



SUDEP Action

Making every epilepsy death count

KEEPING IN TOUCH

December 2014

THINKING OF YOU ...

From the Trustees, Management and Staff, we hope you had a peaceful Christmas. This time of the year may be difficult for some of you. I hope that reading through our newsletter can bring some comfort in knowing you are not alone. Our supporters have been amazing this last year, campaigning, raising awareness, sharing their stories and fundraising, all of which will help us to work towards our aim of reducing deaths from epilepsy. We can't thank you enough.

A lot has happened over the year and you will no doubt find reading some of the stories informative and inspiring. We launched the third SUDEP - Global Conversation, as an online resource, at the American Epilepsy Society Annual Meeting in Seattle, USA in December, 2014.

MP for Wantage and Minister of State for Culture and the Digital Economy ED Vaizey, was appointed as first President for SUDEP Action. The first ever SUDEP Awareness day was held on 23 October and it received support from all over the world.

In this issue, read The Epilepsy Deaths Register report on the findings in the first year, our advice on seizure monitors, and an article on maternal epilepsy deaths. There is a lot planned for 2015 which will be our 20 year anniversary and we hope that you will follow our progress, hold an event and join our campaigns.

The team at SUDEP Action wish you a prosperous new year.

SUDEP.ORG

NEWLY APPOINTED SUDEP ACTION PRESIDENT WELCOMES LAUNCH OF FIRST EVER SUDEP AWARENESS DAY

SUDEP Action held the first ever SUDEP Awareness Day on 23 October, 2014. The day is dedicated to raising awareness and promoting ways that people with epilepsy can reduce their risk of SUDEP.

Newly appointed SUDEP Action President, Ed Vaizey, who is MP for Wantage, where the charity is based said: "I am honoured to be the first President of SUDEP Action, a Wantage-based charity with global reach which works on such an important but little-known cause. I am also delighted to have supported SUDEP Awareness Day on October 23rd which I hope will help many more people to be aware of the risks some of us face and, in particular, how they can be minimised."

Ed, who is also Minister of State at the Department for Culture, Media and Sport and the Department for Business, Innovation and Skills, with responsibility for digital industries, hosted a reception at parliament in support of SUDEP Awareness Day. The reception was attended by nine Members of Parliament: Maria Eagle, Helen Goodman, Ivan Lewis, Andrew Stephenson, Rob Wilson, Henry Bellingham, Philip Hollobone, David Tredinnick and Paul Maynard. SUDEP Action supporters Rachel Shah and Vivek-Anand Dattani attended the reception to talk about their personal experience of a loved one dying from epilepsy. Rachel Groves, SUDEP Action's Fundraising and Operations Manager was there on behalf of the charity. MP Stuart Andrew also supported SUDEP Awareness Day through a statement on his website.

Karen Osland, Acting Chief Executive for SUDEP Action commented: "We are delighted that Ed has agreed to take on the important role of Charity President and for supporting



our SUDEP Awareness Day campaign. The charity has grown a lot in the last 20 years and is now recognised as a global leader in its field. While people are increasingly far more aware of the risk of SUDEP, there is still much more for us to do. We are confident that Ed will help us, not only to keep epilepsy mortality high on the political agenda but in supporting us where he can to deliver our message."

SUDEP Awareness Day is part of SUDEP Action's Call for Openness Campaign, which calls for a common sense approach to alert people at risk of ways to reduce their risk. The campaign encourages people with epilepsy to be open about their condition, to report their seizures accurately and to take their medications regularly and as prescribed. It also encourages doctors and nurses to talk about risk, including the risk of SUDEP, on or soon after diagnosis.

On the day, the charity urged people with epilepsy, through the tag line 'Be smart, be safe', on ways in which they can reduce their

risk. SUDEP Action held a stall in Wantage where members of staff provided information and answered questions from the public about SUDEP and reducing risk for people with epilepsy. The charity raised funds for SUDEP research and commemorated those who have died from the condition.

Many SUDEP Action supporters organised various activities in support of SUDEP Awareness Day which will be held annually. We were fortunate, for example, to achieve press coverage across much of the UK, and reached over 4 million people in total with stories about SUDEP. Much of this coverage was thanks to individual supporters getting in touch with their local paper to share their story, so thank you very much to those of you who were able to help in this way.

We also received 23 times the usual number of visits to our website information section on this day.

We also had requests for well over 1,000 of our “be smart be safe” leaflets to be sent out and over twenty of our supporters visited their GP to ask them to display our epilepsy and risk leaflets at their surgeries.

We aim to build on this success for 2015. For more information on how you can take part this year, please contact SUDEP Action on 01235 772850 or email info@sudep.org.



UCL AND CHARITIES WELCOME \$5.9 MILLION BOOST TO UK SUDEP RESEARCH

A research team at UCL is one of nine projects to share \$5.9 million from the US government to speed up the pace of research into Sudden Unexpected Death in Epilepsy (SUDEP). The announcement comes at the same time as two of the UK's epilepsy charities have invested major funds in essential infrastructure to support this research.

Dr. Thom and her colleagues at Epilepsy Society Brain and Tissue Bank, based at the UCL Institute of Neurology, will use a variety of techniques to examine the brain in SUDEP. The team have access to one of the world's largest collections of brains from individuals who have died from SUDEP as well as to tissue collected from individuals undergoing epilepsy surgery. Together with US colleagues in the Center for SUDEP Research, they will look at the role of two chemicals, adenosine and serotonin, in SUDEP.

SUDEP Action's Epilepsy Deaths Register will promote the project in the community and provide support for bereaved families and coroners in the UK. In the US, this role will be performed by the SUDEP North American Registry. Epilepsy Society, which established the Epilepsy Society Brain and Tissue Bank in 2013, will lead on promoting the initiative with people living with epilepsy in the UK.

Seizures are common, affecting almost 1 in 20 people. Epilepsy-related death occurs at a younger age than in most other conditions. Epilepsy is the fifth leading cause in males, and eighth in females, of avoidable years of life lost. Causes of death include accidents, suicide, status and Sudden Unexpected Death in Epilepsy (SUDEP).

Each year, SUDEP occurs in 1 out of 1000 people with epilepsy, often in people between 20 to 40 years old. SUDEP refers to deaths with no known causes in individuals with epilepsy. In the UK, it is estimated that there are 600 deaths a year from SUDEP. Current efforts are focused on risk reduction through control of seizures, but there are no proven prevention strategies.

The UCL team is one of nine groups of scientists who will receive funding totalling \$5.9 million, over five years, to work together on increasing the understanding of SUDEP.

Maria Thom who leads the research team at UCL said: "This funding from the United States means we can speed up our efforts to prevent SUDEP deaths. This injection of funding from the US will enable us to make best use of our valuable resources, working with SUDEP Action and the Epilepsy Society."

Karen Osland from SUDEP Action said: "These deaths are sudden and, like cot deaths, are traumatic. Families want answers. Funding raised by bereaved families in the UK has been used to establish an Epilepsy Deaths Register that can provide a supportive environment for families to help research, and can coordinate work with coroners. We are delighted to work closely with the team at UCL."

Angela Geer, Epilepsy Society's chief executive said: "This is an exciting project combining our research with that carried out in the United States and a huge opportunity to understand more about epilepsy related deaths. The sooner we can turn our research into clinical practice the sooner we can save lives."

Source - Epilepsy Research UK

EPILEPSY DEATHS REGISTER – THE FIRST YEAR

W HENRY SMITHSON, PROFESSOR OF GENERAL PRACTICE, UNIVERSITY COLLEGE CORK, NATIONAL UNIVERSITY OF IRELAND

JANE HANNA, CEO, SUDEP ACTION

KAREN OSLAND DEP. CEO, SUDEP ACTION

The Epilepsy Deaths Register (EDR) was set up in March 2013. The register is owned and managed by SUDEP Action in collaboration with research teams (<https://www.epilepsydeathsregister.org/en/expert-team>). The Project Management Committee includes senior researchers from King's College, London; University College, London; University College, Cork; Exeter Medical School; University of Cardiff and the University of Glasgow.

To help prevent deaths, researchers need to find out what happened in as many cases as possible. The EDR helps this by:

- Providing a secure and supportive environment for participation in research.
- Collecting vital information on the circumstances of the death.
- Supporting families wishing to donate tissues for epilepsy and SUDEP research.
- Improving awareness amongst professionals and the public.

The data provided by the EDR is a valuable supplement to the registers of people monitored in epilepsy monitoring units and gives a wider range of risk groups. We know that a significant number of people who die are not in regular contact with specialists. The EDR helps give researchers a clearer picture of epilepsy-related deaths.

We now have over 300 registrations which is a great start and reflects the motivation of families and the dedicated team at SUDEP Action who promoted the register online and through liaising with professionals and patient organisations. A similar register set up by experts and bereaved families in France in 2010 relies on a network of neurologists in regions and has attracted 160 reports so far.

The EDR offers a dedicated reporting service via telephone, online registration and by post. The Epilepsy Deaths Register team based at SUDEP Action helps people with any difficulties they may experience when making a registration and provides a caller-led support service.

SUDEP Action has a professional infrastructure with experienced counsellors trained in supporting bereaved families in research. It is vital that families who may be traumatised are supported by professionals who understand the complexity of the experience of families in the aftermath of an epilepsy-related death.

"It's the first time we have written down facts and feelings concerning our daughter's death... We printed the form first so we could spend some time thinking about what we wanted to say, then we made a pot of tea, took a deep breath and wrote everything down. In the end it was a cathartic experience and we were glad to do it."

There is no restriction on reporting so long as the reporter is over 18. A reporter may choose to only participate in the first part of registration which takes about 10 minute to complete.

The question frame for families was developed through literature review & panel meetings with families and professionals. These were used to develop the question frame that was then tested by bereaved families, by Professor Smithson and the register research assistant Brigitte Colwell (Sheffield). The team has ethical approval for the EDR - family study.

Outcomes from the first year of the register include:

- Families were keen to use this secure platform for the reporting of epilepsy deaths and to help 'others benefit from our experience'.
- In the first year (March 2013-February 2014) 275 cases were registered. The number of deaths recorded as SUDEP (102/214) suggests that the knowledge of SUDEP has increased amongst pathologists and coroners.
- The majority of people have chosen to use the online facility for reporting suggesting a value in reporting from the comfort and the privacy of their own home.
- The overwhelming majority of reporters do choose to participate in detailed questions, but they are able to choose the time when they want to participate and can revisit their registration over 7 days.

- The information has been high quality and detailed.
- Emerging themes show that the use of SUDEP on death certificates has increased suggesting improved awareness; but families reporting gaps in knowledge of SUDEP persist.
- A collaboration agreed between The Epilepsy Deaths Register and the Epilepsy Society Brain and Tissue Bank, a joint initiative of University College, London and the Epilepsy Society. SUDEP Action is informing all people who register that there may be an opportunity to donate tissues to research and is also encouraging coroners to raise awareness of The Epilepsy Deaths Register and the Epilepsy Society Brain and Tissue Bank with bereaved families.

Emergent themes from free text comments include gaps in knowledge and support.

"...feel that if we had been told about SUDEP and how we could have helped reduce the risk or even prevent it, then R could still be here".

"We were invited to speak to T's GP, who was sympathetic but seemed unaware that people could die from epilepsy".

"After T's death I learned that the consultant was aware of SUDEP but believed patients should not be told of the risks".

"I will never come to terms with losing my son who was a strapping healthy young man who had no problems other than suffering from seizures which were kept reasonably under control...It has been 13 years since R passed away and time does not heal..."



Looking Ahead

The Priority so far has been to focus on family reporting which through collaboration with other initiatives will contribute to a better understanding of epilepsy-related mortality. Family reporting can provide information not readily available in health or coronial records. Families are usually vital to access data from coroners and third party sources and family consent is vital to donation of tissue after death.

Looking ahead, we need to maximise registrations and develop coronial reporting. We are very pleased to report that we have recently appointed Sammy Ashby, Policy and Development Officer, based in England and Chris Jeans, Development Officer for

Scotland. They have now started liaising with Coroners and Procurator Fiscals.

At least 28 Coroners have already agreed to support the register in principle and it is hoped that a memorandum of understanding can be developed to maximise reporting. We will be meeting with the Chief Coroner for England on 5th January 2015 to take this forward.

Academic and not-for-profit organisations in the UK and around the world have begun to promote the EDR.

Please support the EDR and ask organisations you are in contact with to promote it. There are publicity materials available and we are happy to write for any magazines.

INCREASED COMMERCIAL INTEREST IN SEIZURE MONITORS – SUDEP ACTION ADVICE

It is great to see in recent months new alert monitors on the market. Increased commercial interest in this field is to be welcomed and offers hope that one day we will have evidence of a monitoring system that is proved as a reliable intervention for SUDEP. In the meantime, these monitors can offer some peace of mind. People must discuss with their doctors the pros and cons of each device. It is important to ask for the evidence on reliability and also evidence on false alarms which can be disruptive for the family.

However, there is a danger that people with epilepsy and their physicians, faced with a bewildering range of devices may have difficulty in coming to a balanced interpretation of the marketing. The best way to prevent SUDEP is to stop seizures occurring in the first place, and this priority must not be lost.

The families and loved ones of those who did not use such devices may feel guilty that they



missed something. Given the current state of knowledge and research it is still likely that some deaths will occur even when devices are being used, which may lead to a backlash of anger.

For more information read the Risk and Avoidance article by Professor Stephen Brown at www.sudepglobalconversation.com

RESEARCH FINDS MATERNAL DEATHS HAVE INCREASED OVER THE LAST 30 YEARS IN WOMEN WITH EPILEPSY AND SUDEP ACTION OPENS THE DEBATE: WHY?

Women with epilepsy overwhelmingly have healthy babies, but research published this month reports an increasing trend in maternal deaths from epilepsy over 30 years. Earlier research this year estimated that 1:1000 women die each year from epilepsy during or shortly after pregnancy and that epilepsy-related mortality appears to be a significant risk (Nashef 2014).

The team from Nottingham University Hospitals NHS Trust who published the paper this month conducted a retrospective review of confidential enquiry into maternal death reports (1979–2008) encompassing 21,514,457 maternities.

The research found 92 maternal deaths from epilepsy over this period. The total proportion of maternal deaths from epilepsy over 30 years was 3.7% and showed an increasing trend. Sudden Unexpected Death in Epilepsy (SUDEP) was the single greatest cause of maternal deaths from epilepsy over this period followed by aspiration during seizures and drowning during bathing.

The research does not answer why there has been an increase and opens an important debate. SUDEP was not defined until 1997 and before this a myth existed that people did not die from seizures. SUDEP Action led a government funded and high-profile national report into epilepsy deaths in 2002 and new guidelines on reporting of deaths were introduced in 2003. Awareness of epilepsy-mortality has continued to rise.

Jane Hanna, SUDEP Action said:

“Improved reporting of epilepsy deaths is likely to explain the rise, but we need to continue to

carefully monitor these deaths through the confidential enquiries and The Epilepsy Deaths Register. We are aware from bereaved families quite how traumatic these deaths are and the urgent and deep need to prevent these deaths. We need the lessons from this research and other reports in the last 15 years to be put into practice”

The research team commented: *“This research shows that women with epilepsy continue to have a risk of SUDEP in pregnancy and emphasises the importance of keeping epilepsy under good control to reduce this risk. Women can be understandably anxious about continuing Anti-Epilepsy Drugs in pregnancy because of the risks to the baby but it is paramount that decisions about changes in medication only take place after informed discussion with specialist obstetricians and neurology teams.”*

Lessons from other reports and research to date have highlighted:

- Pre-conception counselling for women of child-bearing age
- Specialist obstetric care with neurology input neurological teams in pregnancy to improve maternal and fetal outcomes.
- Special care of medicines during pregnancy including regular checks of lamotrigine levels during pregnancy.
- Essential information to women to include risks of seizures.
- A review of maternal deaths in women with epilepsy by Dr Lina Nashef was published on 5th December on www.globalconversation.org. (SUDEP Action; SUDEP Aware, Epilepsy Australia partnership making sense of science in the real world).

Source

Article Kapoor D and Wallace S Trends in maternal deaths from epilepsy in the United Kingdom: a 30-year retrospective review. *Obstet Med* December 2014; Vol 7: 4 pp 160-164



IAN COLE CYCLES 600,000 METRES, A METRE FOR EVERYONE WITH EPILEPSY IN THE UK IN HONOUR OF HIS SON

Exercise Coastal Passage Challenge is something that I really wanted to do after the loss of my 5 year old son Aedan Cole. I felt that I needed to raise more awareness of Epilepsy and funds for the charity. If I can just help one person and prevent the roller coaster of emotions that my family and friends have had to go through since my son's unexpected death, that would be enough.

I have always been highly motivated, and working as a physical trainer in the Royal Navy I am fairly fit. I looked at the number of people estimated to have Epilepsy in the UK, which is 600,000 and decided to cycle 1 metre for every person. I conveyed this on a map of the UK and Dover to Falmouth was my preferred option. Also, as winter was approaching, I thought the South Coast would be the better option for weather

and I could request support from the Royal Navy in order to get the challenge running smoothly.

My son's death impacted not only my close family and friends but also my work colleagues. I work with very fit and highly motivated people and when I proposed my plan to close friends, they did not hesitate to get involved. My friends, Leona Young, Ian Robinson and Dwayne Hinds decided to join me. One member of the team has a son with Epilepsy, so this was something that he wanted to be involved with.

I didn't really anticipate how tough the challenge would be. We travelled 150km (93 miles) per day with stops at Brighton, Salisbury, Exeter and Plymouth. The first day, Dover to Brighton was a rude awakening. Heading out of Dover was tough but a lovely





cycle along the sea front. We stopped for a cake and coffee in Hastings, which was a little bit of a mistake as we found out that cake is not the best fuel for the body when you are doing an endurance challenge like this. One of the lads started to feel the pace and turned a little white. We got him in our support van, fuelled him up and continued the rest of the cycle.

We sorted out our diet for the second day (Brighton to Salisbury) with a lot of sugary sweats, nuts and about 10 litres of water. The

third day, Salisbury to Exeter was emotional, Hills on Hills on Hills on Hills. We anticipated that this day would be the toughest and it didn't disappoint. We cracked on as a group with a smile on our faces and just peddled through the pain. We were tackling hills more suited to the Tour De France. The cycle was hard but we are made of strong stuff and got it done. When the days got tough we all supported and motivated one another. I didn't want to let myself down and the people that had sponsored the group, but the memory of my son was a huge motivator for me.

LUCY BIDGOOD CAME UP WITH THE 'SUCK A LEMON FOR SUDEP' CHALLENGE, HERE IS HER STORY

I lost my husband in July 2013. It was devastating, and like many, I had never heard of SUDEP. I was with my husband when it happened, so I knew what had happened, I just didn't understand it. After a few days, I did an internet search and came across the SUDEP Action website. Feeling the need to be proactive, I contacted The Epilepsy Deaths Register team at SUDEP Action to register my husband's death.

I called the SUDEP Action bereavement support line and had a long conversation with Tracy Cowdry. She was wonderful and helped me deal with a lot of guilt I had over not being able to revive my husband. Tracy was truly amazing. For me, she probably helped me more than she will ever understand. Talking on the support line took a huge weight off my shoulders. I will say there will always be an element of guilt, that just goes with the

territory of loss, but it was hugely lessened by Tracy.

In the beginning, my family took shifts in caring for my children and running the house. As I grew stronger and as the shock wore off, I realised that my children needed me and my family needed their lives back. As time went by, there weren't as many people as before. During the day I was okay because I had the children to look after but the evenings became unbearable. Alone, every night I began to torture myself with the 'If but's, maybes, should have, could have's'. So I decided I needed something to keep me busy.

I got involved with SUDEP Action. I began fundraising and held a number of events, including a purple party. My daughters approached their headmaster about a non-uniform day. I was grateful for the support but I started to notice that the same people were supporting us. So I decided to broaden my horizons to get money from new sources.

One day I decided I would hold an event. My friend Jess and I decided on a Masquerade Ball, partly because I had never seen one locally and secondly because I liked the message it sent, the hidden truth, the facts behind the mask.

I have used the advertising campaign for the Ball to get SUDEP out there with stories published in my local paper and an online paper. I realised that choosing a unique idea helped to get attention. Terrifyingly, the only people who had heard of SUDEP are people who know me.

I decided to run an eating challenge to raise funds for SUDEP Action. They told me the first SUDEP Awareness Day was in process so I decided to launch the eating campaign in time for the day. I knew that humour sells so I tried to think of something that would be funny to watch; hence the 'Suck a lemon for SUDEP' social media campaign. The lemon

was chosen because it was funny, and it was a kind of a slogan, the bitter truth. Although the challenge has not raised fortunes, I feel it created a lot of awareness.

I am always thinking of unique ways to raise awareness and funds for the charity. Next year I would like to hold something for SUDEP Awareness Day, to break a world record or something, as that would give us great tabloid coverage. I hope to inspire people outside the Epilepsy/SUDEP circle to get involved.

I am so very grateful for the support I have received from the SUDEP Action bereavement support team and want that to be available to everyone. I have learnt that I need to keep moving to enable me to keep going. Too much time to think leads to too much sadness and I have four children to consider. Talking to others who have suffered loss to SUDEP is a great comfort to me but I like to balance it with being proactive. SUDEP Action has introduced me to some wonderful people.



SUDEP Nails



Lucy Bidgood and Alex Stirling



CARON ROBINSON WALKS ON FIRE TO RAISE AWARENESS OF SUDEP

Caron Robinson and her friends recently did a firewalk to raise awareness of SUDEP in memory of her daughter Nikey Robinson. Nikey died from Sudden Unexpected Death in Epilepsy (SUDEP) in March 2013. Her mum Caron has organised various events and activities to raise awareness of the condition and funds for SUDEP Action.

The charity firewalk was one of the most challenging activities Caron has ever done. She said: "The idea of the firewalk came about when a local pub called Georges asked for walkers to do the challenge for some local charities. I contacted the Pub owner and asked if he would consider a firewalk for SUDEP Action in memory of Nikey since she was a regular customer at his pub. He agreed and asked if I would be able to get many people to support it. So I announced it on our Facebook page dedicated to Nikey and invited all my crazy friends to do it with me."

Caron's firewalking team included Nikey's friends Jade Harley and Terri Harley, Nikey's cousin Trevor Hanley and Caron's neighbour Paula Knott. Others were Doug Miles, whose wife was one of Nikey's colleagues and Caron's friend, Becky Edgley-Cooper.



Commenting on how she got the courage to walk on the burning coals, Caron said: "Our instructor told us the temperature of the coals was 550 Degrees Celsius, but still, pulling out of the firewalk never crossed my mind. The trainer told us that once you step on the coals, you had to keep walking, keep a positive attitude and focus on the end. We were given training beforehand but I really was not concerned, for me, a blister or two is nothing. I didn't have any burns or marks, in fact, we all did the firewalk twice."

Becky commented: "I decided to support SUDEP Action because, apart from Nik, I have

a colleague who has epilepsy so I wanted to make people more aware of the charity's work to prevent epilepsy deaths. It was amazing as you are only given a little spark of adventurousness. You mustn't lose it".

Paula, who suffers from Fibromyalgia, decided to take part, to give herself a new challenge: "It is difficult to tell anyone why I accepted the challenge to walk on fire in aid of SUDEP Action. I have had the privilege to meet many remarkable and inspirational people throughout my life, Caron and Nik are but two."

"I was injured during military service and subsequently developed Fibromyalgia for which I received treatment. Recently, I suffered further medical problems and a friend encouraged me to get help. Although I have had a difficult year, there is now light at the end of the tunnel. The Firewalk marked the start of me regaining control over my mind and body. What could be more fitting

than to do it in honour of a beautiful young lady who faced challenges head on and loved life?"

Caron said: "I am pleased we all completed the challenge as a group. Like always, everything I do is in memory of Nikey and I always cry my eyes out at the end of all our events. Nikey faced challenges every day, all day, my firewalk challenge lasted only for seconds. Nikey is my inspiration and she always knew I was a little bit crazy."

"All my firewalkers were very proud of themselves for completing something different for charity. None of them had ever done anything like it before. I would do it again, but to be honest I am more likely to organise something different for those of my courageous friends who wish to challenge themselves. After Christmas, I am booking about five or more friends to do a 160ft bungee jump in Cambridgeshire on 13th June, 2015."



CHERYL WOOLLARD RAISES AWARENESS FOR SUDEP AWARENESS DAY

My sister Nicole (Nic) was 28 when she passed away from Sudden Unexpected Death in Epilepsy (SUDEP) in June 2013. She was happily married with a 6 year old daughter and an extended family.

Nic had been volunteering with an Epilepsy charity and 'manning' the Epilepsy information desk at our local hospital, she was very proud of this. Nic loved writing poems and entered poetry competitions. She enjoyed sewing and loved reading, completing books in a day on several occasions. Nic was selfless and despite her seizures, she did her best to keep an upbeat attitude. She is greatly missed by our family.

After Nic passed away, one of my mum's friends made us aware of SUDEP Action as she had also lost someone to SUDEP. I then looked up SUDEP Action on the internet, Facebook and Twitter and have been following and supporting wherever I can.

I decided to raise awareness for SUDEP Awareness Day because sadly, our family were unaware of SUDEP until after my sister passed away. Despite Nic being diagnosed with epilepsy aged 14, no one from her medical team had ever raised the subject of SUDEP. Our main worries regarding her epilepsy were the injuries she would sustain during a seizure. We never, for one second imagined this could happen. If we had known, we would have done some research and tried our best to help prevent this from happening.

In preparation for SUDEP Awareness Day, I contacted my local GP surgery and asked them if they would display the SUDEP Action information leaflets in their waiting rooms. I asked them to give the leaflets to their medical staff they happily agreed. I ordered and dropped the leaflets off to them a few weeks prior to SUDEP Awareness day.



I also wrote a small piece in our staff bulletin telling them about SUDEP Awareness Day and why I was raising awareness of SUDEP. I told them where I would place the SUDEP information leaflets and where they could access the downloadable copies.

On SUDEP Awareness Day, I placed leaflets around the building. I brought cakes into my office, either orange in colour or flavour, and made a poster saying that in order to have a cake they needed to take and read at least one leaflet. They all did this and we happened to have some large meetings happening in the building so the attendees were shown to our office. Everyone asked questions and read the statement from the bulletin. I also had a few emails requesting printable copies of the leaflets so I downloaded them from the SUDEP Action website.

Unbeknown to me, my amazing colleagues did a collection after the day from the staff in our office and raised £35.00, this was a great surprise. I was really pleased with the response and how the day went. I have the pleasure of working with health professionals



and only a few people had ever heard of SUDEP, the rest were totally unaware. Some of the meeting attendees said they had been unaware until recently when it had happened to someone locally or to a friend of a friend. Everyone was very interactive and keen to hear about what could be done to help. I think SUDEP Awareness Day is a great idea and should definitely be something that is continued every year to raise awareness and support. Hopefully it will grow and get bigger each year.



Alan at Arran

CHRISTINE DONALDSON CREATES CHARITY CALENDAR IN MEMORY OF HER SON

Christine Donaldson has created a lovely calendar in memory of her son Alan Donaldson. Alan died in January 2010. The calendar is packed with beautiful photos taken by Alan and his friends.

Christine said: "Alan got on well with everyone due to his friendly, down to earth personality and sense of humour. He loved a good discussion. He had the quality to listen to others as well as putting his own views forward. Alan read widely and was interested in Politics, he gained a 1st class honours degree followed by a masters

in politics and economics. He enjoyed an eclectic variety of bands, classical, everything really and he played the guitar. Alan loved football."

Determined to keep Alan's memory alive, Christine decided to create a Calendar to share Alan's photographs and to raise awareness of SUDEP Action.

Christine said: "Alan enjoyed travelling, both abroad and at home. He never travelled far without his camera. He visited Australia, Singapore, many European countries and

most importantly his many friends and his family, especially his three sisters. We loved him dearly. As we have many lovely photographs I decided to produce the calendar to show them to others. I also use a photograph each year on my Christmas cards."

"It was difficult to choose the best ones so I came up with the idea of asking his friends to choose their favourite photograph, which they duly did. This also helped publicise the calendar as we want to reach as many people as possible".

Now with help from her friend, a local printer, the calendar has gone on sale with all proceeds going to SUDEP Action. Alan's Calendar is available for just £5 each and £1.50 for postage if purchased by email. The calendars can be purchased locally in Lochwinnoch, Scotland or by emailing Christine at **christine39forever@hotmail.com**. Donations can also be made at **www.justgiving.com/alan-donaldson** or to SUDEP Action.

So far, Christine has helped raise about £30,600 in aid of SUDEP Action in memory of Alan. In October 2014, Christine ran a half marathon in aid of the charity, describing the event she said: "There was a tremendous atmosphere surrounding the Glasgow Half Marathon and the course

was excellent, taking us over the Kingston Bridge, through Pollock and Ballahouston Parks and round by the Hydro where we knew the end was nigh!! Well done to the pipers who marked every mile and kept our spirits up. I completed the half marathon in 1 hour 54 minutes and 3 seconds - not as fast as last year but as I hadn't trained as much, I suppose all in all it was okay! Here's to next year!"

Earlier in the year, Christine and her three daughters also hosted a fundraising Swish Night for about 20 friends. She commented: "It really was a great night and surprisingly straightforward to organise. We laid on a finger buffet and wine which helped the night go with a swing! We asked everyone to bring up to three items which could consist of clothing, shoes, accessories etc. along with a small cash donation. The clothes were displayed on rails, which I borrowed from a friend, and the accessories were displayed in another room."

"Firstly everyone had a wee look at what was available, then they chose one item to start. As the night wore on, the clothes disappeared and the guests, much to their delight, ended up with new dresses, jackets, shoes, jewellery, handbags and much more. This was a lovely way to raise money, meet friends and have a most enjoyable evening."



Christine

FUNDRAISING UPDATES

Fundraising is what makes our work possible. All contributions, big or small, help us to carry out the work that we do. We truly appreciate all the efforts from all our fundraisers.

We have had lots of great fundraising events since the last news edition but we always need more for our work to continue. Please email fundraising@sudep.org or call **01235 772850** if you would like to help.

Support the Wearable Apnoea Detection Device



We need to raise £165,000 by March 2015 in order for Professor John Duncan to test a device that detects

when someone has stopped breathing on 50 people with epilepsy. At present, we have roughly a third of the amount needed so we urgently need more people to fundraise for us in order for the project to go ahead. Please play your part and help us fund the research into this potentially lifesaving device. Email fundraising@sudep.org or call 01235 772850 to inform us about any WADD fundraising activities you have planned, or to ask for advice and inspiration.

Memorial Tribute pages



Memorial Tribute pages are a good way of remembering a lost loved one. You can post photos, poems, videos, music,

messages and memories to the tribute. The memorial tribute site has been updated so you can now add fundraising events to the site as well as make donations. Go to memorial.sudep.org to set up your own.

Donation box



These boxes are great to have around the house to collect spare change or for fundraising events with friends and family. You can personalise

your box and send us the pictures. We have decorated ours with stars. Email fundraising@sudep.org to request a free box.

London 10K



We have plenty of places for the 2015 London 10K on Sunday 12th July. Deposits are £35 per person. Email fundraising@sudep.org if you are interested in

running. Places are on a first come first serve basis so get in touch as soon as possible to avoid disappointment.

WEBSITE FEATURES AND SOCIAL MEDIA

- Help support The Epilepsy Deaths Register campaign by filling in our online form at www.sudep.org
- Create a memorial for a loved one on our memorial page
- Join our forum discussion on the 'Someone has died' section.
- Follow us on Facebook for regular updates.
- Follow us on Twitter and help us raise awareness .

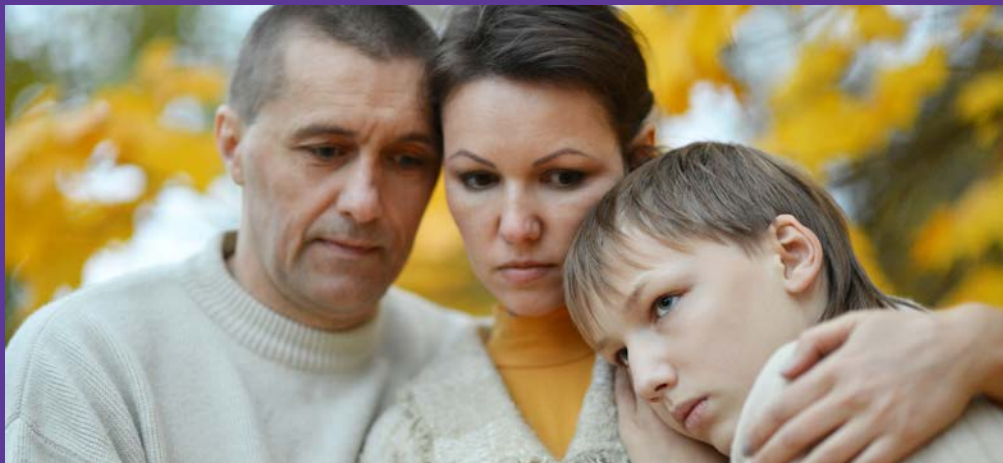
CHANGES

Chris Jeans is our new Development Officer for Scotland. Chris says: "I look forward to my new role with SUDEP Action. We can now provide a more local service here in Scotland that people will be able to access more easily. I am privileged to be part of the charity that I am so passionate about. I too, am an epilepsy bereaved Mum who strives for answers and changes."



Sammy Ashby is our new Policy & Development Officer. She has a background in Adult Training and Secondary Education with a Teaching qualification from Oxford University & an English/Psychology degree from the Open University. She is looking forward to working with the team, ambassadors & supporters to continue helping the charity meet its aims.





Reaching Out

*Our hearts are reaching out to you,
For what you're going through;
We're thinking of you frequently
And praying for you, too.
If there is something we can do,
Anything at all,
Think of us thinking of you,
And don't hesitate to call.*

Adapted from an original poem by Joanna Fuchs

Bereavement Support

Please make use of the support line if you would like to talk. Remember, we also support people by email, you can email us any time, day or night; you may not get an instant response, but we will reply to you as soon as we can. Remember, if you can't sleep, or have continuous thoughts going round and round in your head, putting those thoughts down in an email, and clicking send can be very therapeutic. Please don't go through this on your own, we are here to help in any way we can.

The support team at SUDEP Action is available on 01235 772852 or email us at support@sudep.org

THE
EPILEPSY DEATHS REGISTER
Making every epilepsy death count



SUDEP Action is committed to preventing Sudden Unexpected Death in Epilepsy (SUDEP) and other epilepsy related deaths through research, awareness and influencing change. We also work to support the bereaved and to help them channel their grief into preventing future epilepsy-related deaths.

Bereavement support:

support@sudep.org

Getting involved & campaigns:

fundraising@sudep.org

Media:

info@sudep.org

SUDEP Action
12a Mill Street
Wantage
Oxon OX12 9AQ

Call: **01235 772850**
Email: info@sudep.org

SUDEP.ORG