Cost of charitable activities					
Direct Charitable Expenditure	5	7,147	157,478	164,625	201,035
Governance Costs					
Governance costs	6	-	5,837	5,837	6,236
Total Resources Expended		<u>7,147</u>	<u>189,185</u>	<u>196,332</u>	<u>217,389</u>
Net Incoming Resources for the year		<u>5,500</u>	<u>(2,565)</u>	<u>2,935</u>	<u>(39,919)</u>
Gross transfers between funds					
Funds brought forward at 1 April 2011		-	96,939	96,939	136,858
Funds carried forward at 31 March 2012		<u>5,500</u>	<u>94,374</u>	<u>99,874</u>	<u>96,939</u>

REGISTERED CHARITY NO: 1050459

EPILEPSY BEREAVED

	NOTES	2012 £	2011 £
Fixed Assets			
Tangible Assets			
Current Assets			
Cash at bank and in hand		105,881	102,000
		<u>105,881</u>	<u>102,000</u>
Creditors: amounts falling due within one year	9	(6,007)	(5,061)
Net Current Assets		<u><u>99,874</u></u>	<u><u>96,939</u></u>
Funds			
Unrestricted Funds	10	94,374	96,939
Restricted Funds	11	5,500	-
		<u><u>99,874</u></u>	<u><u>96,939</u></u>

This report has been prepared in accordance with the Statement of Recommended Practice - Accounting and Reporting by Charities (SORP 2005)

The financial statements were approved by the Board of Trustees on 12th May, 2012



S Brown

EPILEPSY BEREAVED

NOTE TO THE ACCOUNTS

YEAR ENDED 31 MARCH 2012

1.1 Basis of preparation

The accounts have been prepared under the historical cost convention in compliance 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.

1.2 Funds

Unrestricted Funds - these are funds which can be used in accordance with the charitable objects at the discretion of the trustees.

Restricted Funds - these are funds that can only be used for particular restricted purpose within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for a particular restricted purpose.

1.3 Income

Donations and similar income are included in the financial statements on a receivable basis. All other income is included on a receivable basis.

Legacies are credited to incoming resources when the charity becomes entitled to the income, the receipt is certain and the amount is quantifiable. Life interest and other residual legacies, where the amount to be received is uncertain, are not accrued.

1.4 Expenditure

All expenditure is included on an accruals basis and is recognised when there is a legal or constructive obligation to do so.

- Charitable activities include expenditure associated allieviating those who have lost a friend or relative through epilepsy, and the promotion of support, mental and physical research and education relating to sudden unexplained death due to epilepsy and the nature of grieving and bereavement.
- Governance costs include those incurred in the governance of the charity and its assets and are primarily associated with constitutional and statutory requirements.

1.5 Taxation

Epilepsy Bereaved is a charitable organisation and does not carry out activity sufficient to be subject to corporation tax.

1.6 Tangible fixed assets and depreciation

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the costs less estimated residual value of each asset over its expected useful life, as follows:

Office equipment	20% straight line
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EPILEPSY BEREAVED

NOTE TO THE ACCOUNTS (continued)

YEAR ENDED 31 MARCH 2012

2	Donations	2012	2011
	Unsolicited Donations	44,561	35,805
	Solicited Donations	-	-
	GAYE	384	392
	Total for Unrestricted Funds	<u>44,945</u>	<u>36,197</u>
	General	-	5
	Family Support	-	-
	General Research	4,305	285
	Total for Restricted Funds	<u>4,305</u>	<u>290</u>
3	Grants	2012	2011
	Various	12,550	1,250
	Total for Unrestricted Funds	<u>12,550</u>	<u>1,250</u>
	General	-	-
	Family Support	-	500
	General Research	5,500	5,000
	Total for Restricted Funds	<u>5,500</u>	<u>5,500</u>
4	Fundraising	2012	2011
	General Fundraising	103,817	109,093
	Collecting Boxes	1,482	438
	Sale of Group Products	1,035	1,094
	Total for Unrestricted Funds	<u>106,334</u>	<u>110,625</u>
	Family Support	-	1,101
	General Research	2,842	3,706
	Total for Restricted Funds	<u>2,842</u>	<u>4,807</u>

EPILEPSY BEREAVED**NOTE TO THE ACCOUNTS (continued)****YEAR ENDED 31 MARCH 2012****5 Costs of activities in furtherance of the charity's objects**

	Restricted Research 2012	Restricted General 2012	Restricted Family Support 2012	Unrestricted 2012	2012	2011
Cost of Generating Funds						
Fundraising Expenses	-	-	-	5,028	5,028	10,118
Salaries and National Insurance	-	-	-	20,842	20,842	-
	-	-	-	25,870	25,870	10,118
Cost of Charitable activities						
Postage and Stationery	-	-	-	3,947	3,947	6,962
Telecommunications	-	-	-	4,039	4,039	4,678
Printing	-	-	-	7,357	7,357	7,702
Salaries and National Insurance	-	-	-	104,964	104,964	117,421
Pension	-	-	-	216	216	-
Consultancy other staff costs	-	-	-	614	614	14,239
Travel, Accommodation & Subsistence	-	-	-	7,872	7,872	9,210
Research	7,147	-	-	2,853	10,000	10,000
Affiliations to Other Groups	-	-	-	873	873	843
Other Group Items	-	-	-	-	-	-
Development of Web Site	-	-	-	1,200	1,200	3,356
Cost of Support Group Meetings	-	-	-	2,879	2,879	3,880
Memorial Service	-	-	-	1,084	1,084	334
Bank Charges	-	-	-	18	18	8
Training	-	-	-	546	546	60
Insurance	-	-	-	1,418	1,418	-
Office Costs & Equipment	-	-	-	14,953	14,953	21,280
Conferences & Seminars	-	-	-	2,406	2,406	602
Sundry Expenses	-	-	-	239	239	460
	7,147	0	0	157,478	164,625	201,035

6	Governance Costs	Restricted 2012	Unrestricted 2012	Restricted 2011	Unrestricted 2011
	Postage and Stationery	-	-	-	-
	Staff Costs	-	2,500	-	2,000
	Insurance	-	-	-	1,096
	Cost of Trustees' meetings and AGM	-	2,617	-	2,420
	Independent Examiner's Fee	-	720	-	720
		-	5,837	-	6,236

7	Staff Costs	Restricted 2012	Unrestricted 2012	Restricted 2011	Unrestricted 2011
	Wages and Salaries	0	128,306	3,233	116,188

There was an average of 5 employees (FTE) during the year.
The Trustees received no remuneration during the year.

8 Taxation

No taxation has been incurred for 2012 (2011: nil)

EPILEPSY BEREAVED

NOTES TO THE ACCOUNTS (continued)

YEAR ENDED 31 MARCH 2012

	2012		2011		
9 CREDITORS: amounts falling due within one year	Restricted	Unrestricted	Restricted	Unrestricted	
	2012	2012	2011	2011	
Travel and Subsistence	-	743	-	786	
Office costs	-	888	-	-	
Postage and Stationery	-	724	-	944	
Telecommunications	-	65	-	198	
Printing and Copying	-	104	-	1,108	
Affiliated groups	-	172	-	-	
Independent Examiner's fees	-	720	-	720	
Trustee Expenses	-	86	-	-	
PAYE	-	2,433	-	-	
Pension	-	72	-	-	
Fees and Consultancy	-	-	-	1,305	
	<u>-</u>	<u>6,007</u>	<u>-</u>	<u>5,061</u>	
10 UNRESTRICTED FUNDS			2012	2011	
			£	£	
Balance brought forward			96,939	136,181	
Incoming Resources			186,620	166,873	
Transfers			-	-	
Outgoing Resources			(189,185)	(206,115)	
			<u>94,374</u>	<u>96,939</u>	
11 RESTRICTED FUNDS	Balance	Incoming	Outgoing	Balance	
	1.4.11	Resources	Resources	31.3.12	
	£	£	£	£	
Research	-	7,147	7,147	-	
General	-	-	-	-	
Family Support	-	5,500	-	5,500	
	<u>-</u>	<u>12,647</u>	<u>7,147</u>	<u>5,500</u>	
12 Analysis of net assets between funds					
	Tangible	Debtors	Cash at bank	Creditors	Total
	Assets		and in hand		2012
Restricted	-	-	5,500	-	5,500
Unrestricted	-	-	100,381	(6,007)	94,374
	<u>-</u>	<u>-</u>	<u>105,881</u>	<u>(6,007)</u>	<u>99,874</u>