

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 www.sudep.org or via our support team on our local rate telephone number **0330 088 1220**.

If you have already registered and have indicated you would like to proceed with part 2 of the questionnaire, you will be receiving contact shortly advising you how to provide further information.

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 Sheffield 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

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Making every epilepsy death count

KEEPING IN TOUCH

January 2014

THINKING OF YOU ...

From the Trustees, management and staff, we hope you had a peaceful time during the Christmas period.

Any time of year can be hard when you have lost someone, but for some this time of year can be even more difficult, so please make use of the support line if you would like to talk.

We hope that by reading our news and stories you will know that you are not alone, that others are there for you. We also hope you can gain comfort from knowing that your support of the charity is valuable and appreciated and that by contributing to our work you are making a difference.

In 2014 we will be pushing on with our projects and we hope that our members will be supportive of what we do. As always funding is crucial and even though these are difficult times, you have never let us down. There is so much left to do and we assure you that your money will be spent wisely on the things that you tell us are important to you.

For all your efforts in 2013 - raising funds; raising awareness; attending meetings and supporting others, we thank you, without you we couldn't continue.

Inside, we have tried to highlight a selection of events and stories, together with an update on our research projects.

SUDEP.ORG



JANE HANNA SPEAKS AT FIRST EVER SUDEP ROUNDTABLE IN THE NETHERLANDS

SUDEP Action Chief Executive Jane Hanna OBE spoke at the first Netherlands Epilepsy Roundtable held on 18 November 2013. The meeting was organised by The Epilepsy Institutes of the Netherlands Foundation (SEIN).

Dr Roland Thijs, from the SEIN Institute said this was the first time a joint SUDEP meeting was held for all stakeholders in the Dutch epilepsy community. Attendees included representatives from the neurological societies, Dutch League against Epilepsy, epilepsy centres, charity funds and patient organisations.

Jane said the meeting was the first important step to tackle SUDEP in the Netherlands - bringing together representatives across research, services and support.

At the meeting, Jane talked about the work of SUDEP Action. Attendees consulted Jane about how SUDEP Action tackles epilepsy deaths in the UK. They also asked how SUDEP Action made changes to practice in the UK.

Dr Thijs highlighted the meeting outcomes and commended SUDEP Action's contribution saying: *"The working parties aim to launch new education material by June 2014 and will explore the possibilities to start up a nationwide registry. We are very grateful to Jane Hanna and SUDEP Action for attending this meeting and sharing her great experience in this field."*

Jane commented: *"I was honoured to be invited to share the work of SUDEP Action and our experiences from the UK in addressing epilepsy deaths. The outcome of the workshop is an action plan – to develop a SUDEP awareness campaign; information on SUDEP and critically establish a SUDEP register."*

Jane also met up again with a bereaved mother she had met many years ago. She said: *"It was an emotional moment meeting a mother whose child died suddenly and who has also been working to raise the cause of SUDEP ever since."*

Dr Thijs said that the meeting was well attended and successful.

CARDIFF STUDY ASSESSES PROVISION OF SUDEP INFORMATION TO PARENTS OF CHILDREN WITH EPILEPSY

Researchers in Cardiff have carried out a service evaluation to identify whether parents of children with epilepsy are informed about SUDEP by healthcare professionals.

The study carried out at 3 hospitals in South East Wales found that although 52% of those involved in the study were aware of SUDEP only 16% had been informed by a healthcare professional. It also found that 70% found information about the risk via alternative sources.

The study concluded that all parents of children with epilepsy should receive tailored information about SUDEP as this could help minimise risk factors and help reassure the parents if necessary. It also concluded that providing parents with tailored information could prevent the use of less reliable information sources.

"SUDEP Action who currently campaign for openness endorse the findings of this study, and would urge anyone who is concerned about their child's condition to discuss it with the health professionals involved in their care."

Jane Hanna OBE, SUDEP Action Chief Executive Officer.

The SUDEP Action Call for Openness campaign promotes a common sense approach of informing people at risk of ways they can reduce their risk of SUDEP.

One way is to minimise the risk of seizures with good patient education and medical management. Disclosure can help patients understand the importance of accurately reporting their seizures, taking their medication as prescribed and making lifestyle choices with seizure trigger minimisation in mind. Openness can also help reassure people who may have heard about SUDEP that in fact they have a very positive prognosis.

Sources - Welsh Paediatric Society website, Journal of Neurology, Neurosurgery and Psychiatry website.



RESEARCH UPDATES

The Epilepsy Deaths Register to be taken to the next phase

The Epilepsy Deaths Register will soon be taken to the next phase. The register has received 286 registrations since its launch in March 2013 and has also attracted the support of 24 coroners. This gives us a flying start in developing a vital resource for research into prevention of deaths in the young.

For this next phase of the register, SUDEP Action will be contacting everyone who has registered to ask for more information to be added to the register. The charity would like to appeal to all those who have registered to please respond and help us work to save lives.

Please let us know of any death that you might know of in your area of someone with epilepsy. Please also help us inform people about the register as well as SUDEP Action. Remember we are interested in prevention of all deaths in people with epilepsy whether sudden and unexpected or accident or from injury or other causes.

SUDEP Action will be meeting with UK research teams in January 2014 to plan the next steps. There is no national funding for register development in the UK, but we are now in a great position to seek funding with researchers keen to work with the register.

Cornwall Epilepsy Life Project



SUDEP Action will be taking work forward with coroners in the South-West following the completion of the first phase of the Cornwall Epilepsy Life Project funded by K'ts Fund. The research into epilepsy deaths in Cornwall over the last 9 years was made possible by K'ts Fund. The next step will be to complete research with patients attending accident and emergency and doing our best to use the research to influence the local NHS to improve epilepsy services in the area. We will soon be starting work with the Plymouth coroner to help us move towards our goal of developing standardised reporting by coroners across the UK.

Meanwhile in the USA

The US has made funding available for research into SUDEP and a registry of deaths in the young has been launched across 17 US States aiming to get vital information from those involved in the investigation of sudden deaths. Funded by the National Institutes of Health and the Centers for Disease Control and Prevention, the registry will collect comprehensive information on sudden unexpected death in the young up to the age of 24.

The register will become a resource for researchers. Those responsible for investigating sudden deaths in the US are being invited to apply to work with the register.

Source - Epilepsy Research UK

SUDEP Action 
Making every epilepsy death count



REPORT CALLS FOR EPILEPSY PASSPORT TO REDUCE DEATHS AND IMPROVE CARE FOR CHILDREN

The Child Health Reviews-UK report 2013 has recommended that every child with epilepsy has an epilepsy passport to reduce deaths and help improve communication between health professionals involved with their care.

The report calls for an epilepsy passport which clearly identifies one lead clinician to coordinate care; names the other professionals involved; includes the medications and sets out clear emergency plans. It also highlights that it is important that parents receive on-going support and care where a child has died.

The research found that there is need for improved care for children and young people with epilepsy. The report which was launched on 23 September 2013 found that nearly a quarter of deaths in children with epilepsy were potentially avoidable. It calls for simple measures to reduce the likelihood of future deaths and improve care.

The report was commissioned by Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme: Child Health Reviews-UK. The study looked at data from a total of 162 children with epilepsies including 61 in-depth case reviews of mortality and children in intensive care. The review led by the Royal College of Paediatrics and Child Health looked at mortality and morbidity in children and young people with epilepsy.

The study found that 85% of the children who were in intensive care or who died had complex conditions; 39% experienced seizures at least once a week and 49% had attended hospital because of prolonged seizures in the previous year. Also, 43% had more than three health professionals involved in their care.

The study found that there have been substantial improvements in the involvement of specialists in the care of these children, in comparison with the last national review of epilepsy care. The clinical care received by children and young people with epilepsy who have died has not been reviewed since the 2002 National Sentinel Clinical Audit of Epilepsy-Related Death which found that 59 % of child deaths were potentially avoidable. The latest report has found that overall care was good, but that simple interventions could improve care and reduce the risk of future deaths.

The report has highlighted problems of communication between professionals and between professionals and parents as well as lack of recorded access to an epilepsy specialist nurse in nearly half of the children. This further highlights the need for clear information and advice to parents on key warning signs.

Approximately one in 200 children (60,000) in the UK has a form of epilepsy, making it the most common chronic childhood neurological condition. Furthermore, about 40 to 80 children die from the condition each year in the UK. In recent years there has been a renewed focus on improving care for people with epilepsy. This is partially in response to high-profile cases of epilepsy deaths, with efforts being made to address variations in service provision, high rates of misdiagnosis and mismanagement.



FORMER EPILEPSY SOCIETY CHIEF JOINS SUDEP ACTION AS TRUSTEE

SUDEP Action is pleased to announce that Graham Faulkner has joined the charity as a Trustee. Graham is a qualified social worker by profession. He has 40 years' experience in the charitable, private and local government sectors spending the last 30 of those in senior positions. He was Chief Executive of Epilepsy Society for 13 years, retiring in September 2013. Prior to that he was General Secretary and Deputy Chief Executive with the Leonard Cheshire Foundation (1992-1998) and Chief Executive of Rehab UK (1999-2000), a charity that specialises in vocational rehabilitation for people with disabilities.

In his earlier career Graham was involved in establishing a private company, Retirement Security Ltd that provides very sheltered housing in the private sector, where he was a main Board director.

Graham was a Governor of the UCLH NHS Foundation Trust in London (2004 – 2011), and now chairs a private company, Queen Square Enterprises that undertakes MRI scans and gift aids its profits to the NHS. He also chairs Neurological Commissioning

Jane Hanna OBE, Chief Executive, SUDEP Action, commented:

"SUDEP Action welcomes this report. Bereaved parents will be pleased to see that there have been improvements in the care of children with epilepsy since the last national report into epilepsy deaths in 2002. It remains of great concern, however, that a quarter of deaths were still considered potentially avoidable. Simple measures, not rocket science, appears to be at the heart of what is needed to improve care and we call for the epilepsy passport to be adopted as a matter of urgency."

**Source - Child Health Reviews
- UK website**

Support (NCS), a company established by the MS Society, Parkinson's UK and the Motor Neurone Disease Association to improve commissioning of health services for people with long term neurological conditions. He is also a Trustee of the Roald Dahl Marvellous Children's Charity and the Daisy Garland epilepsy charity.

Graham was appointed as Chairman of the Board of St Loye's Foundation in 2013. St Loye's Foundation is a charity based in Exeter that provides a range of services to promote the independence of people with disabilities and mental health problems.

SUDEP Action Chair of Trustees Professor Stephen Brown commented on Graham's appointment saying: *"On behalf of all the Trustees and staff I am delighted to welcome Graham to the board of Sudep Action. His wide experience both in the voluntary sector and with the NHS in the fields of epilepsy and neurological conditions will of course make him invaluable to us, but in addition he brings personal attributes of commitment, teamwork and shared values."*

SUDEP ACTION CHARITY MEETINGS 2013

Since the last E-News, SUDEP Action has held three regional meetings. In September we were in Exeter and in November we were in Preston and in London for our Annual General Meeting (AGM).

The meetings this year have taken the same theme (with the exception of the AGM) and have included workshops which have provided insight into what is helpful to the bereaved after a death. The outcomes will be compared with the service we currently offer and will help to shape the services we provide in the future. The meetings have been well attended with the numbers larger than previous years.

The AGM which took place in London on 16 November was also well attended by members, staff and trustees. The meeting was led by SUDEP Action Chair of Trustees Professor Stephen Brown and Acting Chief Executive Karen Osland. SUDEP Action Chief Executive Jane Hanna gave an update of all SUDEP Action projects. Other speakers included SUDEP Action Trustee Guy Neely, Fundraising and Operations Manager Rachel Groves as well as Policy and Participation Officer Nathan Sparkes. Attendees heard about charity activities to date; the reasons behind the change of name and how this has increased awareness of our services.

The meeting highlighted the importance of our member involvement and how much we appreciated those who despite having gone through the worst imaginable loss still find strength to work tirelessly to make change. Attendees took part in group discussions, providing vital information about the charities services and work.

The meeting was well attended with some extra people turning up and received really positive feedback, (despite the cramped conditions!). It was great to see everyone being so supportive of the charity and of each other.

Attendees from all SUDEP Action meetings provided important feedback about the meetings and the services provided by the charity. Some said they found the meetings very useful because they met others who were in similar situations to theirs. They felt listening to other people's stories helped them. Attendees said they found the meetings interesting and informative.



BEREAVED PARENTS HIGHLIGHT SUDEP TO THE NEXT GENERATION OF EPILEPSY MEDICS

Bereaved parents Dianna and Gerard Marchand spoke at the ILAE UK Chapter Medical Students/FY1 Epilepsy Teaching Weekend. Their daughter Rachel died of Sudden Unexpected Death in Epilepsy (SUDEP) at the age of 20 in 2009. Here is their story:

Rachel had enjoyed a trouble-free childhood, apart from eczema. She loved facing new challenges, and lived every day to the full. She was academically bright, gaining four grade A's at A level, and playing violin and saxophone to grade eight standard. Rachel was also a competent pianist, but she also loved to party and was fun to be with. Her friends commented on her energy and enthusiasm, and her ability to bring out the best in people. She was kind and caring and a loyal friend.

Rachel's first seizure occurred on a tube train in London. She subsequently went through a whole range of investigative procedures, and there was much debate amongst professionals as to whether her seizures were epileptic in nature. They occurred infrequently, and she never knew beforehand, when one was going to happen. Her consultant told her of possible ways to minimise her risk of attacks, but SUDEP was a word we never heard.

After her first year at university, she started to experience seizures in her sleep. At the next Christmas, she had several in close succession, whilst travelling home. She was hospitalised overnight, and put on medication. From that point she was seizure free for the seven and a half months until her death. She was noticeably happier and more relaxed when she came home at Easter and summer, feeling in control of her body once more.

Rachel spent a memorable late evening chatting to us on August 11th. She was happy and animated, having met up with friends

from school. We had just returned from holiday and enjoyed exchanging news. Little did we know that these were to be her last conversations with us.

I found Rachel dead in her bed the next morning. It was just two and a half years since her first seizure.

Rachel was always determined to carry on with life as normal, and she refused to let her medical condition restrict her in any way. She packed more into her twenty years than many people do in a much longer lifetime. We feel proud and privileged to have been her parents, and she has inspired us to try to move forward positively in the roller coaster of life, whilst not being brave enough to face the real roller coasters she loved so much.

We cannot do anything to bring Rachel back, but we can support SUDEP Action and hope that other young lives might be saved by better information and awareness.

Speaking to Neurologists

On Saturday 13 July 2013 Gerard and I went to speak at a weekend conference on Epilepsy at the University of Birmingham. The conference was entitled "ILAE UK Chapter Medical Students/FY1 Epilepsy Teaching Weekend".

Various Epilepsy specialists including Dr Manny Bagary, Consultant Neuropsychiatrist in Birmingham who spoke at the SUDEP Action Dunchurch meeting in April 2013, gave lectures.

We were paired with Lynn Greenhill, a consultant nurse specialist in epilepsy, from Birmingham. Lynn was very helpful and supportive. We also met Juliet Solomon, who was co-ordinating the event, and who was also very warm and encouraging.

Our presentation was part of small group sessions in the afternoon, with 10 to 15 students in each, as it was felt this would be the best environment for questions to be raised. The downside to this was having to give the same speech six times, so I felt it was important to write everything down. Lynn gave a brief PowerPoint presentation giving the facts about SUDEP. She asked students whether or not they felt it was important to tell patients about SUDEP and at what point in their treatment programme. I then spoke, and Gerard and I answered the students' questions.

EIGHT YEAR OLD IN 21 MILE SWIM FOR SUDEP CHALLENGE!

Eight year old Jessica Soulsby took on the challenge to raise awareness of SUDEP and much needed funds for SUDEP Action in memory of her friend Charlie Burns. Charlie died of Sudden Unexpected Death in Epilepsy (SUDEP) in October 2011. He was only 10 years old.

Jessica decided to swim 21 miles in a 25 metre swimming pool, equivalent to the distance from Dover to Calais, France. She is aiming to raise a total of £1344 to match the 1344 lengths of the swim. She began her challenge in August 2013 and has been swimming 4 days a week at her local pool, finishing the challenge on the 15 December 2013.

In an interview with local radio Spire FM, Jessica talked about Charlie saying: "he was nice; he wore a lovely watch that we now take to swimming with us with his dad. And because it's water proof, when we swim, it goes in his dad's pocket". She added that she was enjoying her swim.

Charlie's family commented: "Jessica set herself this challenge in order to raise awareness of epilepsy and to highlight to

The students seemed moved by what we shared, and asked really pertinent questions. They were asked again about telling patients, and most agreed that, in the majority of cases, patients should be given the information.

We were really made to feel that everyone appreciated our input. Dr Bagary thanked us at the end, and Juliet emailed me on Monday with some very positive feedback from the students. We felt really glad to have done this-even though it was difficult at times, it is important to us to try to bring some good from the tragedy of losing our daughter to SUDEP.

people that it can and does take lives. Despite a personal setback, when her granddad sadly passed away, Jessica still continued in her challenge. She really is an inspiration and should be extremely proud of her achievement, we certainly are."

Jessica completed her challenge at the 5 Rivers Leisure Centre in Salisbury where she was supported by friends and family.

SUDEP Action Fundraising and Operations Manager Rachel Groves was there to support her on the final day. She applauded Jessica's inspiring efforts saying: "What Jessica has done in memory of her friend Charlie is really awe inspiring. What a tribute to Charlie. It reminds me of why our work is so important. Next year we have so much we want to achieve: encouraging doctors to be open with their patients about SUDEP, encouraging more people to sign up for the deaths register and new research into SUDEP. We need money to do all this, which is why we are so grateful to youngsters like Jessica, it just shows that whatever your age you can find ways to help."

HOLLIE CRADDUCK'S IRONMAN CHAMPIONSHIP BID IN MEMORY OF HER NIECE ROSIE

Hollie Craddock became an Ironman in Wales on 8 September 2013, achieving her lifetime dream. She had set out to become an Ironman - endurance triathlon consisting of a 2.4 mile swim, 112 mile bike and a 26.2 mile run which has to be completed in 17 hours. It is said to be the toughest course in the world and Hollie completed it in an amazing 14 hours 5 minutes, exceeding her own expectations.

However, Hollie discovered after crossing the finish line that her 19 year old niece Rosie Carter who had travelled to Tenby, Wales to support her, had died in her sleep. Talking about her experience that day Hollie said: *"With my euphoria came tragedy. My relief and pride was swept with grief."* Hollie describes the day as the best and worst day of her life.

Now Hollie, 22, is aiming to compete in the Ironman World Championship in Kona, Hawaii to raise money for SUDEP Action in memory of her niece Rosie.

Hollie says since then she made it her promise to Rosie to get to the World Championships in Kona, Hawaii in 2015. Hollie says she will stop at nothing until she achieves the championship in Rosie's honour. Hollie stated this would obviously involve a rigorous and very strict training and nutrition plan.

Hollie says Rosie was more like a sister to her. She revealed that she would focus her attention on her next challenge to Kona to overcome her grief and do Rosie proud.

Hollie talked about her work for SUDEP Action saying: *"I believe that raising money for a cause so close to my heart will help the charity as well as give me the much needed motivational boost. This charity does invaluable research into Epilepsy related deaths as well as offer much*

needed support to the families and friends affected by such a tragic death (people like me). If anyone reads this and is kind enough to donate I would be so incredibly grateful - as you will all know it means so much to me and my family as this charity is so close to our hearts."

Hollie has received some good media coverage for her work in her local papers such as the Daily Echo.

SUDEP Action Acting Chief Executive Karen Osland commenting on Hollie's inspiring efforts saying: *"Hollie and her family must be so devastated by the sudden death of her niece Rosie, sadly they are not alone as there are at least 3 epilepsy related deaths each day in the UK. As a small charity we rely on the generosity of people who push themselves to the limit to raise awareness and funds for us to work towards reducing these unnecessary deaths. We wish Hollie all the very best and hope she will find the strength and determination needed to reach her new lifetime goal and qualify for Hawaii."*

If you would like to keep track of Hollie's training, follow her blog at;
holliesroadtoironman.blogspot.co.uk



Hollie Craddock

FINDING SUPPORT - LYNN TATNELL A BEREAVED MOTHER TELLS HER STORY

I had my beautiful twins when I was 32 and was lucky enough to have a boy, James and a girl, Joanna. Joanna was beautiful and a strong, independent character who loved life, people and travelling. She especially loved coming home to the comfort of her own cosy space fortified by love and a little pampering to recharge her batteries.

Joanna had her first grand mal seizure when she was 19. The specialist who saw her would not diagnose her with epilepsy although she was treated with epilepsy drugs. She continued to have seizures and complex partial seizures until she died of Sudden Unexpected Death in Epilepsy (SUDEP) on 27 October 2008. She was only 24, I believe she would be alive today if she had received a proper diagnosis.

After the shocking loss I spent hours surfing the net desperate for help and support. I needed to understand my position after this awful death. I am not sure how I heard about Epilepsy Bereaved (SUDEP Action) but after finding them, it all fell into place, the help, the support, the love.

I contacted the support team soon after my loss because I also had to support my son and my other daughter. I was desperate for help and support.



Joanna Tatnell

SUDEP Action helped me immensely by inviting me to their rural meetings. I also attended their meetings at Dunchurch where I received help and support. Their support line has really been my Saviour. And still, every few months I get such rewarding phone support that really lift my spirits and moral. They remind me that I am not alone in this most shocking bereavement from SUDEP.

I had no doubts about contacting the support team whatsoever. When I contacted them, it was like a family waiting to share my disaster. They were there to listen and to help me follow a positive path which was not so lonely. I have been using the SUDEP Action bereavement support line for five years now and I would describe it as my life line, my friend.

To me the SUDEP Action support line is like the Mum, Sister or partner I do not have. They provide me with the warmth of a supportive voice and a feeling of never being alone again. I would not hesitate to recommend this service to anyone. This service is professional, compassionate and totally confidential; it is a life line, a shelter in the storm. Tracy phones me each month or so to chat and check up on me to see if I am okay. This also helps to keep me in the loop with what is happening in the charity.



James and Lynn Tatnell



SUDEP ACTION TAKES PART IN LONDON SANTA RUN FOR THE FIRST TIME

SUDEP Action entered the biggest Santa run for the first time ever on Sunday 8 December 2013. Six charity supporters dressed up as Santa and completed the full 10K run for the charity in Victoria Park, London.

Nathan Sparks, Policy and participation Officer and Katie Vale, Fundraising and Administration Support Assistant at SUDEP Action were on the side-lines to cheer on the runners. Runners included siblings Adam Jeffreys, Charmaine Jeffreys, Naomi Jeffreys, Roxanne Jeffreys and Lisa Jeffreys who all ran in memory of their brother Aaron Jeffreys. Stacey Biddle ran in memory of her uncle Martin Doran.

The Jeffrey siblings all commented on the race. Adam said it was an amazing race, and it made him feel like he had achieved a lot. Charmaine added that it was an amazing experience and that she cannot wait to do it again. Naomi pointed out that she was very proud to have run in memory of her brother Aaron and that it was a great experience. Lisa said she was very proud of herself for running in memory of her brother and that she felt really good. Roxanne commented that: *"It was a great opportunity to raise awareness of SUDEP. An enjoyable race and after, you feel you have achieved a lot."*

Stacey Biddle explained her reason for taking part in the race saying: *"When I found out SUDEP Action were taking part in the Santa Run I had to get involved. It felt really great to be actively doing something for a charity so close to my heart. I ran in memory of my Uncle Martin and I know he would have had a great laugh at me in that Santa costume!"*

Another supporter Jon Plater had planned to run but was sadly injured. Jon still managed to raise money for the charity in memory of Charlie Burns

Some of the runners wore purple Santa hats made by SUDEP Action supporter Lucy Bidgood.

SUDEP Action Fundraising Manager Rachel Groves thanked the runners saying: *"We really appreciate everyone's effort raising much needed funds for the charity. We really need every penny to ensure we are able to research the causes of these tragic epilepsy deaths."*

The runners met with Nathan and Katie for coffee and hot chocolate after the event.

LUUWHC RAISE AWARENESS IN MEMORY OF EMILY SUMARIA

The Leeds University Union Women's Hockey Club has continued to raise awareness and funds for SUDEP Action in memory of their friend Emily Sumaria. Emily was a student at Leeds University when she died of SUDEP in December 2012 at the age of 19.

In the past, the LUUWHC has raised more than £6000 for SUDEP Action through various activities and events held during the year.

Recently, the LUUWHC raised about £325 for SUDEP Action through the MoRun. On 8 December 2013, they held a street collection as well as a Race Night, raising £1000 for the charity.

The club has lined up a number of fundraising activities, a statement on their website reads: *"This 2013/14 season, our goal is to raise £10,000 for Epilepsy Bereaved (SUDEP Action) and other charities. Our challenges will send club members back to the peaks and the pool, but also to the Yorkshire Dales for the Great Yorkshire Bike Ride and on a raid to a nearby city to raise money for a day in full fancy dress. Our fundraising social calendar promises to be*

bigger and better than ever, with nights ranging from a pub quiz to a fairground-style fun day at our home ground, Weetwood."

SUDEP Action would like to thank the LUUWHC for all their hard work raising awareness and funds for the charity. Community Secretary Issy Croneen has been busy organising the fundraising and awareness raising activities. Other organisers who helped raise the £6000 include previous Community Secretary Charlotte Sansome, current club captain Hannah Crane and former club captain, Shelley Stromdale.



THE HALLIDAYS RUN TWO MARATHONS IN MEMORY OF VICTORIA HANNAH

Elizabeth and Lloyd Hannah thanked their friends, the Hallidays for running two marathons in memory of their daughter saying: *"Our dear friends Stephen and Dianne Halliday have this year completed the Barcelona and Copenhagen half marathons, and with their son Paul, recently completed the Cumbria Total Warrior Challenge in memory of our daughter Victoria."*

remarkable feat saying: *"One Half-Marathon from Stephen and Diane Halliday would have been a great achievement, but two is remarkable! On top of these, they also conquered the Cumbria Total Warrior Challenge with their son Paul. Not only do these feats show incredible effort, but they have also helped raise much-needed funds to support our work"*.

Nathan Sparkes, SUDEP Action Policy and Participation Officer commented on the

Nathan thanked Elizabeth and Lloyd Hannah for their continued support to the charity.

SOMETIMES THE FIRST CALL IS THE HARDEST ONE ...

The Wall

*Every day I faced a wall, a wall that was too high for me to get over.
A wall that was too wide for me to walk around.
Every day just me and this wall, in time this wall became a barrier.*

A barrier I could hide behind, for you see you can find comfort in grief, for in grief is where you should be. So every day I faced the wall.

*A phone number - a day, a week, a month – until I can't face that wall and yet all I can say is that I am sorry for ringing and I put the phone down, and the wall just got bigger.
But, within 5 minutes my phone rang "if you need to talk, you can talk to me" - a stranger at the end of my phone.*

Stranger be a friend for I need a friend, I needed to talk and within that voice of a stranger was a friend, for she helped me look around that wall.

So to you who supported me, may I just say thank you, and to you all at Sudep Action a thank you from us that need you.

Written by a bereaved father, after the death of his daughter.

FUNDRAISING UPDATES

New SUDEP Action Fundraising Blog

Thank you to all our fundraisers! We now have a monthly fundraising blog on our website where we celebrate and thank everyone who has fundraised for us each month. You can visit our blog on our website www.sudep.org by clicking 'Get Involved'. The monthly blog entries are listed in the left panel.

SUDEP Action Winter Warmer

Have you heard about the SUDEP Action Winter Warmer? This is a fundraising evening party pack, filled with great ideas for raising funds for the charity at home this winter time. Email us on fundraising@sudep.org or call us on **01235 772850** if you would like a copy.



LUUCWH fundraising

SUDEP Action Ambassador Scheme

We are training new Ambassadors this spring. If you have some time on your hands and are looking for ways to support our work, becoming a SUDEP Action Ambassador may be one of the best ways you can help us. Our Ambassadors receive comprehensive training on tasks and in representing SUDEP Action.

We support our Ambassadors in all they do, providing materials and briefings for events and meetings as required. As an Ambassador we ask that you are two years beyond your bereavement and that you can give around one day a month. Being an Ambassador is both a rewarding role and immensely beneficial to the charity. If you are interested or would like to find out more, you can call us on 01235 772850 or email us at fundraising@sudep.org.

New SUDEP Action Fundraising Booklet

We now have a new fundraising booklet full of ideas to inspire you to help raise much-needed funds for SUDEP Action!

Give us a ring on 01235 772850 to order your copy.

Legacies

Have you thought about leaving a gift in your will to SUDEP Action? We know that for many charities, this can be a significant source of income and the trustees at SUDEP Action are keen for us to encourage supporters down this route. If you have left us a gift in your will, please do let us know by emailing rachel.groves@sudep.org.

This will be treated in the strictest confidence. For further information on making a will and leaving a gift to SUDEP Action, visit our 'I want to leave a legacy' page under the 'Get Involved' section of our website.

WEBSITE FEATURES AND SOCIAL MEDIA

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

CHANGES

Roger Ambler is our new Office Manager.



His background is in public administration and charity finance. He is a part-qualified accountant and holds a Master's degree from Cambridge University. He is very happy to join the team at what could be a pivotal moment in the charity's history.

DATES FOR YOUR DIARY

- **10th May 2014** - Memorial Service, St James's Church, 197 Piccadilly, London W1J 9LL
- **15th & 16th March 2014** - National Weekend. Dunchurch Park Hotel, Nr Rugby