

Have you registered yet?

It is vital to the success of the register that we capture as much information as possible for researchers. We appreciate this may be difficult, but you need only give as much information as you are comfortable with. The initial information will only take around 5 minutes and can be completed on line via our website or via our support team on our local rate telephone number:

www.sudep.org

Tel: 0330 088 1220 (local rate)

The Epilepsy Deaths Register is the only single point for reporting all epilepsy-related deaths in the UK. It is supported by researchers, professionals and endorsed by government. Epilepsy is among the top ten causes of premature death. To help prevent future epilepsy deaths, we need to find out what happened in as many cases as possible.

The information will help:

- Co-ordinate involvement in research.
- Improve public awareness of epilepsy related risk and SUDEP.
- Identify and prioritise new research.
- Decide where best to put funding to improve services.
- Improve advice and treatment plans.

You can register a death no matter who you are including:

- Relative and friends (as long as you are over 18)
- Doctor, nurse, carer or social worker.
- Coroner, procurator fiscal or pathologist.

Our Epilepsy Deaths Registry team has over 50 years' combined expertise in epilepsy deaths. Research support is provided by Dr Henry Smithson and his research team at Cork University and By Kings Health Partners.

THE
EPILEPSY DEATHS REGISTER 
Making every epilepsy death count

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

Bereavement support: support@sudep.org
Getting involved & campaigns: fundraising@sudep.org
Media: info@sudep.org

SUDEP Action
12a Mill Street
Wantage
Oxon OX12 9AQ

Call: 01235 772850
Email: info@sudep.org
SUDEP.ORG

It does not matter if the same death has already been registered, as the more information the research team has on each death, the better.

Please let us know about any death reported or suspected to be:

- SUDEP (Sudden Unexpected Death in Epilepsy).
- Any sudden death in someone with evidence of a seizure that cannot be explained.
- Deaths in people with epilepsy reported as status epilepticus.
- Accidental deaths in people with epilepsy.
- Deaths reported as cause unknown in people with epilepsy.



SUDEP Action 
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KEEPING IN TOUCH
July 2014

It has been over a year now that we have been working under the new name of SUDEP Action. The move has been very successful and seen us engaging with even more professionals and people with epilepsy than before in our efforts to save lives. We have received over 300 registrations on The Epilepsy Deaths Register and our researchers will be reporting shortly on the findings. But remember there is still much to be done and if you haven't reported yet, please contact the team or visit the web page.

We were delighted to be invited to number 10 Downing Street by Samantha Cameron, who hosted a reception on our behalf on June 10. This gave SUDEP Action the opportunity to highlight a new research project which the charity has pledged to support. Professor John Duncan of UCL has developed a wearable apnoea detection device. We are raising funds to pay for the trial of this device on 50

people with epilepsy to see how effective it is at raising the alarm if people stop breathing following a seizure. SUDEP Action believes that should these trials prove successful, it could be an important step in the prevention of some SUDEP deaths.

We are also proud to be announcing the aims of our Call for Openness campaign. This means we can all work together to bring epilepsy deaths out of the shadows.

All of this exciting work is only possible thanks to you – our supporters. We always enjoy hearing about what you have been up to and there are some truly inspiring stories in this newsletter which reflect your passion and commitment.

Thank you.

SUDEP.ORG



SAMANTHA CAMERON HOSTS SUDEP ACTION APPEAL LAUNCH FOR RESEARCH INTO DEVICE TO PREVENT SUDEP

Samantha Cameron hosted a reception for SUDEP Action at 10 Downing Street on 10 June 2014. The night launched the charity's appeal for research into a sleep monitoring device that could improve prevention of SUDEP. The event was also a fantastic opportunity for the charity to thank some of its dedicated supporters at this world famous address.

Mrs Cameron met with charity supporters and staff at the event which brought together about 120 people including professionals, policy makers and families bereaved by epilepsy. With the support of bereaved families, the charity works to prevent epilepsy deaths including Sudden Unexpected Death in Epilepsy (SUDEP) through research and awareness of risk.

Epilepsy claims at least 1200 lives in the UK every year and about 500 of these are SUDEP. The charity launched the appeal for research into the sleep device that will be used to alert carers to dangerous apnoeas that can cause sudden death. The device is a miniature, Wireless Apnoea Detection Device (WADD) that has been proven to detect apnoeas. It was created by Dr John Duncan of University College London through a partnership between researchers at the National Hospital in London and Electrical Engineers at Imperial College.

Jane Hanna OBE, Chief Executive SUDEP Action commented: "We are very grateful to Mrs Cameron for generously hosting us and helping us raise awareness of this issue. Apnoea is a leading contender as a cause of SUDEP. At the moment there is no reliable method to detect apnoea in the home with the consequences that

there are hundreds of preventable deaths every year in the UK."

"We need at least £165,000 to test this device on people with epilepsy as the next step towards a system that may be highly reliable for preventing SUDEP".

John Hirst CBE, SUDEP Action Trustee and bereaved parent also spoke at the event saying: "When my son died, I could not imagine how life could carry on without him. As many of you here know, life is never the same after you lose a child. But it does not stop. It changes. Now, eleven years after his death, I still grieve but I am also proud to have helped bring together SUDEP researchers from competing research institutions to pool their expertise. I feel proud to support this new apnoea monitor financially and I hope you will do the same".

As part of its work in supporting research, SUDEP Action is also currently promoting the first register of epilepsy deaths in the UK aimed at supporting research into epilepsy deaths. The Epilepsy Deaths Register is providing researchers with vital clues that will help them understand and ultimately prevent SUDEP.

The charity began as a campaign by five women, Jane Hanna OBE, Sheila Pring, Catherine Brookes, Sue Kelk and Jennifer Preston. Jane's partner and Sheila's son Alan died in 1990 (aged 27); Catherine's son Matthew died in 1991 (aged 21) Jennifer's son William died in 1988 (aged 22); and Sue's daughter Natalie died in 1992 (aged 22). William, Alan, Matthew and Natalie were all young and active people who died suddenly and unexpectedly.

THE WEARABLE APNOEA DETECTION DEVICE AND SUDEP PREVENTION

Researchers have developed a small Wearable Apnoea Detection Device (WADD) that could help prevent SUDEP. Professor John Duncan from University College London and Dr Esther Rodriguez-Villegas from Imperial College are working on testing the tiny wearable device to monitor breathing in people with epilepsy. The device will trigger an alarm if breathing stops.

The WADD has been tested in 20 controls on 10 sleep apnoea patients. This confirmed high sensitivity and low false alarm rates. There is currently no such device in production. All the existing systems are bulky and have very high false alarm rates. The ultimate aim is to produce a minute device which could be worn all the time by people at high risk of SUDEP.

The exact cause of SUDEP is not always known. In some cases the heart stops first. However, apnoea has been identified as the most likely cause. The monitoring device could give the alarm when someone stops breathing, providing a chance of saving that life through CPR.

The device needs testing 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 device may need recalibrating following

the first phase of testing. The researchers would then need to test the device on a wider pool of patients. Alternatively, it may be that the research findings are emphatic enough at this stage to seek commercial partners or venture capital funding. Naturally, we cannot predict what the research will show at this stage, but hope that this project will be a significant step forward in the fight against SUDEP.

There are about 600,000 people with epilepsy in the UK. Around a third of these have seizures despite medication. These people are at high risk of premature death. SUDEP claims around 600 lives each year in the UK. Young adults are at particular risk. They are often alone at the time of death.

The project is scheduled to start in June 2015 at the rate of approximately one patient a week for one year.

Research Team

Professor John Duncan is an academic clinical neurologist specialising in epilepsy at the UCL Institute of Neurology and the clinical director of the National Hospital for Neurology & Neurosurgery. Dr. Esther Rodriguez-Villegas is an electronics engineer with a specialism in wearable sensors based at Imperial College.

If you would like to know more about the device or of ways you can help raise funds for the project please contact:

fundraising@sudep.org or ring us on 01235 772850

PATIENT SAFETY IN EPILEPSY MONITORING UNITS – TIME FOR CHANGE



Latest expert opinion based on evidence from international research of Epilepsy Monitoring Units is that they need to step-up their care of patients to reduce the risk of SUDEP and other serious adverse events.

Professor Philippe Ryvlin, Lyon Neuroscience Research Center, France writing for Current Opinion in Neurology highlights in his article that serious adverse events should be a significant concern for Epilepsy monitoring units. About 10% of all patients observed during long-term monitoring experience serious adverse events. SUDEP and near-SUDEPs were also found in more than 10% of European and Australian monitoring units.

Adverse events might be triggered by drug withdrawal and also aggravated

by suboptimal care in some epilepsy monitoring units. Of real concern was the finding that 20% of European and 26% of US-based Epilepsy Monitoring Units did not follow recommended good practice, in particular continuous supervision by a dedicated staff.

Professor Ryvlin, who led the research said: *“Epilepsy Monitoring Units should review their current practice to ensure that current guidelines are being followed. Our research highlights the importance of surveillance in these units and that surveillance of epilepsy deaths and adverse outcomes needs to be a priority going forward”*.

Jane Hanna of SUDEP Action said *“This research shows the importance of surveillance and learning lessons from deaths and serious events. At SUDEP Action we will push hard to get the messages from research out to the public and make sure that vital lessons are learnt and risks are reduced”*.

DR ROSEMARY PANELLI JOINS THE SUDEP ACTION TEAM AS INTERNATIONAL RESEARCH OFFICER

We are delighted to announce that Dr Rosemary Panelli, International Epilepsy Ambassador and champion of global awareness on SUDEP has joined the SUDEP Action team as part-time International Research Officer.

Dr Panelli has a PHD in Public Health and has worked with Australian Epilepsy services for 16 years. In 2011, she was awarded the Ambassador for Epilepsy Award by the ILAE and the IBE for her work over the years on epilepsy and Sudden Unexpected Death in



Epilepsy (SUDEP). Dr Panelli has promoted community understanding of epilepsy especially in regard to SUDEP. She has helped ensure that quality epilepsy information is accessible at all levels leading to the development of valuable programs and resources, including the publication *Sudden Unexpected Death in Epilepsy: a global*

conversation (2005, 2011). The global conversation has encouraged international discussion and collaborative responses. She also initiated the biennial Australian epilepsy memorial service.

Jane Hanna, SUDEP Action Chief Executive welcomed Dr Panelli saying: *“SUDEP Action has enjoyed a close collaboration with Rosey since the 1990s working in partnership on the global conversation on SUDEP. We look forward to Rosey coming on board as a member of the SUDEP Action team”*.

SUDEP ACTION TAKES PART IN PAME CONFERENCE 2014

Newly appointed SUDEP Action International Research Officer Dr Rosemary Panelli represented the charity at the North American Partners Against Mortality in Epilepsy (PAME) conference in Minneapolis, USA.

The conference ran from 19 to 22 June 2014 and united epilepsy researchers, bereaved families, clinicians and advocacy organisations from several countries. The goal was to nurture partnerships, foster knowledge, heighten awareness and hasten action around epilepsy related death generally, and SUDEP specifically.

Topics of discussion included respiratory and cardiac mechanisms of death, possible genetic factors, the collection of information about deaths through tissue banks and registries, and how information about SUDEP should be disseminated to health professionals and the community. Sessions were introduced by a person bereaved by epilepsy and these moving presentations underlined the urgent need to advance research, public awareness, and

prevention strategies.

Dr Panelli supported Professor Henry Smithson who presented two research posters on the development and findings of SUDEP Action's Epilepsy Deaths Register at the conference.

Professor Smithson commented: *“It is a privilege to present the findings of SUDEP Action's Epilepsy Deaths Register at PAME and to promote the development of the register. There is a great opportunity for countries to work together to gather vital information and support for research to prevent deaths. I am grateful to PAME and the Green Park Foundation for the support I received to attend the conference”*.

PAME was a positive outcome of teamwork between organisations and individuals in the North American epilepsy community. SUDEP Action was acknowledged as an important inspiration in the work and international cooperation is seen to be a crucial next step as momentum builds around the world for action on epilepsy mortality.

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SUDEP ACTION HIGHLIGHTS AIMS OF ITS CALL FOR OPENNESS CAMPAIGN



SUDEP Action has highlighted the aims of its Call for Openness Campaign which was launched last year in June 2013. The Openness campaign is aimed at raising awareness and saving lives. It stresses that people with epilepsy need to be fully informed if they are to make the right lifestyle choices to reduce their risk of SUDEP. There are around 1200 epilepsy related deaths a year in the UK and almost half of these are from Sudden Unexpected Death in Epilepsy (SUDEP), most being potentially avoidable.

The call is for a common sense approach to alert people at risk of ways to reduce their risk of SUDEP and aims to:

- Encourage people with epilepsy to be open about their condition
- Encourage doctors and nurses to talk about risk including the risk of SUDEP on or soon after diagnosis
- Encourage people with epilepsy to report their seizures accurately
- Encourage people with epilepsy to take their medications regularly and as prescribed

Although there is much improved awareness around risk in epilepsy, the need for individualised communication about SUDEP

is essential. Communication about risk opens up an opportunity for the patient to share their thoughts and fears which can help them to make informed decisions on medicines adherence and self-management.

Openness about SUDEP is about information being given routinely as part of general epilepsy information. Information given in a positive way early on at or following diagnosis can help people understand whether they are at any risk and what measures they can take to reduce and manage this. People prefer information and discussion with their doctors and nurses. The medical team is also best placed to make a decision to withhold or delay informing someone of their risk where there is good reason to believe that information about SUDEP is likely to cause a person real harm.

Canadian charity SUDEP Aware has applauded SUDEP Action's Call for Openness campaign in an article published in epilepsy journal, *Epilepsia*, entitled 'Our Epilepsy Story'. SUDEP Aware founders Tamzin Jeffs and Dr Elizabeth Donner said "We hugely admire the 18 year work and dedication of SUDEP Action and consider them an invaluable leader in the international call for greater openness on SUDEP"

To sign up to the Call for Openness Campaign, organisations and individuals are welcome to email Juliet.tumeo@sudep.org.

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JANE HANNA'S STORY – BRINGING EPILEPSY OUT OF THE SHADOWS



Motivated by the loss of her partner to Sudden Unexpected Death in Epilepsy (SUDEP) more than 20 years ago, Jane Hanna OBE talks about her journey bringing epilepsy out of the shadows.

Q: Since losing your partner, you have made it your mission to find answers and reduce unnecessary deaths from epilepsy. You have helped to bring epilepsy out of the shadows and encouraged openness which has gone some way to removing the stigma associated with the condition. Did you find this difficult as someone without a medical background?

Jane: At the time I was a young barrister and teaching law at Oxford University. Alan had started having seizures nine months earlier, but we had been reassured that epilepsy was benign. This false reassurance meant that when Alan died, not only did I find the shock of Alan dying suddenly overwhelming, but also extremely difficult to understand.

After searching for some months for answers, I came across Professor Stephen Brown who had written in the *Lancet* highlighting the lack of recognition of SUDEP and realised that Alan

had died and other people were dying because no one was doing anything about it. I decided that I would do all I could to reverse that.

Q: Your partner was only 27 when he died in 1990, you obviously didn't know about the risks at that time?

Jane: No. The information I received on risk was limited – that there was nothing to worry about and that if Alan had a seizure to put a spoon in his mouth. These two bits of advice were both wrong. At the back of my mind though, I was terrified of the seizures because Alan had generalised tonic-clonic seizures and his diagnosis was still quite recent. Deep down I did worry that he might die. We kept being told there was nothing to worry about and there was so little support that in the end we too believed that there was nothing to worry about.

Q: Since then you have been determined to highlight the risks and reduce epilepsy deaths, what has driven you?



Jane: To begin with I was driven by the grief of losing Alan and in many ways I felt I was fighting for him. He was such a wonderful person and helped so many people and I felt a deep injustice that no research or work had been done to try to save him or others like him. I have been working in the field now for over 20 years and what drives me today is the need to do all we can to prevent these deaths, but there are so many other people involved now that today I can see a finishing line.

Q: You set up Epilepsy Bereaved to support others bereaved by epilepsy – how has this developed and how does it help more than from a generic support service?

Jane: The support service grew out of the experience of families and was something we set up to meet the needs that we understood following a Sudden Unexpected Death in Epilepsy. Many of us were also seeing counsellors. The general counselling services were helpful to us, but did nothing to meet our needs to understand what had happened and to support us on the journey that all of us felt we needed to take after the death. Post-mortems, inquests are extremely difficult processes as is the journey that families may take on to find answers such as helping research; raising awareness or fundraising for the cause.

We felt we needed a service that was called and that could make that journey as easy as possible. In the beginning the service was run by the founders of the charity- particularly Catherine Brookes; Sheila Pring and Sue Kelk. As we grew, the demands on the service meant we needed to develop from a volunteer service to a service run by professionals with a combined expertise in bereavement and epilepsy mortality and supported by a panel of

pathologists and research experts.

Today we are proud that the service run by Karen Osland and Tracy Cowdry is a first class service tailor-made for families experiencing sudden bereavement whether from SUDEP status, accidents or suicide.

Q: Did you have much support in the early years?

Jane: Yes I did. Friends and family were really important, but sometimes there is a need to talk to someone who does not know you and who you know will not be upset by the strength of your grief. I felt very extreme emotions in the early years and for two years I saw a counsellor who really helped me during those dark days. The support from the other founders of the charity – Catherine, Sue, Sheila and Jennifer Preston was also vital - that we knew that we were on a journey together and could help each other because we shared the same experience and passion for the cause.

Q: It has obviously been a long journey, was there one particular thing that you feel helped to change things?

The catalyst of change was the International research workshop we organised in London in 1996. This led to some break-through research in the late 1990's, which established that active seizures, mainly generalised-tonic clonic, were the main risk factor and although there have been many more research papers on risk factors, this has only strengthened the message – it has not changed it. In the UK it meant that we were in a position to get government funding to lead a National Audit of Epilepsy Deaths which found that 42% of deaths were potentially avoidable. It is still cited today in all national policy initiatives on

epilepsy services. The international workshop and the Audit were both wake-up calls for the world community and were the beginning of the global conversation that has today brought scientists and organisations around the world together to address epilepsy mortality.

Q: How have things changed during that time?

The change is transformative. In the early years, our experience was that many people did not believe in SUDEP and certainly did not want to talk about it. Today there is a consensus that SUDEP does indeed exist – that it is a priority that must be addressed – and that it needs to be talked about so that it can be addressed. A lot of work has already been done in research and awareness so that when someone says it is tragic but there is nothing we can say or do –there is a clear message from the medical literature that on the contrary, there are things we can do to try to save lives. We can dispel the myth that seizures are benign and in a positive way inform people that some seizures can be risky and occasionally fatal and that is why it is important to take epilepsy seriously.

If people know that there is a good reason not to be complacent about their seizures, it may help all sorts of choices that people make such as whether to tell the doctor about another seizure; whether to take their medication or whether to be careful about drinking or too many late nights. The Chief medical officer in 2002 reported that the NHS did not take epilepsy seriously and that understanding the research on deaths would change this. There is still a long way to go but the work on epilepsy mortality, in particular the evidence from the National Audit, has played a huge part in driving epilepsy up the agenda of the NHS.

Q: In the last 2 years have you seen a greater pace to things?

In the last 2 years there is a real sense of movement on epilepsy and epilepsy mortality. We are no longer the only organisation

in the UK pushing the cause of SUDEP. SUDEP appears in most news magazines of the epilepsy charities in a way it never did before and at SUDEP Action we have seen an increased demand on our team to work to support external initiatives in the UK and internationally. This year alone we have made a major contribution to events on epilepsy mortality organised by Epilepsy Action and Epilepsy Research UK as well as supporting developments in other countries so it does stretch us to the limit as a team. We need more funding so we can ensure when we are asked to provide help that we can always say yes.

Q: Globally what is happening?

Globally both the research effort on SUDEP and SUDEP awareness campaigns have really taken off. By 2012, working with Rosey Panelli and Denise Chapman in Australia and Tamzin Jeffs from SUDEP Aware, we had distributed over 15,000 books on SUDEP – the global conversation. This partnership began in 2005 and was effective in reaching researchers; clinicians and policy-makers as well as supporters.

Research teams from all over the world have undertaken studies across most research questions relating to SUDEP over the last 10 years. International research collaborations are in place in Europe and in North America. Everyone is pretty clear about the direction for future research – where the gaps are and where evidence is weak. In the UK it has meant that we were able to put together a Statement of Research Need relatively easily that is supported by leading researchers across the UK and readers can view this on our site.

In some countries the funding needed to speed progress has been forthcoming. Most notably in the United States federal agencies have ring-fenced major funding for SUDEP research and the development of registries. In the UK national funding streams do not support register development and funding



bids for major funding streams often falter in our experience, because of the argument that the numbers of deaths are small compared with other causes of mortality.

Q: Do you feel The Epilepsy Deaths Register will help to change things and how?

At the moment, although there is research on deaths, the NHS has little to go on in understanding deaths in their area. They have a few statistics but nothing else. By gathering information from reporters we can help change that. The more deaths reported to us the greater our opportunity to change things. Reporting in the first year of The Epilepsy Deaths Register over-took our expectations. This is an opt-in register like the epilepsy pregnancy register and we expected that like the epilepsy pregnancy register it would take some time to get support.

With over 300 people reporting, we have some interesting data from the first year which we will be able to report to readers later this year. Many of the people who have reported have told us that the register has helped them by giving them somewhere to use their experience to help others. The information on the register will be used to help plug the information gap locally and nationally on epilepsy deaths. There has been international interest in our register and we were invited to present The Epilepsy Deaths Register at PAME Conference in North America in June.

Going forward we have a collaboration with researchers across the UK. In particular we are working to develop professional reporting of clinical information and in addition plan to work closely with the Epilepsy Society Brain and Tissue Bank so that together we can ensure we have the greatest influence.

Q: How do you think the work of the charity has and will continue to transform the lives of people with epilepsy?

I hope whilst we have striven to make sure that the epilepsy community has the information it needs on epilepsy deaths, that we have also helped ease the pain at times of all our supporters who are bereaved from epilepsy. Whether we have succeeded in transforming the lives of people with epilepsy is better answered I think by others and I felt very honoured last year in Montreal to receive an award for this from all the epilepsy organisations around the world. We will continue to punch above our weight as we always have because when you are fighting to save lives, that is what is required.

Q: And, what would you like to see for the future?

In the short term I would like to see all professionals and carers in the community access the training they need to understand better who is at risk; to help patients and families access the information and services they need to manage this risk, and to be in a better position to signpost bereaved families to SUDEP Action. I would also hope that with further investment in The Epilepsy Deaths Register we can improve surveillance of epilepsy deaths in the community.

In the medium to longer term I hope for an alert device that can warn people that someone is at risk of SUDEP and for research targeting epilepsy mortality which improves our understanding of individual risk and new interventions. I sincerely hope that by the time these are developed, the work will mean that research has a better chance of being put into practice.

70 YEAR OLD PAUL GRIMELY TAKES ON 70 TOPS CHALLENGE IN HONOUR OF AMY MARSDEN



Paul Grimely is walking the 70 highest tops in the Lake District in honour of Amy Marsden. Amy suffered from epilepsy, but despite her condition was studying for a BA in English at De Montfort University. She died of SUDEP aged just 21 a few weeks before her final exams. The University later awarded her a posthumous degree.

Paul decided to tackle the 70 tops to raise money for SUDEP Action to honour Amy's memory and mark reaching the age of 70.

He explained: "A top may be the summit of a fell (mountain), or a high point on a ridge or plateau. They are all over 2,570 feet (783 Metres) and can be grouped into 14 or 15 walks. I anticipate

several trips to the Lake District doing 2 or 3 walks on each trip with the aim of walking all tops by winter 2014."

So far Paul has walked 24 tops including Blencathra (4 tops), Skiddaw (7 tops), Helvellyn (8 tops) and The Dodds (5 tops). He has 46 tops left.

Paul added: "your sponsorship will be great encouragement to complete the challenge. Epilepsy claims about 1200 lives a year and about 500 of these are SUDEP deaths. About 40% of these deaths could be preventable through education, awareness and regular use of the right medication. SUDEP Action is a small but dedicated charity, please support me and help them to do all that they can to prevent unnecessary deaths from epilepsy. All monies raised will be given to SUDEP Action to support their education and research programme".

If you would like to support Paul please visit his Just Giving Page at: www.justgiving.com/PMGrimley

FAMILY AWARENESS CAMPAIGN IN MEMORY OF DANIEL DENCH



Daniel Dench's family have been tirelessly raising awareness of SUDEP and funds for SUDEP Action in his memory. The family has organised various awareness campaign activities since Daniel passed away in March 2013 as a result of Sudden Unexpected

Death in Epilepsy (SUDEP). Daniel was only 35 when he died and had lived with epilepsy for 20 years.

Daniel's mum Sally Dench explained: "Daniel had his first seizure aged 15 it came completely out of the blue. We have never known the cause for his epilepsy. Daniel always had grand mal seizures but they were never that frequent and he led a very full life, graduating from university with an honours degree in construction management. He was a devoted husband and very proud daddy to his daughters Sophie and Jessica."

"Although through his twenties Dan had to

surrender his driver's licence on several occasions he hadn't had a daytime seizure for almost 6 years when he passed away. Dan had started having the sleep seizures though and in his last year they had become more frequent, about one every two months."

Daniel was a former rugby player for Weymouth. His twin brother Michael organised a successful Sevens tag rugby tournament at Weymouth and Portland RFC in Daniel's memory.

Michael said: "It was a great success and we had a lovely day with glorious sunshine remembering Dan but as always tinged with sadness because it would have been his type of perfect day with family, rugby & beer".

Daniel's mum Sally Dench commented: "The support from the Rugby club was fantastic and we were all pretty choked up when they presented Michael with Dan's formal club shirt, they also provided medals for everyone in the 8 teams who took part and the winners' trophy in Dan's memory. We were so pleased to see it come together for Michael. He misses Dan dreadfully but felt his brother was very much with him when he put on Dan's rugby boots to wear."

"The Dench family had a great day, remembering Dan in the best way possible because of his love

of Rugby and raising £502 for SUDEP Action. The Framed Shirt presented to Michael was a lovely thoughtful gift from the Club. Once again an event where the support in memory of Dan made us feel so proud of our much loved and missed. We, like so many others had never heard of SUDEP and will never know if we had had the knowledge that we now have, would Dan still be with us?"

Sally has been creatively raising awareness. She dyed her hair purple for Purple Day and apart from raising £807 for the charity she also managed to garner good press coverage for her event. Sally and Michael's wife Laura also held a purple cake sale on the day and gave out SUDEP Action information leaflets.

Daniel's family have planned several more events including a Christmas day swim across Weymouth harbour with friends. They hope that the rugby tournament can be staged every year in memory of Daniel and for SUDEP Action.

"We feel very strongly that if by promoting more awareness of SUDEP it helps other people with epilepsy and their families, then any fundraising we can achieve has got to be worth it. We hope as a family to make a life time commitment to raising funds for SUDEP Action in memory of our very much loved and missed Daniel" Sally Dench.

SUDEP ACTION MEMORIAL SERVICE HELD IN LONDON



We held our London Memorial Service on 10 May 2014 at St James's Church, Piccadilly, in London. The service is held in memory of those who have died from epilepsy and is open to people of any or no faith.

The event brought together 160 people and started with an opening prayer from Reverend Lucy Winkett who led the service. This was followed by a welcome message from Chair of Trustees Professor Stephen Brown.



Hollie Craddock read the poem 'Feel no guilt in laughter, she'd know how much you care' in memory of her niece Rosie Carter. The very talented Jane South who attended to remember her brother Joe South performed 'The Feather Theme' by Alan Silvestre on piano. Jane also performed 'Winter Born', on Flute, which she wrote in memory of her brother. This was followed by a reading from Roger Scrivens in honour of his daughter Becky Scrivens.

Reverend Lucy Winkett led the reading of names of those who have died from epilepsy. Jennifer Preston, one of the SUDEP Action founders who attended to remember her son William Preston, read a message from Epilepsy Australia. After this, Julia Stirling read the poem 'Oneness' by Thich Nhat Hanh in honour of her sister Catherine Stirling.

Jane South commented: "Thank you for a really special and wonderful Memorial Service. It was such a special and moving event, it was really lovely how the SUDEP Action team and the Trustees looked after everyone. It was really touching and supportive and gave a really great space for people to just 'be' in a warm supportive atmosphere."

"It was a real pleasure to play that piece for everyone; it was a big step forward personally and really great that the piece was nice for people to hear. It was also really special for me to meet people who'd shared this kind of loss for the first time in my life, and who talked so openly, as well as some of the amazing people who had set up the charity and work so hard for it".

4 HOUR SUDEP SPINATHON RAISES £3000 IN MEMORY OF EDWARD VERGETTE

A SUDEP-Spinathon event raised £3000 for SUDEP Action. The event was held in memory of Edward Vergette who died of SUDEP aged just 17 in September 2013.

Patricia Fitzgibbon added: "The service and readings were beautiful, and the music just wonderful it brought every emotion out of you, but so heartfelt."

Hollie Craddock said: "beautiful memorial service by SUDEP Action. Loved to meet everyone and feel I am not alone in continued grief. Rosie's memory will live on."

Jennifer Neesham was there to remember her son Christopher Nasheem, she commented: "Just to say that I found the Service a really warm and comforting experience and that the booklet is lovely too. Everything around it was something I will always remember too."

Sandra Sandland attended the service to remember her daughter Carolyn Sandland who died in October 2005. Sandra said: "We will always be sad, but it is so important to have these gatherings and gain support. It is always important to comfort one another and the charity enables us to do that. It is very much a supportive family. The charity is almost like a family to me."

"Three of Carolyn's friends attended the memorial; we went for lunch afterwards, which was really special for me. It was all wonderful and many thanks to the charity."

Families and friends also took time to sign the SUDEP Action Book of Condolences.

We wish to thank everyone who attended our Memorial Service and sharing this important day with us. We appreciate the opportunity to join together in memory of those who have died from epilepsy.

Epilepsy is one of the top 10 causes of early death with at least 1200 epilepsy deaths a year in the UK, about 500 of these being from SUDEP. SUDEP Action works with leading



experts to reduce unnecessary deaths from epilepsy through research and awareness. The charity also provides support for families bereaved by epilepsy.

Colleagues of Nicholas Vergette, Edward's father, helped organise and also took part in the SUDEP-Spinathon held in the ground floor atrium of his work place. Four colleagues



completed the gruelling four hour spinning challenge while another 27 completed the challenge on rotor for 15 -30 minutes at a time on two additional bikes. Local gym LA Fitness provided two instructors, music as well as drinks and towels for the event.

Nicholas said: "The main people involved were my secretary, Karen Power, another secretary Sarah Camp, one of my partners John Cumpson as well as Michelle Kershaw and Caroline Allen who are associates at the law firm. Michelle and Caroline split their

slot. There were also lots of other people involved going round with plastic buckets collecting cash from people passing through reception from the various office floors in our building."

"The cash collection raised approximately £1500 which the firm Nabarro very kindly agreed to match making a total of £3000. I'm incredibly grateful and personally very touched that the event was held and am very much in awe of the fitness of the key people. It was also great to see everyone participating with such enthusiasm. In particular I would like to thank Karen Power for providing the inspiration, the organisation and indeed her own participation in the event."

The SUDEP-Spinathon also helped raise awareness of SUDEP with a SUDEP Action banner on display. Several people gathered to view the event from the elevated walkways in the office building.

SUDEP Action Fundraising and Operations Manager Rachel Groves said: "As someone who has only ever been to one spinning class and almost fainted afterwards, I am in awe of these people who managed to endure it for up to 4 hours! What an amazing achievement in memory of Edward Vergette. And for Nabarro to agree to provide match funding for the £1500 raised on the day is just fantastic. Thank you so much to all who were involved. What an incredible achievement."

THE CHANGING PICTURE OF GRIEF – TINA LARKWORTHY'S STORY

Tina Larkworthy talks about losing her daughter Kim Marie Larkworthy and her changing picture of grief.



Q: Could you tell us a little bit about your daughter Kim Marie Larkworthy?

Tina: Kim was a beautiful and caring girl, with a great sense of humour. She was very popular and well loved by her many friends and family and also patients and colleagues of our local hospital where she worked as a staff nurse looking after patients following surgery. She was studying for her nursing degree and was working towards being a sister in the hospital.

Kim was 23 years old and she was due to move into her flat with her boyfriend Mike in three weeks. She was at a really

happy time of her life albeit very busy and she had so much to look forward to. Kim was a loving daughter, we would chat about anything and everything and she was always there to lend a hand. We were more like sisters than mother and daughter and close in every way. She is missed more than words can say.

Q: When Kim died so suddenly could you tell us how this impacted on you and your life?

Tina: That Saturday morning when we discovered Kim in the bedroom facedown, not moving, was to be the start of a different life. The old familiar one ended at that point



I was in the living world again, but without the numbing effect of shock, I was faced full on with grief. The pain, both physical and mental knocked me for six and I just wanted to die. I couldn't believe Kim had gone, she was my daughter, my child, she couldn't be dead. I was angry, hurt and depressed. To make some sense of it the family raised money for SUDEP Action, £8000 in total and raised awareness by taking information to our GP, neurologist and MP. Anything to make sense of the terrible loss, pain and emptiness that life was full of.

Q: Comparing the early days when Kim died to today how is life for you now?

Tina: The first year faded into the second and people expect you to be getting on with your life and getting over it. Many would say to me "well you still have another daughter, and a granddaughter to live for", I felt like screaming that they had no idea what my life was like. You are not supposed to lose your child before you die yourself, it's the wrong order, I would walk away fighting back tears. Then through years, three, four and five, the grief gradually changes so subtly you don't realise its happening. The pain of the early days is lessened, and although there were still bad days, I functioned better.

I met others who'd lost children, and we talked constantly about our lost children, we laughed and cried and supported each other, we understood how we alone felt. I spoke to Epilepsy Bereaved (SUDEP Action), they were great support and gradually albeit slowly I started to live more than exist. Through it all, I remember that Kim was a nurse caring for others, and she would have been devastated to see the pain her death has caused her family and friends.

and a new desperate and unknown one began. In the early weeks, there was a lot to do to keep my mind busy, such as the post-mortem, the funeral, and all the things connected with a sudden death. Then the void sets in; people go back to living and their normality. I was existing, barely registering life. I did the mundane things that life is about without realising I was doing them. In the supermarket, I would put Kim's favourite food in the trolley, and at the checkout realise, Kim's dead.

I was in a bubble surrounded by others living their lives as normal but I couldn't be one of them, I was in that bubble, it was like an anaesthetic, I was numb with shock. I couldn't get beyond it, I tried to return to work after four months and we were all made redundant within two weeks when the company closed. I was back in the bubble, but gradually in that first year the anaesthetic began to wear off, and the bubble burst.



So now I try to move forward with the intense love I have for her and the wonderful memories we had together, still in my heart. I am sad there will never be any new memories made, but I try my best each and every day to make her proud of me and live my life as best I can. It would be fitting for her as a nurse to see me carrying on with my life. It's the only choice I have, and I know this different life without my wonderful daughter in it will always be a very challenging one.

Q: Kim died nearly 8 years ago, what would you tell somebody who was newly bereaved about your journey?

Tina: Although Kim died 7 years ago, I would tell newly bereaved people that I am still on that journey that began with her death. It's a roller coaster that constantly goes up and down with highs and lows. The hole in my life that has been caused by losing Kim never changes, it's always there and never a day passes without me thinking about it. I now realise after all this time that she's not coming back, so I have reluctantly

accepted it but I will never like the fact that I lost my dear daughter to SUDEP, something Kim and I had never heard of, after she had only ever had one seizure and her life was finished.

I realise this is how I will live the rest of my life, my daughter will not return, so I must make the best of what I have, a good husband, another daughter Nicola and husband Mark, two lovely grand daughters and a grandson due in August. Kim would want me to carry on and you never stop loving your children, even when they are no longer with you. I pray she's in a better place and watching over me. This thought keeps me living, and each day I take it as it comes.

I don't beat myself up if it isn't a good day; there is no pattern or timescale with grief. We are all individual human beings and our experiences of grief will vary from one to another. With support and love and enough time, we will live through grief and continue our life to the best of our ability but we will never ever forget or stop loving those we lost to epilepsy.

SALLY LAWRENCE'S 3 WEEK FUNDRAISING CAMPAIGN IN MEMORY OF HER SON

Sally Lawrence's three week fundraising and awareness campaign raised an astonishing £600 for SUDEP Action. Sally lost her son Samuel to epilepsy in May 2011.



Sally's Story

Epilepsy came to Sam late in his life, as an adult, and he had only had it a few years. He only lost his driving licence for 10 months, then, when it was controlled, he was able to start driving his beloved Z4 again. Sam had been an associate member of the Leeds region of the Institute of Advanced Motorists many years before.

Before the fundraising presentation at the SUDEP Conference in March, I hadn't really noticed the opportunities and I hadn't particularly felt like it anyway. Plus, I don't want to lose friends by becoming a 'professional fundraiser'(!), but I've been amazed how cathartic this has all felt, and I really feel that I'm the best I've been since my Son Sam died nearly three years ago.

Soon after the SUDEP conference, some of my Mensa friends at a portmeirion weekend in March helped to contribute the first £200 of the £600 I fund-raised in three weeks. At my tentative suggestion they adopted SUDEP Action as the charity for the weekend.

Next was the Sheffield 'Fun' Run! When I read it was okay to walk it I thought - Yeah I can do



that - and I managed to get £240 in sponsorship.

Finally I was very lucky to have one of the large 1kg Easter eggs donated by Thornton's, I raffled it and it helped me to reach the final total of £600.

I have always found it easy, in different situations, to approach or ask people for help, and that was just how I saw this - asking for help, asking for help for SUDEP Action this time. I feel many were giving because I was in a situation that they never want to be in. I have been amazed - and touched - by the response.

I am grateful to everyone who helped to raise £600 for SUDEP Action who have been, and are still, a huge support since I became a bereaved parent. Not only do they give support they also provide information on SUDEP and risk in epilepsy. Three people a day die from epilepsy, think of the loss of each one of those lives and the impact on all their families and friends.

SUDEP Action sponsor award-winning research into prevention of SUDEP and other epilepsy deaths. They capture data through The Epilepsy Deaths Register; all the information about each death is analysed by researchers. And anyone can register epilepsy death information, not just families.

It is exactly one year since the inquest, and in a couple of weeks there will be a memorial service where I will be handing over the cheque to SUDEP Action.

FUNDRAISING UPDATES

We have had a fantastic start to the year with lots coming in from online donations as well as numerous bank transfers and cheques. This year looks set to be our biggest fundraising year so far. We would not be where we are today without the support from fundraisers and so we truly appreciate all your hard work and efforts.

SUDEP Action Bake Off



Inspired by the recent fantastic cake sales for SUDEP Action as well as Great British Bake Off's Howard Middleton's cake sale contribution, this year we are launching the SUDEP Action Bake Off fundraising campaign! Challenge

your friends, family, or colleagues to a bake off. Bake at home without the other bakers (unless you have a very large kitchen to accommodate everyone) and then bring all the bakes together to be judged. Visit our website for recipes and invites.

SUDEP Action Sizzle



The sunshine is back and that means it's time to dust off your barbeques for the second year of the SUDEP Action

Sizzle! For your event pack which includes recipe ideas, invites, and some useful tips to get you started visit our website: www.sudep.org.

Santa Run

Sign up to run in the festive Santa Run in Victoria Park, London this December and raise much needed funds for SUDEP Action. Choose from either a 5 or 10k run. Full costumes (including beards) are provided. Email fundraising@sudep.org for further details.

Memorial Tribute



You can create a personalised memorial to celebrate a loved one's life at www.sudep.org. Friends and family can upload poems, photos, videos, music and memories as well as make donations to SUDEP Action.

SUDEP Action 
Making every epilepsy death count