

SUDEP Action

Registered Charity No.
1164250 (England & Wales)
SC047223 (Scotland)
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 2018

Chapman Worth Limited
6 Newbury Street
Wantage
Oxfordshire
OX12 8BS

SUDEP Action & linked charity Epilepsy Bereaved

CHARITY INFORMATION

Director	Jane Hanna OBE
Trustees	Stephen Brown (Chair) (Retired as Chair June 2018) Jennifer Preston (Vice Chair) (Retired July 2017) Guy Neely (Retired as treasurer July 2017; appointed Vice-President July 2017) Susan Allen John Hirst (appointed Vice Chair July 2017) (Appointed Chair June 2018) Simon Lees John Lipetz (Retired July 2017, appointed Vice-President 2017) Mark Phillips Alex Stirling Roger Scrivens (resigned November 2017) Graham Faulkner Mike Kerr Malisa Pierri (Resigned April 2017) Rachel Shah (Appointed July 2017)
Charity No.	1164250 (England & Wales) SC047223 (Scotland)
Website	www.sudep.org
Address for correspondence	SUDEP Action 12a Mill Street Wantage Oxfordshire OX12 9AQ
Accountants	Chapman Worth Limited 6 Newbury Street Wantage Oxfordshire OX12 8BS
Bankers	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 2018

The trustees present their report and accounts for the year ended 31 March 2018.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's governing document and the Statement of Recommended Practice, "Accounting and Reporting by Charities in accordance with the Financial Reporting Standard for Smaller Entities" (effective January 2015).

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 31st 2018.

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 as a charitable incorporated organisation (CIO). The Charity is linked by the Charity Commission to the Registered Charity Epilepsy Bereaved (Charity Registration number 1164250), which was constituted under a Declaration of Trust dated 14 October 1995 as an unincorporated charity which adopted SUDEP Action as a working name in January 2013. The trustees of the Board of both charities are the same. Administering the charity as a CIO provides benefits in relation to employing staff, leasing property and entering into contracts. The linking of the two charities protects SUDEP Action from loss of legacy income in the future.

Chair of Board and Officers

Professor Stephen Brown
John Hirst CBE (appointed Vice Chair July 2017)
Rachel Shah (appointed Treasurer July 2017)

Board members

The other trustees who served during the year were:

Susan Allen
Graham Faulkner
Professor Mike Kerr
Simon Lees
John Lipetz (retired July 2017; appointed Vice-President 2017)
Guy Neely (Treasurer retired July 2017; appointed Vice-President July 2017)
Mark Phillips (appointment renewed as member of Board November 2017)

Malissa Pierri (resigned April 2017)
Jennifer Preston (retired July 2017; Vice-Chair until July 2017)
Roger Scrivens (resigned November 2017)
Alex Stirling

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 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 Chief Executive Officer Jane Hanna OBE and nine employees including some who are part-time, equating to 6 full-time equivalent staff members. The office is situated in Wantage, Oxfordshire. Three employees work remotely from other parts of the UK.

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 and an expert panel which provides advice to our support team for families after a death.

During this reporting year the CEO and Chair led extensive individual and group work across the whole charity leading to a restructure of the organisation; an upskilling of the team; an integration of new members and a strengthening of the organisation in preparation for significant growth.

The report that follows covers our mission, why we exist, a summary of our achievements during the reporting year and the full report of how we spend our funds to tackle deaths and support families.

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 that specialises 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 because:

1 in 20 people will have a seizure in their life-time, whilst 600,000 in the UK live with epilepsy. This is an issue which is likely to touch us all during our life-time.

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

There are at least 21 deaths a week in the UK.

10 a week are deaths in the young.

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

Deaths in people with epilepsy have been rising during the last 14 years, as deaths from other conditions have fallen.

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.

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.

We know from our Epilepsy Deaths Register research platform for families, that half of the bereaved taking part (454 participating) did not know that epilepsy could kill and just under 60% never have the circumstances of their loved one's death adequately explained to them. Just under 70% were not invited to discuss the death with a doctor or nurse, despite this being encouraged by national guidelines. Most families report concerns about the events leading up to death. They include 8% where epilepsy was not diagnosed whilst under care; medication issues; life-style issues and with the majority not knowing about risks in epilepsy and ways these could be reduced, including SUDEP. Families wait many months for an inquest to report and most are left with inadequate answers.

They struggle to understand why avoidable deaths that occur in one place and at one time, such as an airline disaster or a fire, attracts appropriate attention and concern, whilst SUDEP and epilepsy

deaths still don't. The persistence of a culture that systematically downplays risk is a major contributor to deaths.

At SUDEP Action our focus is on changing that culture. We have succeeded in changing a widely held view in the medical profession in the 1990's that SUDEP did not exist and that people did not die from epilepsy. Today in the UK because of that work, awareness recognised by SUDEP Action has developed ahead of any other country in the world and solutions and services have been developed to help families and support clinicians. This includes the SUDEP and Seizure Safety Checklist developed in the South-West.

Case Study South-West

SUDEP Action partnered with Cornwall NHS Foundation Trust in 2010. Working locally, it has brought families, the local community and professional champions together. Research we commissioned found many people who died had worsening risk factors 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. 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. Our research in 2018 found reduced risk in patients using the Checklist. Deaths have been observed as falling, with no deaths reported in the learning disability community. A digital tool for patients has now been developed with 3,500 people with epilepsy in UK already registered users.

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

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.

Summary of our reporting year

We are the only charity specialised in supporting those bereaved by epilepsy dedicated to raising awareness of epilepsy risks so that lives can be saved.

SUDEP Action has helped 11,544 people in this reporting year alone:

5,500 people were helped by tailored services addressing individual need.

6,000 people were supported by general educational material.

Our wider influence adds further value. Our communications and policy work brings increased awareness daily as well as influencing organisations in the UK and in countries around the world. Highlights during this reporting year were:

Channel 4 news viewed by 86,000 people

Social media post for the bereaved at Christmas reaching 37,000 and engaging nearly 2,000

Training resources developed with South West Ambulance Service have been adopted by 12 Ambulance crew across the UK alone and may reach up to 28,000 crew

Funded mainly by bereaved families and their communities, we are based in Oxfordshire with a team of 9 (6 FTE). Whilst our services with the bereaved provides personal and highly specialist help for as long as needed, our innovative technology also enables personalised and meaningful engagement with people with epilepsy and participation in research by bereaved families who are difficult to reach. We have been able to do this by working closely with research and clinical teams.

During this reporting year we restructured the organisation, developing the skills of our team, developing our systems for compliance with GDPR, and delivering on our stated ambitions from our last annual report. We:

- ❖ Successfully launched a PREVENT21 campaign to shine a light on 21 sudden deaths a week; give voice to the priorities of the bereaved community and motivate funders to get behind solutions to tackle deaths
- ❖ Brought 14 organisations together supporting a Call to Action leading to planned UK Summit to tackle deaths for 2018
- ❖ Met a gap in resources available for paediatricians and parents, producing up to date information aimed at keeping children with epilepsy safe
- ❖ Funded a researcher to develop our award-winning digital tool EpSMon to support people with epilepsy
- ❖ Increased our support of NHS clinicians using our SUDEP and Seizure Safety Checklist

- ❖ Continued our surveillance of epilepsy deaths using the Epilepsy Deaths Register
- ❖ Developed our service to bereaved families to include a pilot volunteer case worker specialising in inquest support
- ❖ Provided 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

Our full report with case studies and detailed information follows.

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

Offering Support

SUDEP Action leads the world in the delivery of a service to support the traumatically bereaved families after a death. For over 21 years we have listened to and worked with the bereaved to develop our service. The support team run a specialised service around epilepsy related deaths; they have an in-depth knowledge and years of experience working in this complex field.

Our specialist service dealt with 832 support and telephone counselling sessions during the reporting year from people at different stages in their process after a death. We also provided advocacy for 13 families ranging from helping them to ask complex questions during the investigation of the death, right through to attending the inquest with the family.

SUDEP Action is led by the needs identified by research with the bereaved who are usually traumatized and frequently disenfranchised. Over 80% of families express the need for someone to talk to who can help in finding answers and help with understanding so that there can be learning from deaths. Many are strongly motivated to turn private pain into public purpose.

We provide:

- ❖ On-going emotional support
- ❖ Understanding of the investigation process and/or post-mortem
- ❖ Advocacy supporting people through investigations
- ❖ An opportunity to access independent health mediation
- ❖ Opportunities to be with others who have been bereaved by epilepsy
- ❖ Opportunities to meet SUDEP experts and ask questions about epilepsy
- ❖ Involvement in the cause
- ❖ Counselling

No two losses are the same and no two people will grieve in the same way. Early intervention is vital. 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.

"Thank you for all you have done to help me through the most horrendous experience. I am sure I am not alone in thinking you are an angel"

Source: SUDEP Action Support Service Feedback 2017

"SUDEP Action and the support of Tracy has been life changing. She has taken me from despair to hope for the future"

Source: Epilepsy Deaths Register 2018

Our support team is uniquely managed by a qualified counsellor who is 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 can empathise and support the bereaved to understand what may have happened, and why it happened. They know they are not alone and that our team is there for them as long as this is needed.

.... "the whole experience affects the ability to recover from the trauma of sudden death. Where the experience of the Coroners' service and inquest has been bad, counselling does not appear to assist in moving on. Where the counsellors do not understand the particular difficulties experienced by some families at some inquests this itself can have a negative impact"

Source: INQUEST 2002

The findings from nearly 500 people who have registered their experience on our digital research platform, the Epilepsy Deaths Register, reveals the vulnerability and needs of families and the value that they place on a support service from SUDEP Action which is tailored to evidence-based need.

"From my first contact with SUDEP Action, I was given verbal guidance which was swiftly followed up with a template for a letter to be sent to the Coroner along with valuable current research papers about SUDEP. SUDEP Action has continued to provide verbal support throughout the six-year process. In addition to the advice regarding the Coroner's Office, we have received helpful information and suggestions about ways to approach the many and varied challenges along the way".

There is evidence that where the experience of the Coroners' service and inquest has been bad, general bereavement counselling does not appear to assist.

During the reporting year we have recruited a voluntary case worker who is embedded in our specialist support team. Working hand in hand with the support team this helps us provide a unique, tailored and well-balanced service, covering the diverse needs and questions that exist after an epilepsy related death. Early intervention with care, support and reliable information are paramount when navigating and understanding these complex systems, as well as the grief reactions that follow a sudden death. The addition of a caseworker has been extremely successful, and families are appreciating the expert help and support.

"We first contacted the charity a few months after the sudden loss of our much-loved little boy Freddie in April 2017. Through all the horrendous stages and difficult facts, we have needed to take

in, the team at SUDEP Action have helped us with the gentlest of touches and we always felt that our questions really mattered... These wonderful, warm and caring individuals have been there simply to listen when we were struggling to make sense of everything and going beyond a listening ear have helped us understand detailed medical terms and their impact, as well as coronial process. This has been, for us (so far at least) the most valuable part of the support we've received. In particular, advising us practically in advance of and during the inquest into Freddie's death has been so very appreciated. For someone from the charity to attend the inquest alongside us was really important and we are most grateful that this was possible.

As Freddie's parents it's really important to us to be part of SUDEP Action's courageous bereaved community, by leading our own fundraising but also by getting involved with special projects such as the Epilepsy Deaths Register and attending the annual conference for the first time in 2018".

Involving people

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

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

Over 700 families, including 454 in the UK, 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.

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.

We supported 40 volunteers who actively help on a range of initiatives including hosting coffee clubs and engaging local GPs. Just under 1000 supporters were involved less regularly from sharing a case study to involvement with the press.

We involve doctors and nurses across community and acute care and involve people living with epilepsy in the development of our safety tools. 471 clinicians were engaged with the SUDEP and Seizure Safety Checklist alone.

A social media support post from our specialist team at Christmas was viewed by over 37,000 people with over 1,700 people engaging with us during a period of the year which is often extremely difficult for recently bereaved families.

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 have 3,500 people with epilepsy who have used our EpSMon epilepsy self-monitor App to check their individual risk and 6,000 people who have received our generic information on risk.

We have 471 front-line NHS professionals using our SUDEP and Seizure Safety Checklist to support their epilepsy clinics and 627 also receiving our professional e-news updates.

Ambulance crews across 12 regions of the UK took up an educational licence to use SUDEP Action and South West Ambulance Service Foundation Trust's training resources with their paramedic crews.

Professionals were also engaged during the year using our brochures and by receiving our professional e-news updates.

Our 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.

We saw an increase in users of our website use from 100,000 to over 140,000 this reporting year.

Highlights this year in our communications work were coverage in Channel 4 News and Sky New with Channel 4 Facebook video alone being shared 86,000 times.

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. Developed through an 8-year quality improvement drive methodology, 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.

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. Our research in 2018 found reduced risk in patients using the checklist. Deaths have been observed as falling, with no deaths reported in the learning disability community.

The Checklist is supported by a UK-wide development team of GPs, experts and people living with epilepsy. It is 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.

"I have first-hand experience in losing a son to epilepsy & none of my colleagues previously realised people could die - nobody had heard of SUDEP - so now they understand the importance of using tools like the Checklist to monitor risk"

(clinician and bereaved parent)

"I always ask the patients consent to complete the checklist and explain what I am doing. I put emphasis on the positive results and we discuss how they can modify factors that potentially would put them at increased risk. I have not had a negative response."

(epilepsy Specialist nurse midwife)

EpSMon:

In 2013 Plymouth University (NeuroCoRe) partnered with SUDEP Action, Cornwall Partnership NHS Foundation Trust and Royal Cornwall Hospitals, 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. In 2017 it was chosen as one of eight innovations for the NHS Innovation Accelerator Programme and was used as an example of good practice in the NHS 70th year anniversary video.

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

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

A supporter who raises awareness in memory of her son

Both 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

Charlie Burns – Simple Steps Training Package

A simple training package to educate ambulance crews about SUDEP and seizure risk was used by 12 ambulance trusts with a reach of 28,000 crew.

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.

Research

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

During the reporting year we have partnered with Plymouth University to fund ongoing research and development of EpSMon and the SUDEP and Seizure Safety Checklist. This is in addition to our ongoing funding of the Epilepsy Deaths Register Project and the development of technology to alert and enable intervention in the immediate crisis leading up to a likely sudden death:

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 University College London (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. This is underway at 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

The support of this innovation by SUDEP Action attracted the European Research Council who awarded the engineer at Imperial College €2 million to develop this device. SUDEP Action is the Patient and Public Involvement lead on this vitally important project which runs to 2020.

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.

The Epilepsy Deaths Register has proved to be partially therapeutic to families (over 700) who are able to place their experiences in the knowledge that this will help learning for the future. The Register is vital in confirming that the experiences of the families after a death are of equal significance for learning by researchers and clinicians, as the experiences in the lead up to the death and in flagging key areas of concern. These include poor communication before and after a death; poor reporting of deaths and learnings of factors that may have contributed to death.

Collaboration

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

SUDEP and Seizure Safety Checklist: Cornwall Partnership NHS Foundation Trust

EpSMon: University of Plymouth, Cornwall Partnership NHS Foundation Trust, Royal Cornwall Hospitals

EpSMon US: EpSMon partners and Epilepsy Foundation of America

WADD Clinical Trial: University College London (UCL) and Imperial College London

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

Global Conversation: SUDEP Aware, Epilepsy Australia

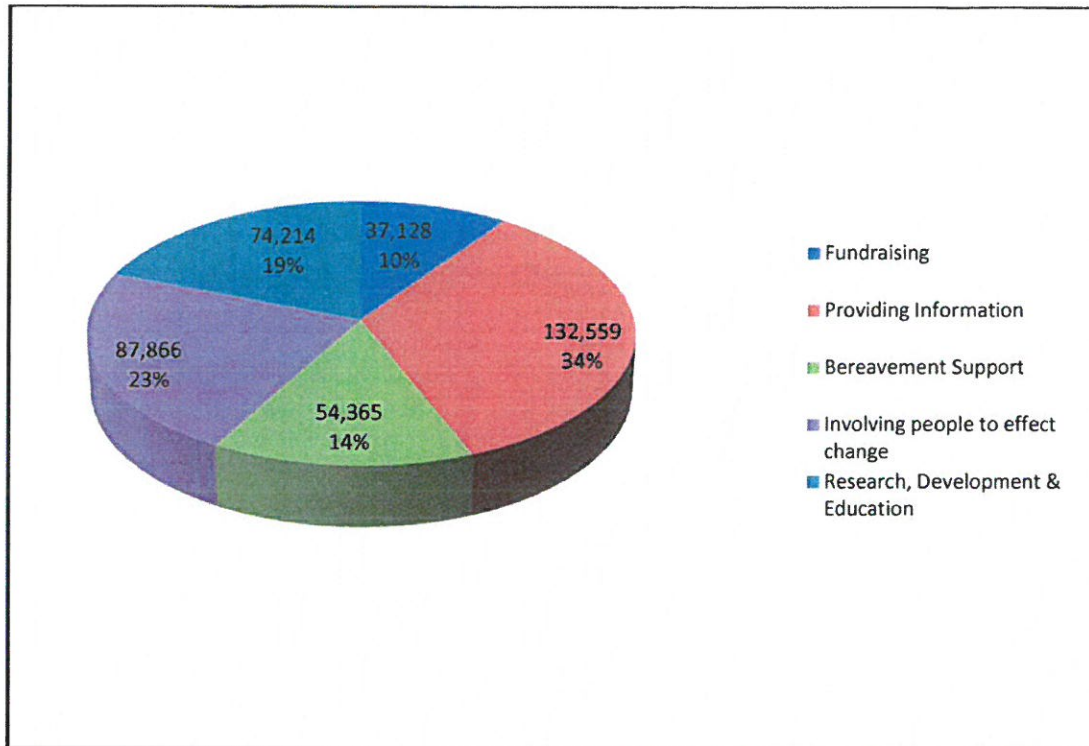
SUDEP Action led a call to action following publication of a government report on rising deaths in people with neurological conditions. This has attracted the support of 17 organisations as well as clinical and research teams for a UK Summit to tackle epilepsy deaths to be convened by SUDEP Action during 2018. In the UK we are members of the Neurological Alliance and support by holding the Vice-Chair of Policy and are 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 Parliamentary Group for Epilepsy and the Epilepsy Consortium. We are members of the IBE (International Bureau for Epilepsy) and ILAE (International League Against Epilepsy).

We continue to lead the global movement to raise awareness using common statistics and common messages about risk reduction. Our projects SUDEP the Global Conversation (a site which combines scientific research for lay people with motivating stories from families) and SUDEP Action Day on 23rd October, enables us to connect and motivate and support 50 country organisations during the year.

A successful closer collaboration developed during the year, when we were funded to work closely with Epilepsy Action Australia to develop its online resources on risk & some key risk literature. We work hard to participate in other initiatives where possible and are the only UK organization participating with organisations in the US at the 2018 Partners Against Mortality in Epilepsy (PAME).

Financial Matters:

Our expenditure during the year of £386,132 was apportioned as follows:



Income and reserves

The charity's income was £443,143 (compared with £395,413 during 2016/17, £431,122 during 2015/16 and £367,058 during 2014/15). £51,272 of income during 2017/18 was restricted funding with the balance of all restricted funds held, including those funds from income received before this reporting year, totalling £121,695.

Since the WADD appeal project (see page 13 for details) the researcher at Imperial College London has received a grant of €2 million to develop a wearable device by 2020. The WADD restricted fund has been used this reporting year by the researcher at Imperial College to collaborate with UCL on the clinical trial on WADD. The research team at UCL and Imperial College London requested an extension of project in January 2018 to September 2019 to reflect this development and this revised agreement was granted in January this year. Remaining WADD reserves will be fully or substantially paid out to University College London and Imperial College London by September 2019 under conditions of research grants agreed with these universities and in accordance with the WADD appeal.

Restricted funds totalling £34,470 to support projects working with researchers and UK clinicians will be fully or substantially paid out during 2018/2019.

Our uncommitted funds or general funds stood at £153,609 at year end or just over 5 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.

Management

During this reporting year we undertook internal work involving all Board members and all staff following our conversion to a Charitable Incorporated Organisation (CIO) and upskilling our team in readiness for planned growth.

During the year the Board completed succession planning with appointments during the year of Rachel Shah as new Treasurer and Professor Mike Kerr as new Vice-Chair and with a planned transition of Chair of Board from Professor Stephen Brown to John Hirst CBE by June 2018.

All staff were consulted and involved in a restructuring of the charity with various staff members promoted and the retiring Deputy CEO taking on a part-time position as Coordinator of the Epilepsy Deaths Register. During the reporting year we recruited a new Finance and Operations Manager.

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

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.

We made the decision to move premises to enable our growth and have agreed a new lease with a planned move to improved premises to meet our needs in Wantage during 2018/19. During 2018/2019 we will complete the planned restructure with recruitment of a new Executive Assistant post to support the CEO and senior management team.

We are forecasting a growth in the organization and during the next year will agree a business case for the charity to take this forward to 2021.

Our Position in 2018

Embracing the power of communities and innovating with technology has enabled SUDEP Action to serve the cause of preventing deaths and rebuilding lives. We have done this without any statutory funding.

The following is a list of world-firsts developed over 21 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 has proved partially therapeutic for traumatized families.
- ❖ **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**
- ❖ **SUDEP Action Day** connecting people and organisations around the world and **SUDEP Global Conversation** providing lay summaries from experts combined with family stories

EpSMon App has been chosen as one of eight innovations for the NHS Innovation Accelerator Programme and will be celebrated during the 70th Anniversary celebrations of the NHS. Our SUDEP and Seizure Safety Checklist has proved itself in reducing risk in people living with epilepsy.

"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.
Awarded by the Association of British Neurologists**

Our track of achievement is evidenced in these national and global awards:



NHS
Innovation
Accelerator



'Neurology Team of the year'



'Healthcare II'



'Education & Training'



Other Awards

- ❖ Chief Executive Awarded International Social Impact Award ILAE/IBE 2013
- ❖ Chief Executive awarded OBE for Services to Families in 2010

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 Prevent21 campaign until 2021 is a call to action which is already speeding up our effectiveness in mobilising communities and organisations to tackle deaths. 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 but knowing that SUDEP Action is working to save others offers a life-line of hope.

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. Our solutions are easily scalable, so our aspirations are without local, national or international boundaries.

Our priority is rolling out our projects and services in the UK to as many people as possible who need these.

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 in local communities. We will do this creatively using technology and by developing outreach to families and professionals.

We also need to strengthen recognition of SUDEP Action as the first and best 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.

SUDEP Action receives no government or statutory funding. Our Prevent21 campaign is already showing the strength of communities in getting behind SUDEP Action to 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 2018/19 we will:

- ❖ **Bring evidence from bereaved families and people with epilepsy who are at risk to the attention of government and policy makers in the UK and globally**
- ❖ **Convene a UK Summit to tackle deaths bringing organisations together to adopt a common position and action plan**
- ❖ **Invest in staffing to roll-out solutions to tackle deaths in local areas**
- ❖ **Invest in strengthening our service for traumatised family by financing new case worker as part of our specialist support for the bereaved**
- ❖ **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**

Signed for and on behalf of the Board of Trustees

A handwritten signature in black ink, appearing to be 'J Hirst', written over a horizontal line.

J Hirst CBE Chair of Trustees

SUDEP Action & linked charity Epilepsy Bereaved

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

For the year ended 31 March 2018

I report on the accounts of the Trust for the year ended 31 March 2018, 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)(c) 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
Chapman Worth Limited
6 Newbury Street
Wantage
Oxfordshire
OX12 8BS
Dated..... 9/11/19

SUDEP Action

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

Statement of Financial Activities For the year ended 31 March 2018

		SUDEP Action Unrestricted Funds 2018	SUDEP Action Designated Funds 2018	SUDEP Action Restricted Funds 2018	SUDEP Action Total Funds 2018	Epilepsy Bereaved Total Funds 2017
	Note	£	£	£	£	£
Income from						
Donations and legacies	2	352,275	-	49,815	402,090	363,054
Charitable activities	3	20,391	-	-	20,391	9,797
Other trading activities	4	18,772	-	1,457	20,229	21,983
Investments	5	433	-	-	433	579
Total incoming resources		391,871	-	51,272	443,143	395,413
Resources Expended						
Raising funds	6	48,721	-	148	48,869	31,517
Charitable activities	7-8	300,396	-	36,865	337,261	410,723
Total resources expended		349,117	-	37,013	386,130	442,240
Net income/(expenditure)		42,754	-	14,259	57,013	(46,827)
Transfers between funds	12	10,140	(10,140)	-	-	-
Net movement in funds		52,894	(10,140)	14,259	57,013	(46,827)
Total funds brought forward 1 April 2017 (2016)		100,717	10,140	107,436	218,293	265,120
Total funds carried forward 31 March 2018 (2017)		153,611	-	121,695	275,306	218,293

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

SUDEP Action

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

Balance Sheet as at

	Note	31 March 2018 SUDEP Action Unrestricted Funds	31 March 2018 SUDEP Action Designated funds	31 March 2018 SUDEP Action Restricted Funds	31 March 2018 SUDEP Action TOTAL	31 March 2017 Epilepsy Bereaved TOTAL
		£	£	£	£	£
Current Assets						
Prepayments		2,566	-	-	2,566	4,144
Debtors		8,778	-	-	8,778	13,714
Accrued Gift Aid		6,411	-	6,215	12,626	7,048
Cash at bank and in hand		151,311	-	115,990	267,303	201,107
		<u>169,066</u>	<u>-</u>	<u>122,205</u>	<u>291,273</u>	<u>226,013</u>
Creditors: amounts falling due within one year	11	(15,457)	-	(510)	(15,967)	(7,720)
Net Assets		<u>153,609</u>	<u>-</u>	<u>121,695</u>	<u>275,306</u>	<u>218,293</u>
Funds						
Unrestricted Funds	12	153,611	-	-	153,611	100,717
Designated Funds	12	-	-	-	-	10,140
Restricted Funds	12-13	-	-	121,695	121,695	107,436
		<u>153,611</u>	<u>-</u>	<u>121,695</u>	<u>275,306</u>	<u>218,293</u>

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



John Hirst
Chair of Trustees

The notes on pages 23 to 28 form part of these financial statements.

SUDEP Action
Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)
Linked Charity: Epilepsy Bereaved (established 1995)

Notes to the Financial Statements
for the Year Ended 31 March 2018

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). Epilepsy Bereaved is the linked charity of SUDEP Action. Epilepsy Bereaved 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.

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. From 1st April 2017 Sudep Action has become active and these results are shown as those of Sudep Action. Epilepsy Bereaved had no activity during the year ended 31 March 2018.

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 2018. 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

SUDEP Action
Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)
Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements
for the Year Ended 31 March 2018**

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 of £12,500 was made to the Royal College of Paediatrics and Child Health for the "Suveillance of Deaths in children with epilepsy on the BPSU reporting scheme Nov 2016-Nov 2017.

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 2018: nil (2017: 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.

SUDEP Action

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements
for the Year Ended 31 March 2018**

	Unrestricted Funds £	Restricted Funds £	TOTAL 2018 £	TOTAL 2017 £
2 Donations and legacies				
Donations	62,315	5,672	67,987	55,076
Grants	46,008	24,695	70,703	30,187
Non-Exchange Grants	42,569	-	42,569	72,290
Gift Aid	12,354	6,333	18,686	26,177
Legacies	30,000	-	30,000	2,000
Fundraising donations	155,950	13,115	169,065	176,186
Collecting boxes	3,079	-	3,079	1,138
	<u>352,275</u>	<u>49,815</u>	<u>402,090</u>	<u>363,054</u>
3 Charitable activities				
Annual charity conference	4,968	-	4,968	-
Fees receivable	15,423	-	15,423	4,295
Contractual income *	-	-	-	5,502
	<u>20,391</u>	<u>-</u>	<u>20,391</u>	<u>9,797</u>
* Contractual income relates to the EpSMon project (see note 12a, Cornwall Fund)				
4 Other trading activities				
Fundraising sales	17,328	1,457	18,785	19,576
Sale of goods	1,444	-	1,444	2,407
	<u>18,772</u>	<u>1,457</u>	<u>20,229</u>	<u>21,983</u>
5 Investments				
Interest Receivable	433	-	433	579
	<u>433</u>	<u>-</u>	<u>433</u>	<u>579</u>

SUDEP Action

Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)

Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements
for the Year Ended 31 March 2018**

	Unrestricted Funds £	Restricted Funds £	TOTAL 2018 £	TOTAL 2017 £
6 Raising funds				
Fundraising Expenses	35,547	148	35,695	19,530
Support costs	13,174	-	13,174	11,987
	<u>48,721</u>	<u>148</u>	<u>48,869</u>	<u>31,517</u>
7 Charitable activities				
Direct charitable expenditure	265,374	36,865	302,239	389,080
Governance costs	1,520	-	1,520	4,229
Support costs	33,502	-	33,502	17,414
	<u>300,396</u>	<u>36,865</u>	<u>337,261</u>	<u>410,723</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 and support costs

Postage and Stationery	3,996	75	4,071	3,710
Telecommunications	2,317	43	2,360	2,465
Printing & Publicity	9,558	2,171	11,729	8,955
Non-Exchange Publicity	42,532	-	42,532	72,290
Salaries & National Insurance	183,591	20,643	204,234	217,282
Pension Scheme Contributions	1,976	106	2,082	917
Consultancy & other staff costs	9,630	-	9,630	4,000
Travel, Accommodation & Subsistence	5,378	1,021	6,399	7,959
Research grants	-	12,500	12,500	58,906
Affiliations to Other Groups	789	-	789	1,012
Development of Web Site	5,961	-	5,961	3,590
Cost of Support Group Meetings	2,275	-	2,275	143
Bank Charges	51	-	51	48
Training	140	-	140	2,042
Office Costs, including Insurance	17,198	306	17,504	18,155
Conferences & Seminars	12,122	-	12,122	4,810
Sundry Expenses	537	-	537	210
Independent Examiner's Fee	825	-	825	1,020
Cost of Trustees' meetings	1,520	-	1,520	2,009
Reconstitution Costs	-	-	-	1,200
	<u>300,396</u>	<u>36,865</u>	<u>337,261</u>	<u>410,723</u>

9 Staff Costs including Pension Scheme Contributions

Salaries & National Insurance	195,235	20,643	215,878	227,975
Pension Scheme Contributions	1,976	106	2,082	937
	<u>197,211</u>	<u>20,749</u>	<u>217,961</u>	<u>228,912</u>

There was an average of 6.4 employees (FTE) during the year (2017: 7.4)

No employee earned over £60,000 in the year (2017: 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.

SUDEP Action
Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)
Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements
for the Year Ended 31 March 2018**

10 Trustee expenses

The trustees received no remuneration during the year (2017: nil).
3 trustees were reimbursed a total of £522 (2017: 4 trustees £731) for travel expenses.

11 CREDITORS: amounts falling due within one year

	Unrestricted Funds £	Restricted Funds £	TOTAL 2018 £	TOTAL 2017 £
Trade Creditors	2,201	510	2,711	993
Sundry Creditors	1,234		1,234	-
Credit Card	503		503	
Receipts in Advance	1,569		1,569	35
HMRC-PAYE/NI	4,293	-	4,293	5,051
Pension	689	-	689	327
Accrued Expenditure	4,968	-	4,968	1,314
	<u>15,457</u>	<u>510</u>	<u>15,967</u>	<u>7,720</u>

12 Statement of funds

	Note	Brought Forward £ Surplus/ (Deficit)	Incoming Resources £	Resources Expended £	Transfers In/(Out) £	Carried Forward £ Surplus/ (Deficit)
Unrestricted funds						
General fund		<u>100,717</u>	<u>391,871</u>	<u>(349,117)</u>	<u>10,140</u>	<u>153,611</u>
Designated funds						
WADD		<u>10,140</u>	<u>-</u>	<u>-</u>	<u>(10,140)</u>	<u>-</u>
Restricted funds						
WADD		62,438	2,110	(3,386)	-	61,162
Cornwall	12a	10,567	56	(12,738)	1,964	(151)
LDA		3,590		(866)	-	2,724
Research		30,841	18,237	(12,644)	(1,964)	34,470
Epilepsy Death Register		-	30,869	(7,379)		23,490
Total		<u>107,436</u>	<u>51,272</u>	<u>(37,013)</u>	<u>-</u>	<u>121,695</u>

12a Special Projects

Cornwall Fund:						
CELP		2,365	-	(2,365)	-	-
EpSMon		8,202	56	(10,373)	1,964	(151)
		<u>10,567</u>	<u>56</u>	<u>(12,738)</u>	<u>1,964</u>	<u>(151)</u>

SUDEP Action
Registered Charity N°: 1164250 (England & Wales), SC047223 (Scotland)
Linked Charity: Epilepsy Bereaved (established 1995)

**Notes to the Financial Statements
for the Year Ended 31 March 2018**

13 Details of restricted funds and special projects

WADD	Funding to trial the development of a Wearable Apnoea Detection Device, designed to trigger an alarm when breathing stops in SUDEP. Designated where there is doubt whether the specific fundraising purpose was clearly communicated.
Cornwall	Originally a community study of SUDEP deaths to identify main risk factors, funding is currently focussed on the development of an Epilepsy Self-Monitoring application in partnership with Plymouth University, Cornwall Foundation NHS Trust & the Royal Cornwall Hospital, and the maintenance and development of the underlying SUDEP and Seizure Safety Checklist (EpSMon and CELP projects resp. - see note 11a).
Research	General research into the causes & prevention of epilepsy deaths.
LDA	Learning Disabled Adults - to provide appropriate epilepsy risk information for individuals, carers and professionals.
Counselling	To provide a professional bereavement counselling service. Derestricted at year end, future costs to be met from general funds.
Epilepsy Deaths Register	Funding to develop the Epilepsy Deaths Register and support collaborations to learn from epilepsy deaths. The Epilepsy Deaths Register started in 2013 is a web based data repository enabling reporting of the circumstances and impact of epilepsy deaths.
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

	SUDEP Action	Epilepsy Bereaved	Total
Debtors	23,970	-	23,970
Cash at bank and in hand	267,303	-	267,303
Creditors	(15,967)	-	(15,967)
Total net assets	275,306	-	275,306