Hello there …

We know at SUDEP Action that Christmas may have been hard for many. We send our thoughts and best wishes to you. Don’t forget we are here and never too busy. Karen and Tracy are on the support line and Vicky is our new first point of contact for any query and how to get involved.

Our news at this time is amazing and we hope you will be as encouraged as we are. Read about our SUDEP Awareness Day which reached more than 13 million people and unified more than 266 organisations and groups.

Better still our most important news is about action and prevention. Our epilepsy digital tool EpsMon is backed now by the NHS as one of only eight innovations and we have just learnt we have won the Health Business Award for Healthcare IT!

Just as exciting you can read here that we are now funding a clinical research trial of WADD – a wearable device that alerts people when someone with epilepsy stops breathing.

What we are doing is urgently needed but not easy. We get no government funding. Our fabulous fundraisers and donors make it possible. It is your support that makes SUDEP Action special, respected and influential.

Jane Hanna OBE
Chief Executive, SUDEP Action

SUDEP.org
NHS BACKS SUDEP ACTION’S EPILEPSY SELF-MONITORING APP

An app designed and developed in the South West and which is benefiting the lives of thousands of people with epilepsy, EpSMon, is one of eight innovations to join the NHS Innovation Accelerator programme in its second year.

The NHS Innovation Accelerator (NIA) supports some of the best national and international healthcare innovators with evidence-based innovations to help improve health outcomes and give patients access to the latest products, services and technology at lower cost.

EpSMon is an epilepsy self-management tool which enables patients to monitor their well-being and know when to seek medical support, a behaviour change which could lead to a reduction in the number of deaths of people with epilepsy. It has been developed by a partnership including charity SUDEP Action, Cornwall Partnership NHS Foundation Trust, Royal Cornwall Hospitals NHS Trust and Plymouth University.

EpSMon is based on evidence from the SUDEP and Seizure Safety Checklist, a facility that enables clinicians to monitor changes in risk factors in their patients. The study from which this evidence was derived was funded by K’s Fund, a charity set up in memory of Katie Hallett, a young nurse who died suddenly aged 20 from epilepsy.

SUDEP Action, Cornwall Partnership NHS Foundation Trust, Royal Cornwall Hospitals NHS Trust and Plymouth University.

The app, which was launched last year and which is available free of charge across mobile technology platforms, has won a tranche of industry awards including, most recently, a Healthcare IT Award at the Health Business Awards 2016. The award recognises organisations responsible for implementing a ground breaking IT project that demonstrates clear cost benefits to the wider NHS, and celebrates the wider use of computer technology in the NHS. EpSMon also won the Health Service Journal (HSJ) Award for Education and Training in Patient Safety in July, 2016.

Epilepsy costs the UK £1.5 billion per year and is one of the top 10 causes of death for those under the age of 70 and the third main cause of maternal deaths in the UK. This preventative tool could have a significant impact on the personal and financial costs of epilepsy through reductions in deaths and decrease in A&E appointments.

Jane Hanna OBE, Chief Executive at SUDEP Action commented: “This recognition by the NHS really helps to highlight EpSMon’s significance and potential as a safety tool for people with epilepsy. Hopefully this will encourage even more users to download this free app.”

Dr. Craig Newman, Research Fellow at Plymouth University Peninsula Schools of Medicine and Dentistry and who developed the app, said: “This is great recognition for a self-monitoring tool which is already making a difference to people’s lives. This is a true partnership project combining research, clinical expertise and condition knowledge.”

Dr Rohit Shankar, Consultant Neuropsychiatrist at Cornwall Partnership NHS Foundation Trust and medical lead for the SUDEP and Seizure safety Checklist and EpSMon said: “This is a proud milestone in the growing history of achievements of EpSMon. All the partners recognise this is the start of a very important journey. Not only can this journey transform the way people with epilepsy are cared for, but it could become a prototype for management of other chronic conditions.”

The announcement was made in London by NHS England Medical Director Sir Bruce Keogh and Professor Robert Wachter, international expert on digital health.

Sir Bruce Keogh said: “With rising demand and escalating costs, innovation is not an option but a necessity if we are to build a sustainable NHS. The innovations selected for this programme have the potential to deliver better value for the taxpayer whilst making patient interactions with the NHS safer and more personal.”

Professor Robert Wachter added: “The work you are doing is extraordinarily important. I think it’s the only way that the NHS will be able to achieve the goals of the Five Year Forward View and even beyond that to develop a health care system for the people of England and the UK that delivers the best, highest quality, safest, most satisfying, accessible care for the lowest possible cost.”

You can read more about all the awards that EpSMon has won by visiting our website www.sudep.org.

SUDEP ACTION FUNDS CLINICAL TRIAL OF WEARABLE APNOEA DEVICE (WADD) TO STOP DEATHS

SUDEP Action is thrilled to announce the clinical trial of a device that could stop deaths. There are about 600,000 people with epilepsy in the UK. SUDEP claims around 600 lives each year in the UK. Youn adults are at particular risk. Deaths often happen during the night.

Researchers have developed a small Wearable Apnoea Detection Device (WADD) that could help prevent SUDEP. A collaboration between two teams at UCL and Imperial College London are working on testing the tiny wearable device to monitor breathing in people with epilepsy.

The project team includes Professor John Duncan and Dr Fergus Rugg-Gunn at University College London, the National Hospital for Neurology and Neurosurgery, and a team of engineers led by Dr. Esther Rodriguez-Villegas, an Electronics Professor at Imperial College London.
The clinical trial has been made possible by an appeal to SUDEP Action’s supporters and major donors which has raised £130,000.

Jane Hanna OBE, CEO of SUDEP Action said: “This is only possible because of the generosity of donors as well as some fantastic community fundraising. Funding for research and development of innovation to support patients and families is hard to come by. Bereaved families have backed this priority for many years and can be proud of the tribute this pays to all those that have died”

Why is this research needed?
The exact cause of SUDEP is not known. In some cases the heart stops first. However, apnoea has been identified as most likely in the lead up to a sudden death. The monitoring device could give the alarm when someone stops breathing, providing a chance of saving that life through CPR. The device will trigger an alarm if breathing stops.

WADD has already been researched on sleep apnoea patients and on a group without apnoea, and was found effective with high sensitivity and low false alarm rates. A clinical trial is needed now to test the device on patients with epilepsy. The research would be a significant step towards development of a minute device which could be worn all the time by people at high risk of SUDEP. There is currently no such device in production.

What are the aims?
The research team believe that the WADD alarm is a significant step forward for those at high risk of SUDEP who may experience many seizures. The aim is to test the apnoea alarm on people with epilepsy to see how well it works when people are experiencing regular seizures and whether it is ready for commercial development or whether it will need further research and development.

Professor Stephen Brown, Chair of SUDEP Action said: “People at high risk of SUDEP experience regular seizures. Whilst we cannot predict what the research will show at this stage, the hope is that this project will be another significant step forward in the fight against SUDEP. The alert should activate only when a seizure is dangerous. It is important for good seizure control that people get a decent sleep. A device that alerts only in emergency will work well with a treatment plan that supports self-management and prevention of crisis”

How will the research be carried out?
The device will be tested on 50 people with epilepsy to test how accurate and reliable it is on people having seizures. The patients will be recruited through the National Hospital for Neurology and Neurosurgery EEG unit where they are already undergoing tests and observation for their epilepsy. The medical technology and ethics approvals needed to start the trial with patients have been granted and the team has started work.

What can families do now to reduce risk?
The best way to prevent deaths now is to reduce risks flagged by research. There are many simple steps that can be taken. The starting point is people with epilepsy knowing their risk factors and working on reducing these (where possible) with their doctor or nurse. Our digital tool EpSMon, backed by the NHS as one of only 8 solutions, and our clinician tool SUDEP and Seizure Safety Checklist are freely available to help have these discussions.

There are an increasing number of commercial seizure alert devices and wearables. Our advice is to check what evidence is available and talk through the pros and cons with a doctor or nurse as part of your treatment plan.

SUDEP Action safety tools flagged in International Neurology Journal as interventions which benefit the care of people with epilepsy

“There is nothing so tragic as a life needlessly lost.”

The opening of the latest article on SUDEP in Practical Neurology, a peer-reviewed journal read by health professionals across the world, provides a poignant reminder of the need to tackle the number of epilepsy deaths that happen each year, and the devastation that occurs when lives are not saved.

The article is authored by the BMJ Award Neurology Team of the Year 2016 (Cornwall Royal Hospital; Cornwall Partnership NHS Foundation Trust; Plymouth University and SUDEP Action). The team researched and developed practical tools to support doctors and patients to address lessons learnt from local deaths. Their research on local deaths highlighted that in 90% of SUDEP deaths, there was deteriorating seizure control in the 3-6 months before a death, and that most had not had an epilepsy review for at least a year.

A quote from the article reads: “There is tacit avoidance of discussing the risk of death both in primary and secondary care, while the patient organisations and SUDEP Action vocally support the patients’ view that such risks should be made transparent”.

The researchers argue that a person-centred, shared-care approach which includes discussion of SUDEP, can enable patients to take action to anticipate and prevent crisis. It also enables professionals to identify patients who might benefit from proven treatments or strategies to tackle specific risks; such as tackling seizures with medication, surgery or VNS, or addressing depression or substance abuse with community based interventions.

Women with epilepsy were flagged as needing special consideration because of the complexity of communicating and balancing risks to the unborn child (due to potential medication side effects) and the risk of fatality to both mother and child.

Providing information on risk at an early stage, and revisiting in future, was flagged as important as it can empower people with epilepsy to make informed decisions about their care, helping them be an active part in the management of their condition.

Jane Hanna, CEO SUDEP Action and article co-author said: “Practical Neurology is a fantastic journal to show doctors that simple,
practical tools exists now to assist them in providing person-centred care, in the form of the SUDEP and Seizure Checklist and EpSMon. The research and development of the tools have shown the benefits of a positive and structured approach to sharing of knowledge. They support health professionals and patients to talk about individualised risk positively, sensitively and openly, a process which already happens in other long-term conditions such as asthma and diabetes.”

The article notes, it will be many years before an ideal drug that stops all seizures without side-effects is found, or any other intervention to prevent SUDEP is proven. Regarding seizure detection devices, the article refers to a recent review in the Seizure Journal, which showed ‘no suitable robust seizure detection and safety technology’ is currently available, though some are ‘clearly promising’. This is an area which concerns many people with epilepsy and their families, and where continued research will in future provide evidence to prove the efficacy of devices already commercially available, giving peace of mind to those who use them.

The group that developed the SUDEP and Seizure Safety Checklist and EpSMon are now observing a fall in SUDEP deaths from 6 to 1-2 a year in adults with epilepsy, and from 4/5 a year to none in high risk patients with epilepsy and learning disability. Patients and clinicians receive the intervention positively, and the tools are used to flag up that an intervention or a modification of behaviour is needed.

The article closes by summarising that while further long-term studies into the impact and outcomes of tools such as checklists and apps are needed; using such initiatives raises the profile of epilepsy and epilepsy mortality among health professionals and people with epilepsy. This enhances awareness by encouraging all involved to be responsible for epilepsy management; something that could potentially save lives.

Despite falling on a Sunday, SUDEP Awareness Day 2016 was a great success, reaching around 13 392 284 people. Thank you for being part of this campaign and helping us to reach such a wide audience. We hope to reach even more people in 2017.

Together we:

• Reached people with key messages highlighting steps people with epilepsy can take to reduce their risk.
• Made more people aware of SUDEP globally reaching 99 countries.
• Helped encourage discussion of SUDEP.

Organisations and individuals who helped make the campaign a great success

• This year, 82 organisations and patient groups registered their support for the awareness day.
• At least 266 epilepsy organisations, patient groups and bloggers joined and supported the campaign on social media from 21st to 23rd October.
• People with epilepsy shared our campaign key messages using the campaign hashtag.
• Bereaved families shared memories of their loved ones using the campaign hashtag.

Facebook

Around 155 Epilepsy organisations, groups, Epilepsy and SUDEP bloggers and influential figures joined the campaign on Facebook to help reach a total audience of 2 101 602.

Twitter

On Twitter, the campaign was supported by at least 154 epilepsy organisations, health professionals, epilepsy bloggers and advocates. They helped us reach at least 536 821 people.

Campaign Microsite

The campaign microsite has had around 43 000 visits to date, accessed from more than 99 countries. At least 82 organisations registered their support for the awareness day on the microsite.

Media Coverage

The awareness day generated some UK and international media coverage reaching around 10 761 264 people.

If you were part of the campaign and would like your photos to be added to the SUDEP Awareness Day gallery please email your photos to juliet.tumeo@sudep.org
In memory of Charlie Burns, South Western Ambulance Service launches SUDEP Training Videos to reduce deaths

Following the sad death of Charlie Burns (10) from SUDEP in October 2011, South Western Ambulance Service NHS Foundation Trust (SWASFT) has been working closely with the Burns family and has now launched new training videos to raise awareness of SUDEP.

Charlie, from Wiltshire, had his first seizure on 7 October, 2011, and was attended by a paramedic crew who thought it might be a febrile convulsion. Charlie’s mum Jan then took Charlie to see their GP, who suggested he might be suffering from nocturnal epilepsy and referred him to see a neurologist. Tragically, Charlie had a second seizure and died four days before he could attend the neurologist appointment.

Mum Jan Burns says: “This was an awful situation with Charlie and we want to turn that around into something positive. The end result is that we’re hoping, with these training videos, that a significant number of lives are going to be saved.”

“We wanted to honour Charlie’s memory and are pleased that initiatives are being taken. The training videos and the actions taken by South Western Ambulance Service are all we could have hoped for.”

The Burns family have just marked what would have been Charlie’s fifteenth birthday, and the fifth anniversary of his death.

The SUDEP training package has been developed by SWASFT, together with the Burns family and SUDEP Action, to raise awareness and to help paramedics and other healthcare professionals to understand and identify epilepsy risk factors including those associated with SUDEP, in order to help minimise the risk to future patients. All SWASFT paramedics will be put through the training programme and the materials and training will also be available to other organisations.

Ken Wenman, chief executive, SWASFT, said: “Following Charlie’s sad death, we wanted to take action; wanted to make a real difference and most importantly do something that could support the memory of Charlie, especially to understand what learning we can all take from this sad situation. Working closely with the Burns family we’ve found a way forward and SWASFT has now developed training videos and will adopt the training programme for all its frontline paramedic staff.”

The training will also be offered to all other ambulance trusts by SWASFT via the National Education Network for Ambulance Services, and be made available to other healthcare professionals through SWASFT’s training team.

Jan continues: “Sudden unexpected death in epilepsy is one of the top ten causes of early death. The condition kills more people in the UK than cot deaths. Healthcare professionals need to know more about it and the differences of seizures and convulsions. This training will help make sure our son didn’t die in vain.”
The death of someone you love is devastating and when it is unexpected it can have a huge psychological impact, yet it is sometimes easier to speak to someone outside the immediate family. People can then express their feelings honestly without fear of upsetting those around them. Another barrier to processing grief is the need to be brave or to soldier on.

Prince Harry was just 12 when his mother, Princess Diana died; in a recent media article he was quoted as saying that he had only started speaking about the loss of his mother 3 years ago, some 16 years after her death.

Speaking openly he said: ‘It’s OK to suffer, as long as you talk about it. It’s not a weakness. Weakness is having a problem and not recognising it and not solving that problem.’ During his interview he highlighted how important talking can be, and said that it is extremely important for him to know that people recognise the benefit of it.

Although talking about the death of someone close is not for everyone, it is important that those who need and want to should have the opportunity to do so.

And, it is important that the bereaved are aware of charities that provide this important service.

Grief can be described as a tension that needs to be released in some way, whether by talking about it and expressing thoughts and feelings or in a more cognitive, proactive way, by doing something. If left unexpressed grief can become toxic, and manifest itself in a different way, with some people going on to develop mental health issues if their needs are not addressed.

People also grieve at a different pace, which can be quite confusing to observe within a family unit and misunderstandings can follow. People might feel and think that they are on a different page, that their grief seems more intense; that others didn’t care as much as they did; there is something wrong with me, or there is something wrong with them.

We all have different relationships, different experiences in life and the way we are brought up can shape our personalities; gender difference can also influence how we express our grief.

There is no rule book about grieving, the time it takes, the pace, or the intensity and difference. Grief is a unique experience to each and every individual. The bereaved family work together that we can be achieved when we all stand United Against SUDEP.

Any profits or donations made by SWASFT by sharing the training videos will be given to SUDEP Action. The videos are available via the SUDEP Action website: https://sudep.org/sudep-training-videos.

While investigating the findings of The Epilepsy Deaths Register, we noted that consistently the bereaved highlighted the need to talk, to have counselling and to have information after a death. These findings endorse the Heads Together project.

Epilepsy related deaths are nearly all unexpected and as such are high risk for the bereaved to develop complex mental health issues. SUDEP Action provide services that are highlighted by the bereaved as helpful to them: one off support to help with understanding what may have happened; long term support to help them through the difficult days and telephone counselling if things become unmanageable and they have difficulty with their day-to-day living.

“The death of someone you love is devastating and when it is unexpected it can have a huge psychological impact, yet people often think that the lives of the bereaved soon return to normal. However, we know only too well, that their lives will never be the same again, but can still happen. Charlie, at 10, was very young – one of the youngest.”

Charity Chief Executive Jane Hanna OBE commented on how pleased the charity was with the launch of the training and that it was launched in time for SUDEP Awareness Day 2016 saying: “The theme for our awareness day was United Against SUDEP because we believe that is it only when people with epilepsy, health professionals, carers and bereaved family work together that we can help reduce future SUDEP Deaths. And this joint working between SwasFT, Charlie’s family and SUDEP Action shows just how much can be achieved when we all stand United Against SUDEP. A huge thank you to the Burns family and SwasFT for all they have done in support of the charity in memory of Charlie Burns.”

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Karen and Tracy are generic counsellors who work for SUDEP Action in bereavement support, they have over 20 years’ experience supporting people who have experienced an epilepsy related death; and in-depth knowledge of sudden death and its complexities.

Whatever your needs – talk about them Call:  01235 772852 or email: support@sudep.org

BEREAVED MUM RACHEL SHAH APPOINTED SUDEP ACTION TRUSTEE

We are pleased to welcome Rachel Shah to the board of trustees. Rachel’s appointment brings the number of SUDEP Action trustees to fourteen, of whom seven are bereaved by epilepsy.

Rachel commented: “My youngest daughter, Emily, who only had four seizures, died aged 19 at Leeds University in 2012. My husband and I had no idea that Emily could die and had never heard of SUDEP. The shock and grief were overwhelming but we have found that supporting SUDEP Action has given us a positive focus for our grief. Our eldest daughter also benefited hugely from the counselling she received from the charity. I firmly believe that had we been educated about SUDEP then Emily might be alive today.”

Rachel brings wide experience to the role and expressed her excitement at being part of the team.

“My background as a Chartered Accountant and my various volunteering roles as secretary and treasurer for small societies will stand me in good stead for my trusteeship of SUDEP Action. These are exciting times for the charity as the medical profession and the wider world begin to listen and engage with both the charity's message and its work and I am excited to be part of the team.”

SUDEP Action Chair of Trustees Professor Stephen Brown welcomed Rachel’s appointment saying: “On behalf of all the Trustees and staff, I am delighted to welcome Rachel Shah to the board of SUDEP Action. Her experience both in accountancy and the voluntary sector, and the fact that she is a bereaved parent, make Rachel invaluable to the charity.”

Dates for your Diary

Memorial Service – May 20th at 11am
National Conference – June 10th-11th

THE MOUNTAIN MEN’S 24HR THREE PEAKS CHALLENGE RAISES AWARENESS AND FUNDS FOR SUDEP ACTION

The Mountain Men consists of three friends that met at secondary school, James Gough, Sam Hinere and Tom Perkins. We all grew up in Northamptonshire and now live in London, but we have remained very close.

Whilst at secondary school, a friend that was incredibly close to all three of us died suddenly. Jack Cheatley had been diagnosed with epilepsy, and SUDEP was found to be the cause of his death. We had talked about doing something for Jack and for SUDEP Action, but as the time passed by we hadn’t come up with something that would do justice to this cause.

As with all great plans, this challenge of ours was devised in the pub. We began discussing ideas and as the beer flowed we became more and more ambitious. What started as a large hike of some kind turned into a 24 hour 3 Peaks Challenge! We reached out to the Charity after almost immediately raising a good amount of money through our JustGiving page.

So, what can we say about the challenge itself? Well, it was easy. Could have done it again immediately…. Is what none of us have said since about the Challenge. Ben Nevis was the first peak and this was tough, but by the time we had returned to the base of the mountain we were still filled with fresh faced optimism. The following six hour coach ride to the second peak soon eroded that. Unfortunately, what followed this coach ride was an overnight summit of Scafell Pike. We’d never hiked in darkness, so at this point we were pretty uncertain as to how the rest of the challenge would go. Some hairy moments ensued as rocks appeared from nowhere (apparently) but we made the summit within the time frame.

Ben Nevis Complete!

Struggling with lack of sleep, we were met at our final peak by a fresh guide who, we were informed, would lead us up Snowdon at quite a pace in order to complete the challenge within the 24 hour period. ‘Quite a pace’ is a major understatement and one which left two of us (not naming any names) completely exhausted and almost lifeless with just under an hour’s hike left to go.

Along the final stretch however, everything changed. I don’t know whether it was adrenaline or simply sheer elation that we wouldn’t have to climb again but we jogged the final leg to the summit to complete the challenge with no more than 10 minutes to spare! Our mood completely switched from our mid-summit dejection to pure satisfaction. It was surreal standing at the summit and coming to terms with the fact that we had completed this monumental challenge. We were almost delirious. It is quite difficult to describe that feeling.
Over 50 family and friends gathered on Stowmarket Recreation Ground on Saturday 30th July to unveil a memorial bench on the second anniversary of the day Owen died from SUDEP.

The bench will serve as a reminder of the many hours Owen spent playing on Stowmarket Recreation Ground during his childhood, and it is hoped that many people will find it a place to rest awhile during their busy lives. The Recreation Ground is also home to the annual Stowmarket Carnival in which Owen took part many times over the years.

The bench was unveiled by Owen’s Dad, Steve, his Mum, Ro and his sister Kerry Burn. Ro then scattered some of Owen’s ashes around the bench while his Dad read out a poem that he had written for the occasion.

After the unveiling, Owen’s family and friends, including his two grandmothers and a great aunt all in their 90s, enjoyed a picnic in the sun followed by a game of rounders for the more energetic of the guests – just the sort of event Owen would have enjoyed.

We were so pleased to be able to give such a good sum of money to SUDEP Action. We initially set a target of £1,000 but thanks to the incredible generosity of our supporters, we broke through multiple targets on our way to our final amount. We really hope that this money is useful to SUDEP Action in all their endeavours, and we hope to continue to raise more in the future.

We would like to thank everyone who donated and got involved. We would also like to thank Bryony and Yvonne Gough and Jackie White for your help organising our fundraiser and the raffle. This would not have been anywhere near as successful as it was without you three. Thank you all for your time and patience.

Love,

The Mountain Men

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Diane Player shares her story in memory of her son Richard

On the Tuesday 30th June 2015, my life changed forever, when at 7.30 a.m. I went to wake my son Richard who had learning disabilities and found he had died. The only thing I knew I had to do was phone our son Timothy to tell him and ask for help. He calmly told me to ring 999 and that he would be over. The other was to phone Richard’s day care at The Parchment Trust to cancel his transport.

It breaks my heart still that I never took him in my arms again to say goodbye. I can still see him lying there, when I go into his bedroom.

Timothy phoned his brothers, who all came down to be with us. Everything after that is a blur apart from Timothy coming over the following day whilst we found an undertaker to arrange for his funeral. The undertakers set up an online memorial for Richard which was fantastic.

I phoned Parchment to tell them when the funeral was arranged for, Theresa asked if
My name is Valentine Gibbons; I’m a 32 year old mum of two young boys. I originally got involved with SUDEP Action because devastatingly, I lost my younger brother Ashley on 17th May, 2015. It took over 12 weeks to determine his cause of death; I was searching the internet to make sense of it all when I came across SUDEP.

Ashley was only 26 years old and had his whole life ahead of him. He had suffered from Epilepsy since he was 8 months old and we just thought it was a part of his life. Until Ashley’s passing, none of us had ever heard of SUDEP, or let alone known that he was at risk. So I decided shortly after we had the coroner’s report that I was going to organise a Charity event in Ashley’s Honour; I had never felt more passionate than I did about letting anyone and everyone know about SUDEP.

Ash loved his music and a wide range too. He also loved the social aspect of evenings out with friends and family, therefore I thought there is no better way to mark the first year without him than to have an evening of music, entertainment, food and a load of prizes for people to win and also to raise money and as much awareness as possible. I needed something to focus on that was still connected to my brother, as his absence is as raw today as the day he first went. Until you have lost someone to it, you probably would not have heard of SUDEP.

The night was a ticket only event, and we sold over 150 tickets which was my aim. I managed to book a pop choir (Chaffords Voice), Soul Singer (JB Rose) and Rock Band (Blue Cheese), and DJ’s (EZ Discos), they were all fantastic and there really was something for everyone. The menu included Soul Food, freshly cooked by the best (our family from London), and a cold buffet. We also had a raffle; I was blown away by the amount of gifts we received from Asda, Morrisons and Sainsburys, Vue Cinema, Adventure Island, Harley Davidson, TGI Friday and Disney to name but a few companies that donated to our cause.

My mum gave a speech; this was probably one of the most memorable moments for me. She really is the strongest woman I have ever known and her clear delivery of information about SUDEP Action and why everyone was there made it all worthwhile. Also, with all the tickets sold out, I was really amazed to see how much people loved Ash and turned out to support our cause. Knowing that I had doubled my target of £1000 was the best feeling ever.

I am truly grateful to everyone who helped make my dream of hosting this event in Ashley’s memory a reality. There are too many to mention and I don’t want to leave anyone out so thank you to all family and friends that helped set up, cook, donate and clean up. The performers, the decorations, and everyone that was there or that couldn’t make it but donated anyway. I couldn’t have pulled this off without any of you.

Valentine Gibbons hosts charity fundraising event in memory of her brother

I started filling in the form for registering a death but found it too difficult, so I phoned the number on their website. As soon as I started to explain why I was contacting them, this beautiful soothing voice asked me if I would like help at completing it.

I found it so easy to talk and cry about my loss with Tracy. The feeling of relief was incredible. I have now been talking with Tracy weekly for about six months. She is amazing as is SUDEP Action. I feel that I am so fortunate to have found them. Please don’t hesitate, ring their number and ask for help. I will forever be eternally grateful that I did.

So many people came to the crematorium for Richard’s funeral. All of Richard’s brothers were pall bearers. I was so very proud of them as it was such a courageous thing to do.

The service was a simple one, I had written the eulogy which I tried to make amusing and light as I possibly could.

With Tim’s help we chose the music from some of Richard’s favourite dvds. I can’t remember much about the service or what happened afterwards. Everything seemed so surreal. How was I ever going to survive without him.

What broke my heart was how devastated Richard’s friends were. They found it so difficult to comprehend what had happened. All I could do was hug them. I can’t remember much about the following weeks. My friends and doctor were very supportive.

We had to wait three months for the post-mortem results. When the coroner told us he had died of SUDEP we were devastated as we had never heard of it. When I Googled it I came across the SUDEP Action website.

I would like to have his wake at his beloved Friary Gardeners, in their beautiful gardens and that they would organise everything for us which was incredible.

My mum gave a speech; this was probably one of the most memorable moments for me. She really is the strongest woman I have ever known and her clear delivery of information about SUDEP Action and why
Our Coffee Clubs provide an invaluable opportunity for bereaved people to seek out those that they can identify with, who may mirror their way of grieving. People can swap ideas for fundraising; for raising awareness or discuss strategies for coping with day to day life, whatever your reasons for meeting up – the main outcome of the meetings is to know you are not alone. People bereaved by epilepsy are spread throughout the UK and access to local meetings can be a life saver while they struggle to understand what happened and why.

We ask for feedback from every event we hold because it helps us to understand what is going well and how we might improve our services and support for you. Below we have created a “You said, We did” area that highlights some of the ways in which we are responding to your suggestions.

• You said: “It would be useful if we knew of smaller projects which could provide a stimulus for fundraising on a smaller scale.”

We have received a few similar requests in Coffee Club feedback so have created a new information hand out for you called “Ways to get involved”. We understand that it can be helpful to have something in front of you that gives a summary of what next steps you might be able to take. From the grand to the modest, we sincerely appreciate it all. You will find the handout available at your next Coffee Club meeting.

• You said: “Maybe more often to meet”.

Our Coffee Clubs are usually planned for around twice a year per region. This provides approximately double the meetings available nationally, per year than we were able to offer with staff hosted regional meetings. We hope this creates a regular meeting point for those attending, without it becoming too time consuming for the leaders. We also hope to have more meeting locations as the programme progresses and we of course continue to hold our annual conference. There are also several other awareness events throughout the year that you may like to be involved in with more details on our website. If you think you might be interested in hosting a Coffee Club in your area, please contact the team for an informal conversation.

No email? No problem! Just give us a call or drop us a note in the post to let us know and we will add you to our hard copy, posted mailing list.

FUNDRAISING UPDATES

Our 2016 supporters were brilliant, with lots of brilliant fundraising. Thank you to each and every person who has supported SUDEP Action in 2016, we truly appreciate your help.

If you would like to discuss your fundraising plans, or need help thinking of an idea, call our Fundraising and Administration Officer Katie, she is happy to help with advice and inspiration.

We have ten places for SUDEP Action supporters to attempt Skyline’s Tandem World Record. The event takes place on June 17th, 2017. Our 10 places are reserved at Swindon’s Redlands Airfield. To register your interest, please email fundraising@sudep.org or call Katie on 01235 772850.

MEET OUR OUTREACH COORDINATOR VICKY

Hello, I’m Vicky the new Outreach Coordinator for SUDEP Action and I started with the team at the very end of July 2016.

I’m happy to say that my role here is quite varied and means I get to work with most areas of the charity and speak with many of our supporters on a day to day basis. As the Outreach Coordinator, I am part of our Community Hub and responsible for ensuring our supporters are well looked after. Working closely with the support team I will often be the first person responding to phone calls and emails to the charity, making sure we are putting everyone in touch with the right part of our team to meet their needs.

I am excited to be involved in several projects that are all looking toward the continued growth of SUDEP Action and its vital work and support services. These include managing and supporting our volunteers, the care of our Coffee Clubs around the country and seeking new ways to encourage supported engagement with the charity and its services.

The more I have learned about SUDEP Action’s history and continued efforts and plans for the future, the more inspired I feel to be part of such a dedicated team and worthwhile charity.
Silent Tears

Each day as evening starts to set
    The ache builds in her chest
    She knows she must go to bed
    And try to get some rest.

She hugs her tear stained pillow case
    When no one is around
And cries for one she loved and lost
    And screams without a sound

    Others see her in the day
    And think she’s doing well
But every day as evening sets
    She enters her own hell

Time hasn’t healed her pain at all
    Or quieted her fears
So every night, alone in bed
    She sheds those silent tears

Anon

There is no time limit to grief, don’t go through this on your own; if you feel the need to speak to someone, please call the support team. Email support and counselling is also available.

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

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