



**SUDEP Action** 

*Making every epilepsy death count*

**KEEPING IN TOUCH**

**June 2016**

## HELLO THERE ...

In this issue, you can read about what you have achieved through supporting the charity. Thanks goes to Kt's Fund for funding and backing work in Cornwall that led directly to SUDEPAction sharing Neurology team of the Year 2016, for innovation to tackle epilepsy deaths.

This amazing endorsement by the British Medical Journal Awards, backs a positive approach that has changed culture and practice. Support tools are what is needed to bridge the gap between guidelines and practice. Thanks to all our supporters who have been with the charity every step of the way.

We need your support more than ever now. Thanks to all our fantastic fundraisers. Please read about other things you can do as a

Champion4change. We are aiming for 100 MPs to sign our Early Day Motion calling for support for Safety tools, and to get as many GPs as possible taking up our free SUDEP and Seizure Safety e-learning. The resource, produced by RCGP covers issues relating to girls of childbearing age, and the safety tools which support a simple checking of risk for anyone over 16 (Our development group is working on children now).

SUDEP Action presented on How we Speed up Advocacy; Disclosure of risk and The Epilepsy Deaths Register at a major conference – Partners Against Mortality in Epilepsy in Washington DC from June 23rd-26th.

Jane Hanna OBE

Chief Executive, SUDEP Action

**SUDEP.ORG**

## SUDEP ACTION AND PARTNERS WIN NEUROLOGY TEAM OF THE YEAR BMJ AWARD FOR INNOVATION TO REDUCE DEATHS IN PEOPLE WITH EPILEPSY

SUDEP Action and its partnership of researchers, doctors and bereaved families scooped the prestigious BMJ award for Neurology for enhanced patient safety in epilepsy.

The award, sponsored by the Association of British Neurologists, went to Cornwall Partnership NHS Foundation Trust; Plymouth University and Royal Cornwall Hospitals partnered with the charity SUDEP Action to deliver a comprehensive and innovative approach to reduce sudden death in people with epilepsy. It recognises the team as having measurably improved outcomes in neurology through innovation and high-quality care.

The neurology team led by Dr Rohit Shankar was supported by SUDEP Action and the local project made possible by funding from Katie's fund, a charity set up in memory of Katie Hallet from Cornwall. Katie was a young nurse who died suddenly aged 20 from epilepsy.

The team developed the SUDEP and Seizure Safety Checklist which has been incorporated into the Epilepsy Self-Monitoring app EpSMon. People with epilepsy can use the app to self monitor their condition and keep track of their wellbeing. EpSMon is part of the national epilepsy commissioning toolkit and the Checklist is now in use in clinical practice in the UK.

The Judge on the BMJ Award panel commented: *"A comprehensive and innovative approach to reduce sudden death in patients with epilepsy, and easily transferable outside the UK."*



SUDEP Action Chief Executive Jane Hanna commented: *"Like other people with asthma I am called in for a check against known risks. People with epilepsy are ten times more likely to die, and die much younger, but do not benefit from this. The award gives recognition that when teams unite behind the goal of saving lives, anything is possible. Bereaved families want investment now in safety tools so that best practice can be spread and lives can be saved. The project has no statutory funding and thanks must be given to all our bereaved families who have raised and are raising funds for the charity, and the commitment of all the partners"*

Dr Rohit Shankar *"The checklist has been used in epilepsy clinics for the past three years, and deaths have halved"*

The project was carried out as a study led by Dr Rohit Shankar in Cornwall. With the cooperation of the local Coroner, the study looked at all epilepsy deaths in Cornwall between 2004 and 2012. Researchers found that all those who died in this period had changes in clinical factors in the months before their deaths such as failure to treat anxiety or depression and poorer compliance with medication.

Dr Brendan McClean, Consultant Neurologist at the Royal Cornwall Hospital, who uses and researches the Checklist in his neurology service said: *"I think this will be the best thing that has happened for patients and families for a while"*.

Liz Hollingdale who set up Katie's Fund in memory of her daughter Katie said: *"We are delighted to learn about this prestigious award. I hope this will encourage even more people with epilepsy to download EpSMon, and more medical professionals to use the SUDEP and Seizure Safety Checklist."*

*The conversation about risk between doctor and patients with epilepsy needs to be accepted as routine, just as it is with other chronic conditions. Katie would be overwhelmed at what has been achieved in her memory."*

Dr. Craig Newman, Senior Research Fellow & Mobile Health Tech Innovations Lead at Plymouth University Peninsula Schools of Medicine and Dentistry, who designed the

app, commented: *"We are delighted to have won this award. This is a great partnership project and one which has true potential to change the lives of people with epilepsy. It is a project which has captured the imagination of the health care community and those with epilepsy and constitutes a superb multi-disciplinary approach to helping people to manage their health. Clearly, apps are the way forward not just for patients but for clinicians too"*.



## CHAMPION4CHANGE CAMPAIGN GAINS MOMENTUM WITH BACKING FROM 29 MPS

Twenty-nine MPs have signed our EDM supporting the spread of best practice in epilepsy risk management across the country and the signposting of families to SUDEP Action after a death.

The Early Day Motion (EDM) was tabled during National Epilepsy Week as part of our Champion4Change campaign. MP Norman Lamb, Former Minister of State for Department of Health, and Valerie Vaz MP, Chair of the All Party Parliamentary Group for Epilepsy, tabled the Early Day Motion in parliament. An EDM is a 250 word statement submitted to Parliament to draw attention to a specific cause. It calls for supportive MPs to sign up and show they stand by the points raised. EDMs are 'live' for 12 months and in

order for an EDM to be actioned it needs to have 100 signatures. With 29 signatures, our EDM needs 71 more signatures to get to a hundred, and we need your help to achieve this!

The EDM:

- Urges NHS England to support the dissemination of best practice across the country and the signposting of families to SUDEP Action after a death; commends innovative approaches to self-monitoring and the management of risk factors, such as the SUDEP and Seizure Safety Checklist and EpSMon.

- Raises awareness among MPs of the need to improve epilepsy care and signposting of bereaved families after an epilepsy death.

If your MP has not signed the EDM, please contact them and encourage them to do so. We want as many supportive MPs as possible to sign their name on the EDM and pledge their support on behalf of the bereaved community.

You can get resources to contact your MP by emailing: [samantha.ashby@sudep.org](mailto:samantha.ashby@sudep.org) (please mention your constituency & MP's name). You will receive a template letter for your MP with information about the EDM and how they can help.

The EDM draws to the attention of MPs that there have been 14,926 reported deaths since governments across the UK pledged to take action to save lives following SUDEP Action's National Audit of Epilepsy Deaths in 2002. It also acknowledges the fall in the number of epilepsy-related deaths in Cornwall, due to the work of the Epilepsy Life Project which saw the development of the SUDEP & Seizure



Safety Checklist, with no deaths reported in the community-based learning disability service in the last five years. There was also a reduction in deaths among the general epilepsy population across Cornwall Services.

Thank you to everyone who has supported the campaign and contacted their MP.

## SUDEP ACTION & RCGP LAUNCH SUDEP E-LEARNING COURSE FOR HEALTH PROFESSIONALS

SUDEP Action and the Royal College of General Practitioners have launched The SUDEP and Seizure Safety E-Learning course to help health professionals. The course is aimed at supporting GPs with their annual and routine reviews of people with epilepsy.

Launched during National Epilepsy Week, the E-Learning is a free, 30-minute course that health professionals, students and trainees can access as part of their professional development. The course has been created alongside the College's Epilepsy knowledge update and highlights the importance of risk management among patients with epilepsy and their health professionals.

This course uses video and case studies to illustrate various points in the clinical management of patients with epilepsy.

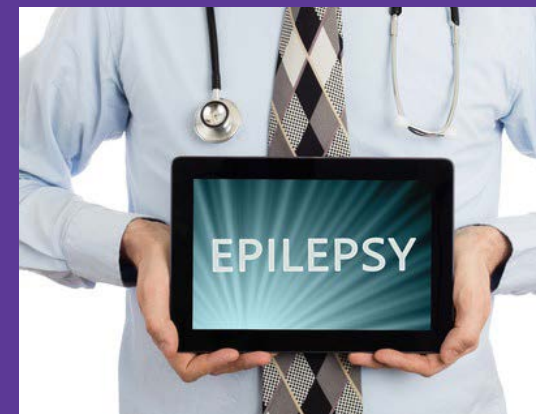
The course is authored by Professor Smithson who led the development of NICE guidelines following his role for the RCGP in the National Audit of Epilepsy Deaths in 2002 that found 42% of deaths could be avoided. It is co-authored by Jane Hanna OBE, CEO of SUDEP Action who led that report.

People with epilepsy are 11 times more likely to die early than people without the condition. The most common cause of death from epilepsy is Sudden Unexpected Death

in Epilepsy (SUDEP). The SUDEP and Seizure E-Learning course uses e-technology to bring GPs knowledge to support flagging of risk in patients and also gives practical education on the aftermath of unexpected deaths when a practice will be caught up not only with the coronial system but also be the main point of initial contact with the bereaved family.

General Practice has an important role to work with people with epilepsy and their families to minimise the impact of the condition and the risk of death. This can be done by carrying out epilepsy reviews in primary care, by referring to other services where necessary, by signposting patients to resources and by liaising with the family after an epilepsy related death.

An editorial in the British Medical Journal last year highlighted that many deaths were in the community, and that many were in people who were not being seen but did have known risk factors and a deterioration in their condition before they died.



Jane Hanna from SUDEP Action commented: *"Bereaved families working with clinicians and researchers have driven our work to tackle epilepsy deaths, first defining the problem, championing research and surveillance, and now the development of safety tools and education to help professionals and families. GPs can help by giving 30 minutes to take this course on SUDEP and Seizure Safety".*

# SAFE AND SOUND? A SYSTEMATIC LITERATURE REVIEW OF SEIZURE DETECTION METHODS FOR PERSONAL USE



considers the available evidence in order to help people with epilepsy, their families and clinicians make informed choices about whether to use such devices as part of their care and risk management plans.

The article has been recognized in *Seizure* (the official journal of Epilepsy Action), in which it is published, as the Editors Choice. It was awarded this by Dr Mark Reuber, the Editor-in-Chief because of its 'medical or social importance for people with epilepsy and researchers in the fields related to epilepsy'. Because of this, the article has been made freely accessible to read and download, and the editors have written a commentary about the article.

Published earlier this year by the team involved in our EpSMon project, including SUDEP Action CEO Jane Hanna, this article investigates the range of seizure detection methods and devices that are increasing in popularity among the epilepsy community. The review of literature into these devices



## KEEPING PREGNANT WOMEN WITH EPILEPSY SAFE AND WHY DISCUSSING RISKS AND MATERNAL DEATHS IS VITAL

For over 15 years SUDEP Action has been raising the issue of maternal deaths, and the increased risks faced during pregnancy for women with epilepsy, with policy makers; drawing attention to previous confidential enquiries into maternal deaths and supporting families in the aftermath. It is estimated that women with epilepsy are at a 10 fold-increased risk of death during this time. An estimated 1 in 1000 women died from epilepsy (mostly SUDEP) during or shortly after pregnancy (Nashef, 2014).

While this may be alarming for expectant mums to hear, it is important that pregnant women with epilepsy have conversations about risk with their epilepsy specialist so they can make informed choices for both their baby and importantly regarding their own safety. Pregnancy and being a new mum impacts on epilepsy in a range of ways, affecting medication absorption, changes to seizure frequency, stress, tiredness...; so a holistic approach to risk and seizure management, involving all specialists, as well as primary care clinicians, where the woman is fully involved in all decisions and options is important.

All women and girls of childbearing age should receive pre-conception counselling prior to this, providing essential information about risks and the steps to take to keep them safer if pregnancy happens, as part of their yearly review (even if they are not currently planning a pregnancy). In doing this, discussions about risk become less worrying and more about being able to make sensible choices to suit the individual.

In the current climate of the media highlighting the potential medication risks on unborn babies, it can create a sense



of fear and uncertainty at an already challenging time for expectant mums, where often the focus on the mum's wellbeing & potential risks are not always fully considered or openly discussed alongside these issues about their baby's health. This unbalanced view to risk management does not allow women with epilepsy to make informed choices for themselves and their baby; which can result in a fatal outcome, something some of our bereaved families are all too aware of.

Guidelines, such as those recently launched by the Royal College of Obstetrics & Gynaecology (RCOG), are a necessary step to help improve care in this area, but those available are currently not sufficient on their own in supporting clinicians and their patients to understand, discuss and put plans in place to address risks associated with epilepsy such as SUDEP. Guidelines regarding risk communication need to be strengthened and specific in order to support clinicians. Implementation of such guidelines in practice is also an issue, one which impacts on providing standardised risk management for pregnant women across the UK.

We welcome this increased focus into an area of risk that as a charity we know has been long neglected and publically misunderstood. However, guidelines and information about epilepsy risk management during and after pregnancy need to be strengthened and balanced to assist both clinicians and their patients to make tailored and informed choices with all facts available to them. This should be open, honest and detailed in order to be

truly effective in improving outcomes. Tools such as the SUDEP & Seizure Safety Checklist, EpSMon & our SUDEP & Seizure Safety E-Learning help address this gap by providing information and a communication framework which help keep expectant mothers, and therefore their baby, safer.

To find out more information about SUDEP and Pregnancy visit [www.sudep.org](http://www.sudep.org)

## SUDEP ACTION HIGHLIGHTS RISK INFORMATION AND TOOLS TO EPILEPSY NURSES AT THE ESNA CONFERENCE 2016

SUDEP Action attended the 2016 Epilepsy Specialist Nurses Association National Conference (ESNA) in Manchester. Attended by Epilepsy Specialist Nurses from across the UK, the conference was a great opportunity to raise awareness of the charity's services, information and communication tools.

The two-day conference from 19 to 20 June, involved a series of presentations, one of which was led by Dr Rohit Shankar who talked about the SUDEP and Seizure Safety Checklist and EpSMon projects'. He discussed the projects development and motivations; sharing statistics and personal stories about the impact of epilepsy deaths on individuals, families and the National Health Services. Dr Shankar also talked about the work done by SUDEP Action to raise awareness of risks, providing tools to support both patients and clinicians. He highlighted how health professionals can play an important and vital role by telling bereaved families about our specialist Bereavement Support services and The Epilepsy Deaths Register.

SUDEP Action had an information stand running throughout the conference, managed by Trustee Simon Lees who has



experience attending similar events. Simon met with many of the attendees, informing them about SUDEP Action services, in particular the SUDEP and Seizure Safety Checklist, EpSMon & The Epilepsy Deaths Register. Many of them took away information leaflets and expressed their support for the charity. Over 45 Epilepsy Specialist Nurses asked for further information, resources & to be kept up to date with charity news and there has been a surge in clinicians registering for the SUDEP & Seizure Safety Checklist since the conference!

Simon summed up the conferences by saying: "It was great to get the opportunity

to represent SUDEP Action at the ESNA Conference and to meet many nurses who are both supportive of the charity and dedicated to provide the best care for their patients with epilepsy. As someone who has epilepsy, it was reassuring to speak to health professionals dedicated to keeping people with epilepsy safer and who were enthusiastic about SUDEP Action and their new communication tools, EpSMon & the SUDEP & Seizure Safety Checklist."

If you're a health professional & would like to find out more about how our communication tools can support you and your patients' epilepsy management & risk awareness, please visit the SUDEP & Seizure Safety Checklist and EpSMon pages.



Health Professionals can also take part in our free SUDEP & Seizure Safety E-learning course, which counts towards CPD.

## EPILEPSY MEMORIAL DAY ONLINE EVENT BRINGS TOGETHER FAMILIES BEREAVED BY EPILEPSY

The first online Epilepsy Memorial Day event held on 10 May brought together families and friends bereaved by epilepsy. The day helped remind families that they

are not alone. Hundreds of bereaved families and friends joined the event on the SUDEP Action Facebook and Twitter pages by sharing memories of their lost loved

### Forever Remembered

Even after life is gone  
In our hearts your love lingers on  
Even after you have left our sight  
In our thoughts your light shines bright  
Even after you are gone  
In our memories you forever live on.

By Injete Chesoni

THANK YOU TO EVERYBODY WHO  
WAS INVOLVED, please know that our  
hearts are with you everyday as you travel  
on this difficult journey.

[www.sudep.org](http://www.sudep.org)

ones. These posts received around 4000 likes and reached over 193,000 people.

Some families and friends who took part in the event commented on the charity Facebook page:

*"The Memorial Day was excellent. Well done and thank you to whoever thought of it and organised it. The only difficult thing for me was to see the number of families that have been devastated by SUDEP. Also to see so many young beautiful people whose lives ended too soon. Many thanks again for all your efforts."*

*"So many beautiful pictures today and just all too sad. Well done on excellent awareness idea. Love and strength to each and everyone of you."*

*"Hard night seeing so many peoples loss. Realising we are not alone in our sorrow but*

*also how many of us were unaware of this possibility that this could happen to our loved ones. And scarily some of them didn't know either."*

Epilepsy Memorial Day will be held annually and is in addition to SUDEP Awareness Day in October and our Memorial Service held in London once every three years.

Thank you again to everyone who supported Epilepsy Memorial Day. We understand that some of you may have found the day difficult and we would like to remind you that our Bereavement Support team is here for you. We have more than 20 years' experience supporting families bereaved by epilepsy. If you would like to speak to someone, please contact our support team on 01235 772850 or email [support@sudep.org](mailto:support@sudep.org).

## SUDEP ACTION'S NATIONAL CONFERENCE 2016 – SUMMING UP THE BIG CONVERSATION SO FAR

By Jane Hanna

A huge thanks to everyone who came to our weekend conference. So many friends reunited and brave families making connections for the first time. We always say this is the club that no one wants to join but we are so grateful to all of you who have told us that the opportunity to come together is so precious to you.

My talk – 'The Power of Communities' was aimed at showing how there was a real opportunity for a coordinated and concerted push to achieve what the bereaved families have been fighting for, for so long.

The challenge of preventing avoidable deaths is an important part of the overall

empowerment of people and families living with the condition. SUDEP Action works to support the Epilepsy Bereaved Community by representing the voices of the families and involving and supporting them to share their stories, get involved in campaigns or get involved in research.

A big thank you to Dr Colin Dunkley painting a realistic picture of the challenges facing epilepsy care, but also in helping the families to see the positive work and the energy going on in some places to tackle the serious issues that families face.

The contribution of all the families just by being present was hugely helpful to the charity and the sharing of the struggles that you face day by day helps inform how we move forward. This was all part



of our 'Big Conversation' to involve you in our campaigns and our priorities. This conversation is also informed by the 500 reports to The Epilepsy Deaths Register from families sharing their experiences with us.

On Sunday we worked together on the start of a Charter for our Community: a document outlining the needs and expectations of our bereaved community. This charter, once complete will help SUDEP Action to move forward by nurturing connections that help us meet these needs; ensuring that the collaborations we develop are with people who likewise respect our bereaved families and stand for what we believe in; we really hope you can add your voices to it.

*"This was our first conference after the loss of our son. We thoroughly enjoyed the weekend and made lots of new friends. The informality made it very relaxed*

*and enjoyable. Great work being done by SUDEP Action"*

*"All wonderful - Thank you for bringing us all together and or all you do"*

Thank you again to all those who attended the conference, supported us from afar or are there for us throughout the year – your support makes all the difference.



## NATALIE'S WING WALK IN MEMORY OF HER SISTER KATHRYN

My Name is Natalie Treadwell. I am a normal person, and like all normal people I have a story. I don't do that much work personally for charity, but that is because there is only one charity that stole my heart. On December 23rd, 2006, my youngest sister was ripped out of my family's lives forever and I not only lost my sister, I lost my best friend too. Here is our story.

It was like any other Christmas, excitement was in the air, everyone was dashing around buying food and last minute presents, going out with friends ... until that morning when the whole world melted away. 'Sudden Unexplained Death' perfectly named if you ask me, simply explained to us as an adult's version of 'Cot Death'. I had never heard of it before, but as my parents have come to realise through conferences they attend



– many families suffer the consequences of it every day. Due to my sister having had a fit in the previous 18 months, the Coroner announced the cause of death as 'Sudden Unexplained Death in Epilepsy' (SUDEP).



Kathryn was offered medication for her epilepsy but she turned it down; she had just started university and wanted to enjoy her experience there and not have the drugs interfering with her studies. If she had been more aware of SUDEP, would she have taken the medication and enjoyed more of the university experience and of life? We will never know - but I would like to be able to help somebody else's family understand, and help those other families that have been torn apart through the loss of someone who didn't deserve to go.

Her name was Kathryn, she was truly beautiful inside and out, she was intelligent, funny and quirky in a special Treadwell kind of way that made her lovable. Her funeral was breath-taking; the amount of people that attended made our hearts ache. The number of lives she touched for such a young age made me proud to be her sister. She wanted to be a Librarian or Historian, and I have no doubt she would have achieved her goal – she was both ambitious and determined, if she only would have had the chance.

They say no parent should have to bury a child, no big sister should have to bury one who's younger – no one should not have the chance to say goodbye to their best friend.

It will be 10 years this December, a decade without such a shining star; sometimes I wonder how there has even been light in our lives since she was taken.



Natalie with her sister Kathryn

Luckily there are charities such as SUDEP Action to help people with their loss; they help you find your way again. SUDEP Action have helped my family and I want them to be able to help others too.

Five years ago I did a Skydive in her memory and I raised £2,500 for the charity. This time I wanted to do something else I know she would have been crazy enough to do with me! She was extremely selfless and would not have thought twice about doing something for charity – so I feel that bit closer to her.

Once I had decided to do a Wing Walk there was no going back and it was fundraising all the way until a beautifully sunny (but a little windy) day in May when it became a reality. Climbing onto the plane and standing there waiting to take off was really scary and as I looked across at my partner Ian, he just smiled and winked at me – and I knew then that I could do it!

When the plane took off I felt like a bird, and it was really scary to start with believe me - it was cold and windy! But what an experience once I was up there! At one point I looked up to heaven and said I love you to my angel – I felt that bit closer to her then.

So far my Wing Walk has helped me raise £3,500 for SUDEP Action. I have been totally overwhelmed by the love and support that people have shown to me during my fundraising, but I'm also thrilled to know that all of those people are now

## CHRIS STEPHENS CONQUERS KILIMANJARO IN MEMORY OF HIS WIFE

I am 38 years old and have two children, a son aged 15, and a daughter aged 12. I became aware of SUDEP Action following the sudden death of my wife Katie, last year. She was 37 years old when she died. Katie was a fitness instructor who had no previous signs of epilepsy. However, she suffered two seizures, the second of which led to a massive brain haemorrhage which led to her death. Following an inquest, and finding out about SUDEP, I researched the condition as I had never heard of it.

I decided I wanted to raise awareness of this condition, and some much needed funds for SUDEP Action. I thought Mount Kilimanjaro would be an interesting challenge, which would also combine my love of travel. I had never been to mainland

aware of SUDEP, and have contributed towards helping SUDEP Action help more families.

I would like to thank my Mum and Dad, they were amazing and they are the most inspirational people I know; I feel honoured to be their daughter and I could not have completed the walk without the support they gave me. Also, Ian Pugh; I know I was a nightmare from the time I decided I was going to do the Wing Walk to the celebrations he had to carry me home from afterwards! He remained my rock throughout, supporting me and loving me – even though he never met my sister, I know she would have loved him. And finally I would like to thank all my friends and my colleagues who supported the raffle, the bake sale, the dress down days and the spin class that helped me raise this fantastic amount for the charity which will always be close to my heart.



Africa before, so I thought this would be an ideal challenge.

I am a member of a gym, and train four to five times per week. As there is no way of preparing for the altitude without going in an expensive simulator, I just concentrated on keeping my general fitness levels up. In the couple of months before the trek, I increased this to include two sessions per day, a couple of times each week.

Once in Tanzania, we started off for Kilimanjaro at around lunchtime on Friday, 12 February, 2016. We set off for the summit at midnight on Tuesday, 16 February. It was pitch black and freezing cold. Before too long my feet were frozen solid! It was a difficult few hours because all you can do is trudge along, focusing on the feet of the person in front of you. Because it is so dark you cannot see the top of the mountain when you look up, so you have no idea how close or far you are from the top, all you see is a line of lights from head torches bobbing along the side of the mountain.

Summit night was difficult. The main thing that gets you through is the thought of those that have supported you, and those that you are doing the trek for. That and

the support of your fellow trekkers, and the wonderful support crew who guide, and at times physically carry you along!

I arrived at Uhuru Point, the highest point of Kilimanjaro, at around 7am on Wednesday, 17 February. It was a surreal feeling, filled with a range of emotions - relief and happiness that you have made it, tinged with sadness as you think about your reason for being there. It was also physically and emotionally draining, but also wonderfully fulfilling and worthwhile. I have memories that I will carry with me for a long, long time.

I met some wonderful people, our team of guides and porters were truly amazing. It is difficult to explain what it is like to be trudging up the side of a mountain at over 5,000 metres above sea level, kitted out in all of your expensive equipment, only to be overtaken by a porter wearing jeans, a t-shirt and a pair of trainers, carrying a 20kg pack balanced on his head!

I am proud to have raised over £3,000 for SUDEP Action. This is a charity that does vital work in looking to prevent more deaths, and support people affected by this little known condition.



## UNITED IN GRIEF WALK RAISES AWARENESS AND FUNDS FOR THE CHARITY

Two bereaved Dads, Craig Ferguson and James Deveney, climbed Ben Lomond in Scotland in memory of their children.

Craig's son Aston died from SUDEP in August 2014.

"Aston, or Aston Tails as he was known, was diagnosed when he was 11, and was seizure free for two years before he passed away. In all the years he had it, we didn't know anything about SUDEP. People just aren't aware of it. I was speaking to him on the Friday night and on the Saturday he was gone. He died in his sleep aged just 20," Craig said.

James' daughter Ashleigh was 23 when she died in 2013. Ashleigh was working away from home in the Greek Island of Kos when she contracted a virus and passed away after suffering multiple heart attacks. Craig wanted to contribute to SUDEP Action to help raise awareness of the condition which took his son's life while James wanted to raise funds for a charity in his daughter's memory.

The two Dads decided to join forces and do a sponsored walk up Ben Lomond in memory of their children. They both contacted Rangers FC and Celtic FC, who kindly donated a football top to both of them.

"We decided to call the walk United in Grief to show that Rangers and Celtic fans can unite in bad times. The support from both sets of fans has been phenomenal," James said.

The two Dads completed their walk on 4 June, Aston's birthday. The day brought a range of emotions for his father Craig, but he explained that spending the occasion conquering such a feat helped him get through it.



"People were at the top of a mountain handing us money. It was an incredible day, and I even joked to James at the top 'that's 1-0 to Rangers, I beat you.'"

"People were stopping us and couldn't understand why we were in Rangers and Celtic shirts climbing together. It was emotional. If we were two guys wearing two ordinary t-shirts the photos of us at the top would've meant nothing, but the football shirts mean much more."

Craig and James have raised over £1,295 which will be shared between the two charities.



"We never expected this to go as far as it has, it's been unbelievable, really. At the start, we both said we'd be happy to raise a few hundred pounds, but we never imagine it would be like this - it's crazy," explained Craig.

Craig added: "Losing our children leaves an unbearable pain and we live with it every day. It's all about learning to live with it, I thought I would never have to deal with it in my lifetime. I miss him, I miss him badly."

"I just hope Aston and Ashleigh are looking down and see what we've done."



Their Just Giving page stops on 20 July, Ashleigh's Anniversary.

Sources **STV** and **Scottish Daily record**

## JOHN COLEY'S GOLF EVENT RAISES FUNDS FOR SUDEP ACTION

We held a charity golf event at the Lyme Regis Golf Club in Dorset, to raise funds for SUDEP Action and another epilepsy charity.

I am currently the Club Captain at Lyme Regis Golf Club. Every year, the Club Captain and the Lady Captain nominate a charity or charities for whom they raise funds throughout their year on tenure.

This year Lady Captain Caroline Baker and I decided to join forces to raise funds in the fight against sudden death in epilepsy. We nominated SUDEP Action as one of the two charities that were going to share the results of our collections.

We decided to raise funds for these charities because there is a couple at the golf club who lost a child through sudden death in epilepsy some years ago. I also have a mature niece who has mild epilepsy, and a colleague whose young son also has the condition.

On Saturday, 4th June, we held our big golfing event. I successfully completed my hoped for 4 rounds of golf and exceeded

my 120 points with 127 points. I played from 06:15am to 19:30pm, with only a 90 minute break for a rub down with The Sporting Life.



I played as many holes of golf as possible in the day, and sought sponsorship not on how many holes I played, but on how well I played. One of golf's scoring systems is with Stableford points which are won according to how well each hole is played. To play to one's handicap, 36 points was the target. I



play off a handicap of 7, aged nearly 67; I needed all my stamina, as well as skill, to play from dawn to dusk.

Each round was well over 4 miles, and the terrain is not flat. I completed at least 3 rounds (54 holes) and 4 (72 holes) before my arthritic hips screamed to stop.

## STUDENTS AND TEACHERS COMPLETE GRUELLING RACE IN MEMORY OF EDWARD VERGETTE



At Churcher's College, Petersfield, East Hampshire, we sadly lost a student, Edward Vergette aged 17, to SUDEP in 2013. Since then, SUDEP Action has been supported by his pastoral house, Grenville. We ran the Hellrunner in his memory.

Many students were eager to run the race in early September. Others needed to be persuaded later on; some trepidation was felt at first! A couple signed up one week before the event!

On Friday 16th January, twelve students and two members of staff from Churcher's College, ran the formidable Hellrunner. Zac Guyer, Ben Morgan, David Morgan, Dean Porter, Joseph Twitchen, Toby Remington, Joe Mullender, Anastasia Pillar, Gemma Swan, Eleanor Morrison, David Thirkeld, Penny Harper and Michael Murray all completed the race.

It's great to know that I am raising funds to help prevent unnecessary epilepsy deaths. It seems to be an underestimated danger and the more I have spoken about it, the more people I discover are unaware of the risks. As well as raising funds, the event helped us to raise much needed awareness.

The Hellrunner comprises mud, hills, and bogs, including the notoriously freezing, neck-high 'Bog of Doom.' This was the toughest but everyone approached it with good humour, and no one ran it alone. It was freezing when we came out! There were some parts of the race that were gruelling, but the higher purpose spurred us on.

Some of the pictures of various Churchers' running, struggling on in the race tell more than a 100 words and on seeing the photos, many gave generously to the cause. Our fastest runner, Joseph Mullender, completed the race in 1 hour, 39 minutes and 9 seconds, finishing in 47th place.

The whole run was tough but worth every difficult mile. It meant a lot that we were raising money for a good cause.



Ultimately everyone enjoyed the event and it was great when everyone got together for a picture with the SUDEP banner. We are really pleased to have raised money for SUDEP Action, we were glad to raise awareness of SUDEP and contribute towards research.

## TRACY STEPHENS - A BEREAVED MUM SHARES HER JOURNEY SO FAR

I was feeling very alone with my thoughts, and feeling every door I turned to, seemed to only offer to help for a short while. One day, a lady said 'have you heard of Epilepsy Bereaved?' as SUDEP Action was known then in May 2012. It had just passed a year from my son Stephen falling asleep, I was so sad, empty and heartbroken beyond any words can describe.

The lady from SUDEP Action rang me following me contacting the bereavement support line, she introduced herself and we began a beautiful relationship. We made arrangements for her next call, I think it was about eight calls every two weeks apart, and I so longed for that call, as I could speak to someone who not only listened; she cared, and understood me. Many people in my life would say unwanted words such as, 'think of your other children', which I always did but that didn't ease the pain, or they would say 'he enjoyed his life'; but at just 23 years, that also felt painful as his life was taken too soon, and so unexpectedly. Apart from his epilepsy, Stephen was very fit and well.

I could talk about anything, family members, pets and mostly what I wanted was to talk of Stephen, I could cry lots and used to apologise to Tracy on the support line, and she would reply, 'no, no Tracy its okay to be upset', which meant the world and more; as others would say 'he wouldn't want you crying'. She would always want to know my plans for the day and encourage me to make

Edward's father, Nicholas, commented: *"Carole and I are very impressed at the time and effort that the staff and pupils at Churcher's College continue to put in to support SUDEP Action. It was a fantastic effort by everyone involved and they should be very proud of what they have achieved"*



a cuppa, I would say I am going to try and get out with the dogs, and she would want to know all about my walk at Lyme Park National Trust, which inspired me to place a bench there just for me and Stephen; and for others to enjoy the beautiful place.

As my last call came, I felt that the special friend I had made, even though I had not seen her, would be needed more in my life. She said if ever I couldn't sleep, I could email her about my feelings, or email her anytime and she would ring me. This was so wonderful to hear; it made me cry with a smile; that it wasn't the end as others had been.

Often, I would contact her, during the night via email, or if any nice things happened; the support and understanding was always there for me. The same person, so she knew all about me! I didn't need to explain, it just continued. Grief is never ending and the continuity of the support is so important.

Our calls were full of tears and smiles, I didn't realise it then, but it was the beginning of a changed me. In 2015, I was diagnosed with cancer; and now after treatment in full remission, I made my first annual SUDEP Action weekend conference at Woodland Grange, and shared a truly lovely weekend of emotion and bonds that will last forever.

I feel so blessed to have found Tracy Cowdry at SUDEP Action, and still love her calls. I have now found work at a lovely nursery/school, and have completed a 3 hour Zumba smileathon as well as the Great Manchester 10k run for charities very close to my heart; Christies Beechwood and SUDEP Action, raising £1390.88 kindness from so many. I do things each day for Stephen, which makes me smile at the end of every day, at what I have achieved for us both.

## FUNDRAISING UPDATES

## FETES AND FAIRS

Many villages, towns and cities across the UK hold a summer fete or fair. Often they need people to host stands so it is a great place to fundraise and raise awareness at the same time. If you would like to host a stand then get in touch with the event organiser or your local council to see if stands are available. You can also contact our Fundraising and Administration officer Katie for help and advice. Tombolas, raffles, guess how many sweets are in a jar, or lucky dips are just a few of the types of stands that you could hold.

## FUNDRAISERS BLOGS

Our monthly fundraiser's blogs are a place to thank and celebrate our fundraisers. You can find the blogs on our website by searching **Fundraiser's blogs**.



If you would like to speak to someone on the support team please call 01235 772852 or email [support@sudep.org](mailto:support@sudep.org)



## SUDEP ACTION COFFEE CLUB MEETINGS



meetings is to know you are not alone, that others have been there too.

Our last meeting in Guildford was a great success with one attendee commenting: "This coffee morning was friendly and uplifting, even though we all shared some very sad stories. The feeling of support was very strong and a sense of 'belonging' almost. On another note, although I only visit the page occasionally, I like the online memorial pages where I can light a candle."

SUDEP Action coffee club meetings are intended to be informal and are a way to meet others who have been bereaved by epilepsy. It is a great way to share stories gain support and discuss what has helped you through this most difficult journey. You may want to swap ideas for fundraising; for raising awareness; for getting through the inquest or discuss strategies for coping with day to day life, whatever your reasons for meeting up – the main outcome of the

The host also commented:

*"As long as people are happy to come, I am happy to host the coffee clubs. The overall feeling in the group was that the coffee club worked because it was casual with no pressure on anyone. It felt like a group of friends getting together."*

If you are interested in hosting or attending a meeting please call 01235 772852 or email [tracy.cowdry@sudep.org](mailto:tracy.cowdry@sudep.org)

## SHARE YOUR STORY

My Story - is an important and powerful way for you to join our campaign. As 'the voice of the bereaved' for over 20 years, we use information shared with us to good purpose. We are very experienced in supporting those who wish to share their stories and who find it helpful to know that they are part of the 'voice.'

The stories are those of people who have died from epilepsy, whatever the cause. With permission we share these stories where they will have most impact in highlighting epilepsy mortality. You can find out more at [www.sudep.org](http://www.sudep.org) or email [juliet.tumeo@sudep.org](mailto:juliet.tumeo@sudep.org) to share your story.

## SAVE THE DATE - SUDEP AWARENESS DAY 23RD OCTOBER.



Our SUDEP Awareness Day campaign is an annual event aimed at raising awareness of Sudden Unexpected Death in Epilepsy (SUDEP). The day also commemorates all those who have died. We will be sending out information soon on how you can get involved and help make this year's SUDEP Awareness Day bigger.



# Remember Me In Your Heart

To the living, I am gone,  
To the sorrowful, I will never return,  
To the angry, I was cheated,  
But to the happy, I am at peace,  
And to the faithful, I have never left.

I cannot speak, but I can listen.  
I cannot be seen, but I can be heard.  
So as you stand upon a shore gazing at a beautiful sea ...  
As you look upon a flower and admire its simplicity ...  
Remember me.

Remember me in your heart:

Your thoughts, and your memories,  
Of the times we loved,  
The times we cried,  
The times we fought,  
The times we laughed.  
For if you always think of me,  
I will never have gone.

**Author Unknown**

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](mailto:support@sudep.org)**

Getting involved & campaigns:

**[fundraising@sudep.org](mailto:fundraising@sudep.org)**

Media:

**[info@sudep.org](mailto:info@sudep.org)**

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**SUDEP.ORG**