



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.

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SUDEP Action 
Making every epilepsy death count

KEEPING IN TOUCH
July 2015

HELLO THERE ...

The new charity year got off to a great start this year and we hope you will enjoy reading all our news. You can read about our new developments including our Safety App – a digital version of our Check List which is also featured. The Check List has raised rates of discussion of risk and has received great feedback from both doctors and patients. Thanks to all of you who helped raise awareness of these cutting-edge projects during our National Epilepsy Week Stay Smart campaign.

We will be launching the app on the 14th July and if you feel you could help us in any way please contact us. We have a Twitter and Facebook campaign planned so if you are able to follow us on that, you will see the live action. To all our wonderful fundraisers – thanks for making all this happen. Together we can make sure that people with epilepsy and doctors have the knowledge they need to talk about reducing risks.

Jane and Karen
CEO and Deputy CEO

SUDEP.ORG

SPECIAL STATEMENT FROM JANE HANNA OBE, CHIEF EXECUTIVE

We are thrilled to be announcing new tools available to support people with epilepsy and clinicians.

For the first time, clinicians can register for access to our SUDEP and Seizure Safety Check List, and people with epilepsy can register for EpSMon, an App which is designed to help people in between visits to doctors.

We owe a great deal to Liz and Bob Hollingdale, and all at Kt's Fund in Cornwall who raised the funds to support this project following the sudden death of their daughter Katie Hallet. Katie was a young student nurse who was unaware she was at risk and died before she could access services. Huge thanks to the local coroner, who allowed access to the records of people who died suddenly in Cornwall over 9 years. With her help, we discovered that many people who died had a worsening of known risks in the 3-6 months before they died, but were not in contact with their doctor.

We know people have to make choices daily and that things can change. People live busy lives and may only see their doctor once a year and some less frequently than that. EpSMon has been designed to help people by prompting them to use their App every three months, to keep track of risks from seizures.

For me, this all seems a long way from the 1990's when there was really no knowledge on SUDEP or how people could make decisions to reduce some risks. We know there is no proved intervention for epilepsy deaths, but bereaved families say they wish that their loved ones had the information so that they could make choices. In this information rich world, people living with health conditions deserve information that is both accessible and helpful. These new tools have already changed medical practice in Cornwall, and we hope that making them available to all, will start to make a real difference to people's lives.



SUDEP ACTION LAUNCHES FIRST RESEARCH BASED SELF-MONITORING APP FOR ADULTS WITH EPILEPSY

SUDEP Action has launched the first research based self-monitoring app that brings life saving knowledge to the fingertips of adults with epilepsy.

The Epilepsy Self Monitor (EpSMon) app - a world first - has been developed by a team of partners, including clinicians, patients and health technology information experts, at Plymouth University; Cornwall Partnership NHS Foundation Trust; Royal Cornwall Hospital Trust and SUDEP Action.

EpSMon is a self-monitoring app aimed at people who experience seizures. It allows them to assess their risk every three months and prompts them to see their doctor when their risks increase. EpSMon also suggests simple ways they can lower their risks.

It does this by asking questions including about their last appointment, their epilepsy, their seizures and their well-being. The app analyses the answers and creates advice ranging from 'all clear, no further action required' to 'make an appointment with your doctor now'. The app analysis can be shown to their GP to help them decide the best treatment regime for them going forward and helps them facilitate meaningful person centred communication of key risk issues.

In essence whilst a person with hypertension might use a domestic blood pressure device, someone with epilepsy can use EpSMon to check they have a planned review of their epilepsy in the future or go earlier if they are reporting a worsening of risk factors.

SUDEP Action Trustee Simon Lees, who has epilepsy commented: "EpSMon is just what



"I need to monitor my risk in between visits to doctors. It helps me take actions at all times as it measures my own particular risks of epilepsy. It can act as a safety net, being an excellent reminder of the importance of taking medication correctly and seeing my GP on a regular basis."

There are around 600,000 people with epilepsy in the UK. About 87 people are diagnosed with the condition every day. Epilepsy accounts for 1,200 deaths in the UK every year, at least 600 of these through SUDEP. Research shows that about 42% of these deaths may be preventable through better management of known risk factors.

EpSMon is based on evidence from the SUDEP and Seizure Safety Check List, a facility that enables clinicians to monitor changes in risk factors in their patients. It was developed by researchers, GPs, people with epilepsy and the Coroner in Cornwall. The study was funded by Kt's Fund, a charity set up in memory of Katie Hallet, a young nurse who died suddenly aged 20 from epilepsy.

Katie's mum Liz Hollingdale, who set up Kt's Fund with her husband Bob Hollingdale said: *"The conversation about risk between doctor and patients with epilepsy needs to be accepted as routine just as it is with other chronic conditions. I wish that the new safety app had been available to Katie; this would have allowed Katie to record important information on her mobile which could have been stored and then used to see if there were any triggers leading up to her seizures."*

The SUDEP and Seizure Check List

The SUDEP and Seizure Check List is a tool used in a 10-minute consultation that provides clinicians with the latest evidence on risk factors for premature mortality in epilepsy. The Check List was used to analyse nine years' of deaths reported to the Coroner in Cornwall and found that 90% of people had a worsening of risk factors in the three to six months before their deaths, but that few had contact with their medical team.

The Check List was introduced into routine practice in Cornwall in 2013 and has received positive feedback from 200 people with epilepsy. It is being used in routine clinical practice in epilepsy services in Cornwall including neurology clinics and community based telehealth. EpSMon will provide useful information for GPs which can be used in conjunction with the Check List to manage and fine tune care for those with epilepsy.

"Doctors and patients alike have welcomed these communication tools. Clinicians in the South-West found that using the check list raised discussions from 10% to 80% of all people within epilepsy services over 2 years. This compares with a recent audit from a Scottish epilepsy clinic which found that communication about risk increased from 4% to 34%. The App and Check List are easy to use and although it is early days we are not seeing the numbers of deaths that we would have expected in this local population." Dr Rohit Shankar, Consultant in Adult Developmental Neuropsychiatry at Cornwall Partnership NHS Foundation Trust.

Professor Stephen Brown, from SUDEP Action commented: *"Only recently there was media coverage regarding a plea to the Prime Minister from women with epilepsy to address the confusion around the risks to pregnant mothers from an epilepsy drug. The app will ask women of childbearing age if they have had pre-conception counselling and flag up whether they need to see their GP if not. Women need a balanced view of the risks from medications to their unborn child and risks of seizures to them and they need it well in advance of getting pregnant - this is what EpSMon helps women to get."*

The NICE clinical guidelines encourage people with epilepsy to manage their condition through information and discussion. There is a call for patients to be full partners in their care including advice on SUDEP, the importance of seizure control and being aware of the dangers of night time seizures, EpSMon will help to achieve this. The data collected through the use of EpSMon will be used for future research to achieve a better understanding of epilepsy and to fine tune care available.

BMJ REPORT POINTS OUT NEED TO MONITOR EPILEPSY RISKS AND KEEP PATIENTS SAFE

The BMJ Quality Improvement published a report in March, 2015 highlighting the need for the SUDEP and Seizure Safety Check List as a way to address the issue of discussing and monitoring risk with people with epilepsy. The report was authored by Dr Rohit Shankar, SUDEP Action Chief Executive Jane Hanna, and Dr Craig Newman among other experts in the field.

The report highlights the development of the SUDEP and Seizure Safety Check List, which was developed to help guide discussion of Sudden Unexpected Death in Epilepsy (SUDEP), for health teams looking after people with epilepsy. Through the use of the checklist within GP surgeries the aim is reduce the number of potentially avoidable epilepsy related deaths.

The SUDEP and Seizure Check List has been developed through SUDEP Action's Epilepsy Life Project. The project was made possible by Kt's Fund, which was set up following the sudden death of Katie Hallet.

The NICE guidelines recommend that people are told of risk, including the risk of SUDEP, on or soon after diagnosis, but there is evidence that this does not always happen. A recent editorial in the British Medical Journal highlights premature mortality in epilepsy. It also highlights the lack of screening methods in place to assess and 'flag up' the risks for

people experiencing seizures. The SUDEP and Seizure Check List has been used in Cornwall to support improved engagement between Health Professionals and their patients.

The BMJ report highlights that, tools such as the SUDEP and Seizure Safety Check List could help reduce the public health burden of Epilepsy on the NHS by empowering patients to work with their health care teams, to monitor and manage their condition within a primary care setting.

The report discusses how there is no wide scale intervention or national surveillance of epilepsy mortality. The SUDEP and Seizure Safety Check List is a simple and practical tool that can be used to address this issue. Furthermore, it comments that the Check List can also help give some assurance to bereaved families that every effort was made to reduce risk and prevent a fatality.

Jane Hanna OBE, from SUDEP Action, commented on the report: *"We were thrilled that introducing the Check List into routine practice meant that 80% of people seen by services in Cornwall had their risk assessed and reported this as helpful. National guidelines introduced in 2004 encouraged discussion, but it has not been happening in many places. We hope that clinicians will like this simple approach that encourages a positive discussion of risk"*.



CALL TO 'RED-FLAG' PEOPLE AT RISK IN GENERAL PRACTICE AND CUT EPILEPSY DEATHS

An editorial published in February in the British Medical Journal, a highly regarded resource for health professionals, calls for GP screening of people with epilepsy at high risk of premature death to allow for a step-up of care. It calls on General Practitioners, who already routinely collect and use patient data on stroke; heart disease and cancers, to also use the data they have on patients with epilepsy to step-up care.

The feasibility for screening using electronic medical records to 'red flag' people at risk is based on a pilot study led by Leone Ridsdale, Professor of Neurology and General Practice at Kings College London recently highlighted in an editorial in the British Medical Journal. The study was commissioned by SUDEP Action and a team of researchers at King's College, London (The SUDEP Research Initiative) and researched mortality in a very large general practice population.

Whilst information that epilepsy deaths are potentially avoidable has been known in the UK for some time, the editorial highlights the need for a national risk assessment tool to support lessons from research being put into practice.

The editorial highlights the main risk factors and suggests how they can be 'red flagged' by General practitioners using electronic medical records to identify people with epilepsy who are at high risk of death. The red flags that exist for epilepsy and could be used include:

- Patients experiencing injury in the previous year
- Patients not collecting their medication prescription
- Patients with epilepsy and depression
- Patients misusing alcohol

Professor Ridsdale commenting on her editorial said: "Whilst GPs are having funds cut for reviewing people with epilepsy, we know from this research that the risks for many deaths might be identified, and potentially reduced. Screening for risk has halved deaths from cervical cancer. Epilepsy causes more deaths and could benefit in the same way.

If health services research funding is provided, an electronic risk assessment tool can be developed that would help GPs identify people at risk of death in epilepsy, just as they do in heart disease and cancer. If a risk-assessment tool was developed, and GPs funded to use it by the Quality & Outcome Framework, then premature deaths might be avoided, just as they have been for cervical cancer."

In order to capture those at risk, Professor Ridsdale suggested that everyone with epilepsy has to be assessed and this is possible using General Practice records. She points out that detailed records on people with epilepsy were kept by GPs between 2004 and 2014. An in-depth analysis of data between 2004 and 2014 could be used to develop an automatic risk assessment tool that would alert GPs to profiles that had been red-flagged.

Jane Hanna from SUDEP Action: "The development of a risk assessment tool is not rocket science. Of course we will always need more research into new treatments and bio-markers, but bereaved families will always ask why existing research that might save lives is not being used in practice to benefit people with epilepsy".



REVIEW HIGHLIGHTS NEED FOR INTERVENTIONS TO REDUCE PREVENTABLE DEATHS IN EPILEPSY

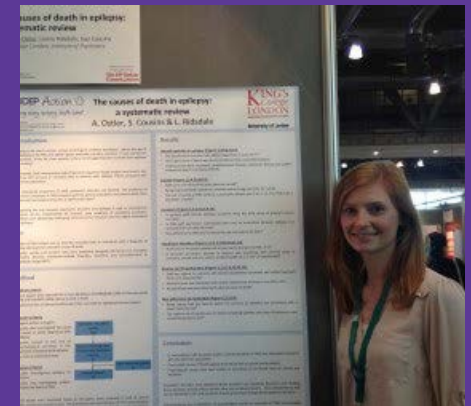
A review of research on epilepsy deaths has highlighted the need for interventions to reduce avoidable deaths in people with epilepsy. The review, published on the SUDEP Action website in March, found that important interventions could help reduce deaths amenable to medical care, such as suicide and accidents. It focuses on behavioural and psychological risks, and the interventions that could help reduce deaths in people with epilepsy.

The review by third year clinical medical student, Alexander Olster, was supervised by Professor Leone Ridsdale, Chair of Neurology & Psychiatry Teaching, and Dr Sian Cousins at King's College London. The study was presented as a poster at the Royal College of General Practitioners National Conference last autumn.

It examines mortality, suicide and accident rates, together with risk factors for mortality including; substance-related disorders, psychiatric disorders, accidents and non-adherence to anti-epileptic drugs (AED).

The review found that being seizure free (no seizures within the previous 12 months) was associated with a lower mortality rate. It also found that not taking epilepsy medications increased risk by 50%, while people with a psychiatric disorder and people misusing alcohol, were high risk groups. The incidences of depressive symptoms are significantly higher in people with epilepsy, compared with the general population and patients with other long-term conditions.

Jane Hanna OBE, from SUDEP Action commented: "It is hoped that this review will stimulate GP research which may address risks for death in epilepsy in primary care. Proven interventions are still lacking but



psychiatric disorders and substance abuse are treatable. Seizures are treatable, and non-collection of prescriptions is detectable and potentially worth addressing in primary care. We were pleased to sponsor a student at King's this year as part of our ongoing collaboration with King's College, London."

Professor Ridsdale from King's College, London said: "Community interventions including patient education and support addressing socio-economic and educational disadvantage, inequality of access to secondary care through lack of agreed pathways, depression, stigma and the reasons why patients are not taking medications need to be developed and supported".

Professor Ridsdale has previously led work on epilepsy mortality trends and risk, using a very large general practice population. This pilot study was commissioned by SUDEP Action in 2011, and identified risks that could be flagged up in general practice and potential for intervention (Ridsdale et al. Epilepsy mortality and risk factors for death in epilepsy: a population-based study. British Journal of General Practice 2011; 61(586):e271-e8)

The review also found that people with epilepsy were over three times more likely to commit suicide. The risk of suicide increased for patients who were not seizure free and being diagnosed with a psychiatric disorder was a strong risk factor.

The study found that accidents were the third greatest cause of excess mortality in people with chronic epilepsy. Not taking anti-epileptic medication increased the risk of accidents by 50%. People with a psychiatric disorder or misusing alcohol were at increased risk of death from injury.



SUDEP ACTION SUPPORTS NATIONAL LEARNING DISABILITIES WEEK 2015

This year, SUDEP Action supported National Learning Disabilities Week, which ran from 15 June to 21 June. The week was aimed at raising awareness of learning disabilities and changing the national perception of what it is like to live with a learning disability.

Every day in this country, 3 people die from epilepsy. Of these around 1 in 3 is learning disabled. There are around 150,000 people in

the UK who have both epilepsy and a learning disability. Studies have shown people with both epilepsy and a learning disability, are at an increased risk of SUDEP.

A recent study in Leicester found that epilepsy is the second most common cause of death for learning disabled people. It was also found that in the majority of cases; no-one had talked to either patients or their carers about their risks (including SUDEP) and how their risks could be minimised. We know from a research project in Scotland, that when people with epilepsy are told about their risk of dying, around 1 in 3 changed their behaviour to reduce their risk.

Most people who have lost someone to epilepsy say they wish they had known more about the risks before the person died. The NICE and SIGN guidelines both advocate discussion of epilepsy risks (including SUDEP) with the patient at the earliest opportunity. However, a survey among UK neurologists

showed that only 4.7% of them discussed SUDEP with all patients and 25.6% with the majority. The rest discussed the risk with very few or no patients.

This is why we were pleased to announce during National Learning Disabilities week, that in the coming months, we will be releasing two new leaflets to help raise awareness of Epilepsy risks aimed at people with learning disabilities and their Parents and Carers. They will take the form of an Easy Read booklet and an accompanying companion guide for Parents and Carers which enables them to go through the information with the person with epilepsy, providing additional information to suit their needs and ability.

If you would like to be kept informed on when these leaflets will be made available and would be interested in raising awareness of them in your area, please contact our Policy and Development Officer Sammy Ashby on 01235 772850 or email samantha.ashby@sudep.org



PURPLE DAY RAISES AWARENESS OF SUDEP THE GLOBAL CONVERSATION

This year's Purple Day, we joined forces with the Anita Kaufmann Foundation, SUDEP Awareness Canada and Epilepsy Australia to bring greater awareness of mortality in epilepsy around the world through Purple Day. The day raised awareness of the latest SUDEP Global Conversation online resource. Purple Day is an international effort to promote epilepsy awareness and research and is held annually on 26 March. We also

marked Purple Day by holding an awareness and fundraising stall in Wantage, Oxfordshire. Purple Day was created by Cassidy Megan in 2008 who was only 9 years old at the time. This year Cassidy wanted to help raise awareness of families impacted by death in epilepsy by promoting the SUDEP Global Conversation website as a recommended resource for reliable SUDEP information.

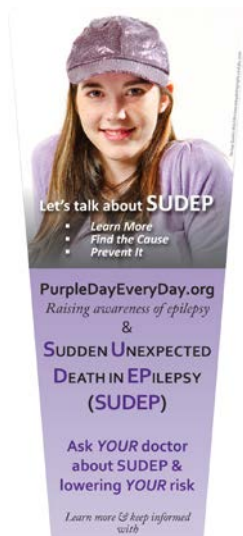


Cassidy Megan said: "SUDEP is still not talked about enough. By highlighting it as part of Purple Day's global awareness effort, we hope to encourage conversation around the world. We need to learn more about it, find its cause and how to prevent it."

SUDEP Action Chief Executive Jane Hanna OBE, commented: "Thank you to Purple Day for supporting the SUDEP-Global Conversation resource in this way. Bereaved families marking our 20 year anniversary this year were thrilled to learn that Purple Day is using its reach to help make sure that anyone with epilepsy has the opportunity to find out about SUDEP."

SUDEP Global Conversation is a unique SUDEP knowledge resource created by a three-way collaboration between SUDEP Action, SUDEP Aware Canada and Epilepsy Australia. It combines the latest research and insight of nearly 60 experts with the powerful accounts of over 35 bereaved families from around the world.

SUDEP ACTION HOLDS 20TH YEAR ANNIVERSARY CONFERENCE



We held our 20th annual charity conference on the 21 to 22 March, 2015 at the Dunchurch Park Hotel and Conference Centre, near Rugby.

SUDEP Action Chief Executive Jane Hanna commented: "Our national conference is part of our 20th anniversary year. Meeting recently bereaved families attending for the first time is a constant reminder to all who are dedicated to the cause that there is so much to be done."

"We had an opportunity to share with our supporters why our 20th anniversary is an exciting time to remind ourselves of the body

of research that now supports the cause of prevention and the massive shifts in thinking and practice that have taken place."

At the conference we highlighted our plans for the next 20 years. Attendees heard from specialists in the field of epilepsy and epilepsy mortality. They heard about the latest research; personal stories and the charity's achievements so far.

On the Saturday afternoon, we had a special memorial white dove release to remember all those who have died from epilepsy including SUDEP.

GREAT NORTH SWIM IN MEMORY OF ROBERT BALDWIN

My brother Robert and I were members of an amateur swimming club when we were younger so swimming was a big part of our childhood. In 2014, I coincidentally found myself near Windermere on holiday during the Great North Swim weekend and decided then I would like to take part in 2015.

This was the first time I have done an outdoor swimming challenge so I decided to go for 2 miles. I knew I could swim a mile easily in an indoor pool and I wanted to push myself. To prepare myself, I started doing a lot of pool swimming, and later in May 2015, I did some open water swimming at USwim in Salford, Manchester.

When I first got into the water which was 11.6 degrees, it was such a massive shock for me and for the first ten minutes I honestly thought I would have to cancel my challenge. Just to show how much of a novice I was, I put the wetsuit on inside out the first time! I also got a bit of a red chafe mark on my neck from the wetsuit soon after I started my training, it was really painful at first, and well, fairly

embarrassing. But every week it got easier, and thankfully warmer; getting the wetsuit on and off became less of a struggle!



Catherine with her mum Hilary Baldwin

The biggest challenge during training was not being able to see where I was going. Without lane ropes and the pool bottom to guide you, it's easy to get carried away and drift off course! I learned that I have a real tendency to drift to the right, so I had to remember to correct myself and keep sighting for the next marker regularly.

When the big day finally came, I was pretty nervous and a bit emotional! I felt confident in Salford Quays but swimming in Windermere and as part of an event was new territory for me. I was worried about the mass start, but it was so well organised, I felt happy and confident before I got in the water. There were a few moments where people swam very close to me and a couple of people crashed into each other in front of me.

I found the advice given to us by the event organisers really useful. They told us to take the first mile (lap) easier and then go for it on the second one so that's what I did. Having done the training, I had a comfortable pace, and after about 1.5 miles I knew I was going to be fine. When I was near the end, I decided to speed up and I was really pleased with my finishing time.

I couldn't wait to get to my family and friends who were waiting for me at the end. They popped a bottle of Prosecco as I came through, it felt great! I had really wanted to challenge myself in memory of Robert and raise awareness of SUDEP Action. So I teamed up with April Weaver who swam 1 mile in memory of her son Christopher Mills and we both raised £500 for the charity. We hope that this money will go towards the research and trial of the Wearable Apnoea Detection Device.

I hope to do more in the future though, as it's been great I was back out swimming the week after the challenge. I also have to swim in a triathlon relay team in August, so it has

made me realise there are lots of events I can take part in.

I would encourage anyone planning on doing an open water swim for the charity to go for it. Open water swimming can be daunting, but it's really good fun and totally eliminates 'lane rage' that you get in indoor pools. There are so many well organised and supervised training sites where you can have lessons and prepare yourself for a great challenge. The Great North Swim is a brilliant event and in such lovely surroundings. It's a really good atmosphere. My supporters and I had a fabulous time and we raised lots of money for a worthy cause.

To show your support visit <https://www.justgiving.com/teams/sudepswimmers>

April Weaver



STEVE HILL RUNS LONDON MARATHON IN MEMORY OF HIS FATHER

I have embarked on several events for SUDEP Action in memory of my father, including climbing Kilimanjaro. However, for many years, running the London Marathon has been something I thought would really capture the attention of family and friends, so that I could raise significant money and awareness for the charity.

For me, the London Marathon is the greatest race in the world. There is no other race where spectators line the entire route cheering you on every step of the way. The atmosphere is amazing, with a mixture of elite athletes, celebrities, fancy dress and charity runners.

This was the first time I had ever attempted a marathon. Although the London Marathon is exactly 26.2 miles, I had covered around 500 miles to be ready at the start line. I love to run, though my distance is more like 8-10 miles before I start to feel worn out. A marathon is a serious feat of endurance, so I started training just after New Year to attain the level of fitness I needed to complete the race.

Training involved running 5 to 6 times a week, whatever the weather. During the week I would go out for an hour or so each evening and do fast and slow intervals uphill and downhill. These mid-week more intensive sessions helped to build endurance. I would then go out on the weekend for a long run, gradually building up the distance over the weeks.

However, with about 5 weeks to go before the marathon, I broke my rib and thought I had blown everything. With the help of professionals and my family, I managed to start running roughly 2-3 weeks before the race, which was just enough time to get my fitness back up to speed, albeit painfully.



During the race, I was under no illusion that the last 5 miles or so would draw upon all my strength. Between the 20-26 mile marks, I promised myself that I would never run a marathon again. To keep going, I began to imagine myself crossing the finish line. I started reminding myself that no matter how hard it got, it would never be as hard as it is for people who deal with epilepsy related bereavement.

Spotting my family, including my 8 week old baby along the course, cheering me on, was one of the best moments and helped me keep going. I had spent so much time and energy on training that actually putting that into practice and crossing the finish line was one of the best feelings, if not a little relieving!

To complete and have finished the London Marathon in a respectable time is something that will stay with me forever. I am also very proud to have run in aid of SUDEP Action, which is the only charity I would have contemplated running for.

I know that the £3195 raised towards the Wearable Apnoea Detection Device (WADD) project will be well spent. 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.

ROSIE'S BALL RAISES AWARENESS AND £15,500 FOR SUDEP ACTION

Rosie had always wanted a big 21st Birthday Party, and since we all knew just how much she liked to party, it seemed an appropriate way for us to celebrate her life. At the same time, we wanted to do something positive in order to try and address the complete lack of awareness surrounding the cause of Rosie's death.

We came together as a family and settled on the idea of making the ball black-tie, in the hope that it would cater for everybody; not just friends and relations but also people who did not really know Rose but simply wanted to support us as a family. We also believed that, a single large one-off type event would provide the greatest opportunity to raise a decent amount of money. This could then be used to fund further research into this little understood phenomenon, and in the hope that other lives may be saved.

Running is very addictive, so I've signed up to do it again next year. I would encourage anyone considering running the marathon in aid of SUDEP Action to do it! It will be one of the most amazing experiences you will ever take part in. Although, a little bit of advice, make sure you put the training in.

We set a date for Rosie's Ball that we knew would be convenient for many, and arranged for the ball to start at 6.30pm prompt, with champagne on arrival followed by dinner at 7pm. We made the decision to start early so people could eat and then we could get the auction completed before the evening guests arrived. It also encouraged people to start relaxing early on and this ensured that the vast majority stayed on late into the evening. The limiting factor of course was space, since we were using our local St Mary Bourne village hall. However, we managed to offer a variety of table sizes for sale to ensure that we had 145 guests for the reception, dinner and auction, and then a further 30 people for the after-party disco.

Quite honestly, we were amazed at the generosity of so many people for contributing, and also then bidding for the auction and raffle prizes, and it was this part of the evening that

generated the most amount of money. We were also pleased to have Katie Piper come along and support us despite doing so much of her own charity work. We were honored that she was able to find the time to attend and enjoy this event.

The music throughout the evening was excellent and was provided by a local band called the Rookies. The band is made up of parents from our children's school, who chose to perform on the night for free. A band would normally cost anywhere between £300 and £800, so savings such as this are fairly significant and can really help increase the amount of money raised.

The ball ended at about 1am and we were pretty exhausted by the end, but also relieved that the event itself had been such a success. More importantly, and despite Rosie not being there, we were pleased that we felt that we had been able to celebrate her in such a positive way. Whilst as a family it was sometimes very sad, it was in many ways also a hugely enjoyable event since we were able to hear so many stories about Rose which at the time we had remained blissfully unaware of.

Looking back at the event, we are incredibly grateful for the support of all our immediate family and a few close friends who helped with the planning, execution (and tidying up!) but especially my good friend Mills. This event would probably never have even got off the floor if it wasn't for the contribution of Mills.

After losing a loved one they often say that your circle of friends can change and this is so true. Mills is somebody who has become a great friend to me and my family since Rose passed away.

We as a family will continue to try and raise money for the charity, and would always be happy to help anybody else who wishes to consider such an event. If you are considering organizing a ball for SUDEP Action, all I can say is don't be afraid and be sure to try and make it as fun as possible! Also, try to engage some close friends who may bring some very different skill-sets to the table. Friends you can count on to help you in setting realistic goals and expectations.



Emma



GILLIAN THOMSON CLIMBS SCHIEHALLION IN MEMORY OF JESSICA MONKS

In January, we lost my cousin's beautiful, kind, fun loving, giggly, and intelligent granddaughter. Jessica Monks was 18 years old and had epilepsy from a young age. Although this was at times a struggle, Jessica never let it hold her back, she loved to run, swim, and coached younger children at taekwondo. She was working in a lawyer's office and was looking forward to starting university after the summer. Jessica was much loved by everyone who knew her and is missed by us all.

Following her death, Jessica's parents, Susan and Steve, Uncle, and some friends decided to run the London 10k in July for SUDEP Action. I knew that I would never manage to run that far, I cannot even run for a bus, but I also wanted to help. As I do not live near Jessica's parents, I wanted to show them that I was trying to support them as much as I could at this awful time. So I felt that doing my bit for a charity that was helping them and that they were in turn also trying to help would be the least I could do.

When SUDEP Action had its Purple Day activities, we decided to make Schiehallion our purple day event. I live in Scotland where mountains over 3000 feet are called Munros. There are 283 Munros in Scotland, and climbing several of them is called Munro bagging. Friends of ours had suggested at the beginning of the year that they fancied bagging their first Munro, so we decided to join them. We chose Schiehallion because it was one of the nearest Munros to where we live and also one of the easier ones, if you believe the guide books!

The forecast for the weekend of our climb was very poor, but when we got up early on the Saturday morning, it was dry and we could see the top of the mountains. Jessica was definitely watching over us, it stayed dry most of the day, very windy and quite cold.

The first two thirds of the climb is on a good path, but the last third is rocky and very hard going, having to constantly watch where you are putting your feet. Using our

walking poles was a huge help at this point.

I have challenged myself in the past, I walked the 96 mile west highland way last year, but Schiehallion was way out of my comfort zone. The mountain has two false summits, the first as you approach, you know it is not the top because you haven't been going long enough. You reach that point and see what you think is the top but when you reach that point you realise there is still another hours of walking to come. At this point I was tired and shocked at how far we still had to go.

Near the top there were a few gullies full of snow that we had to cross. As the ground below the snow was very rocky, it was very difficult because you didn't know if you were standing on a rock or between rocks. At one point I got my leg stuck in the snow,

and my partner Dave and our friends Diane and Sandy, had to dig it out for me!

When we finally got to the summit, there were smiles, hugs and tears all round. I thought of my love for Jessica, her Mum and Dad and the rest of her family.

There was some snow falling as we started our decent. Going down was just as hard as going up. We had decided we would have our bottle of Prosecco when we got back to our lodge. We thought it was best to make sure we managed to get down as well! Jessica loved Prosecco, and we also had purple glasses for SUDEP purple day. I felt a huge sense of achievement. I am not the fittest person around, and carry a wee bit excess weight, so I am very proud of myself that I managed to climb 3547 feet.

SUDEP ACTION LAUNCHES COFFEE CLUB MEETINGS

There are 3 deaths a day from epilepsy and the people affected are spread throughout the UK; access to local meetings can be a life saver for them while they struggle to understand what happened and why. Travelling to a central UK meeting can seem quite daunting in the early period after a death and access to a local venue would benefit the bereaved greatly. That is why the SUDEP Action Coffee Club meetings are launching in areas around the UK in the coming months.

People grieve in different ways, even within the same family. It is helpful for bereaved people to have the opportunity to seek out those that they can identify with, who mirror their way of grieving. Being with others who are similar can help to normalise feelings, highlight coping strategies that may help and provide opportunities to access further peer support.

The first few Coffee Meetings are starting

soon. You can currently book for meetings in:

- London & South East - 18th July in Guildford (10am-12 noon)
- West Wales - 18th July in Narberth (10.30am-1pm)

If you are interested in either attending the above meetings or future meetings, please contact Tracy via 01235 772852 or tracy.cowdry@sudep.org or you can register your interest in future meetings by visiting www.sudep.org/coffee-club-meetings



FUNDRAISING UPDATES

Don't say I wish. Say I will.



If you are writing your will, please leave a gift to SUDEP Action. You can make sure we remember those who died too young and that we can continue to be their voice in years to come.

Walking 20k for 20



The staff team at SUDEP Action will be walking 20k to commemorate 20 years of SUDEP Action because we see the impact of every death & want it to stop. As staff at SUDEP Action, we see at first hand the devastating impact of an epilepsy death on families.

To mark 20 years since SUDEP Action was founded (as Epilepsy Bereaved), we will be walking 20k along the Thames path on August 8th 2015.

The money raised will be going towards the Wearable Apnoea Detection Device. This is a wearable widget which has been shown to be very effective at detecting when someone stops breathing in their sleep. This next phase we are fundraising for is to test this device on people with epilepsy. The tests will be conducted at the National Hospital for Neurology & Neurosurgery in London, where 100 patients who are undergoing tests to see if they are suitable for epilepsy surgery will be asked to participate in this study. If an alarm is raised when someone stops breathing following a seizure, there is a significant chance that administering CPR could stop them dying.

Please give what you can. Or please join us on the day! We will be walking from Culham to central Oxford. If you can't join us in person, please feel free to organise your own 20k for 20 years somewhere near you. To sponsor visit www.justgiving.com/20kfor20years/

WEBSITE FEATURES AND SOCIAL MEDIA

- Help support The Epilepsy Deaths Register campaign by filling in our online form at epilepsydeathsregister.org
- Create a memorial for a loved one on our memorial page.
- Join our forum discussion on the 'Someone has died' section of our website www.sudep.org
- Follow us on Facebook for regular updates.
- Follow us on Twitter and support our online campaigns. @SudepAction
- We are now on Pinterest
- We are now on Google+
- Subscribe to our YouTube Channel for our latest videos!

SUPPORT SERVICE

The shock and trauma of an epilepsy related death can be devastating as in most cases it is sudden and unexpected.

Sudden death is known to lead to complications for the people left behind. People can have many questions about the death which leaves them stuck and unable to move through their grief, which in turn may cause extreme psychological difficulties in the future.

SUDEP Action offer immediate telephone support after a death, as well as on-going support for people where deaths have happened years before. Each milestone and anniversary can be difficult, our support is ongoing and open ended.

Once the bereaved have reached out and made initial contact, we reach out to them providing regular calls until they are ready to stop. This continuity of support is quite unique within bereavement charities. The majority of time the bereaved are able to speak to the same person within the team and we know from feedback that this can be very comforting.

At SUDEP Action we provide specialist information about epilepsy deaths as well as information on the inquest process, which for most can seem very daunting.

CONTACT US

Please give us a call; 01235 772852 or email us; support@sudep.org

