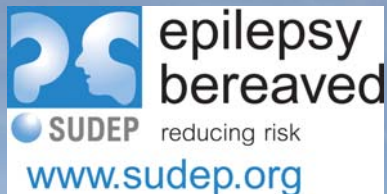


# Epitome



Registered Charity No. 1050459

The magazine for people bereaved by epilepsy  
November 2009, issue 27

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- Letter campaign update
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- EB members join Living Art Project
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Photograph by Chris Southwell  
of Bradninch, Devon



## **Epilepsy Bereaved**

**We are the only charity dedicated to research and prevention of SUDEP and other epilepsy-related deaths and the support and enablement of people affected by these deaths**

### **What we do**

**Support people affected by SUDEP and other epilepsy deaths  
Reduce risks in people with epilepsy by information and education about SUDEP**

**Campaign for improvements to epilepsy services  
Campaign for improvements to the investigation of SUDEP and other epilepsy deaths**

**Conduct and fund research into SUDEP and other epilepsy deaths**

**Enable people affected by SUDEP to be involved in the cause**

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**Front cover photo shows Francis Ash running in memory of her son Nigel—see story on page 30**

Please send any photos of what you do to support the charity. If these can be emailed as .jpeg files, that is helpful – otherwise please send a hard copy that we can scan in.

Please send any letters, poems or any other contributions to the PO Box address or email to the office at [information@epilepsybereaved.org.uk](mailto:information@epilepsybereaved.org.uk)

*Due to magazine space constraints we do have to edit contributions submitted. We try to do this sensitively in order to retain the overall message of the story.*

## Epilepsy nurse Jo Pearson explains new service standard

**Jo Pearson, a Clinical Nurse Specialist in Epilepsy at Sheffield Teaching Hospital's NHS Foundation Trust, explains how she is developing a Standard of Service after a death of a person with epilepsy:**

*"I have been an epilepsy specialist nurse working with adults for almost five years and have closely followed the work of Epilepsy Bereaved during much of that time.*

*"My role is varied but I feel one of the most important aspects is to offer support and advice to people regarding their diagnosis of epilepsy. I work hard to empower and support my patients and those closest to them, with regard to any aspect of living with epilepsy.*

*"Epilepsy is a condition often not openly discussed. There are many reasons why this may be the case but I would hope ignorance will never be one. Whilst fully respecting the individual's right to deal with their epilepsy and seizures in their own way, I see the sharing of information as a way of enabling people to make informed and positive choices.*

*"With this in mind I strongly believe all people have the right to be told of the risks of SUDEP/epilepsy-related death, associated with uncontrolled seizures. Clearly*

*there is a need for sensitivity as to when and how to hold such discussions but I cannot think of a single reason why issues would not be discussed.*

*"Unfortunately, many epilepsy-related deaths are not preventable. It is an inevitable part of the nurse's job to deal with some of the aftermath of such a tragedy.*

*"Following the loss of a loved one many families and carers seek information from the epilepsy nursing service in order to try to comprehend what has happened.*

*"Whilst nothing can prevent the immediate shock and disbelief of a sudden death, a structured and professional approach from the epilepsy specialist nurse may contribute in some small part to the beginning of the grieving process.*

*"If anything can be done to alleviate some of the stress associated with the loss, every effort should be made to make that happen.*

*"With the NICE guidelines making recommendations as to how an epilepsy-related death should be dealt with, I felt it appropriate to develop a local standard within the service where I work. As well as ensuring all bereaved parties experience a consistently high standard of support, this tool can be used to*

*provide guidance to our nurses and hopefully reassurance that everything possible was done to ease the distress of those affected.*

*“The standard is simple and closely mirrors the NICE recommendations. It is based primarily on ensuring bereaved parties are given the correct information and support, and advised where to go for specialised bereavement support. The other side of this is to ensure professionals are educated about availability of appropriate charities such as EB and their valuable work in research.*

*“Ultimately, I would hope the standard may one day become unnecessary as epilepsy-related deaths reduce and maybe even cease altogether.”*

*“Most premature deaths among people with epilepsy are directly related to the epilepsy itself. Every year in the UK about 1,000 people die because of epilepsy. SUDEP is the principal cause of death in people with chronic epilepsy and has been estimated to account for about 500 deaths each year.” (Hanna et al)*

*“Where families and/or carers have been affected by SUDEP, healthcare professionals should contact families and/or carers to offer their condolences, invite them to discuss the death and offer referral to bereavement counselling and a SUDEP support group.” (NICE, 2004, p11)*

## **Standard for supporting families/carers after an epilepsy-related death Sheffield Epilepsy Liaison Service**

Clinical Nurse Specialist of patient should:

- Ring to express condolences
- Offer opportunity to discuss bereavement
- Provide verbal and written contact details for Epilepsy Bereaved and explain the advice they can provide in answering questions, providing information about the post mortem and inquest process and supporting them through their loss
- Send out pack for health care professionals designed by Epilepsy Bereaved to relevant GP surgery
- Ensure Consultant Neurologist is made aware
- Liaise with coroner to establish actual stated cause of death
- Inform hospital clerk who deals with deceased notifications to ensure no future appointment correspondence is sent from hospital – if possible, provide date, place and cause of death
- Depending on level of support previously offered by ELS, it may be that CNS wishes to attend funeral (at invitation of family/carers)

## Letter campaign update

A big THANK YOU to all who responded to our request to contact your local MP earlier in the year.

This coincided with National Epilepsy Week in May but the objectives are longer term. The aim is to build strong relationships with MPs to gain their support over the months ahead especially in the run-up to the King's/Epilepsy Bereaved research bid being submitted.

Many members have corresponded over the past few years with their elected politicians and, as a result of your recent efforts, we have gained additional supporters in Parliament.

The four key areas we are campaigning on are:

### **1/ Standards for investigation of death**

Epilepsy has been highlighted as an area where standards will be set.

With your help we have raised awareness of the experiences of people affected by an epilepsy-related death.

The charity will work to ensure policy-makers, coroners and pathologists do not lose sight of the commitment to uphold standards when investigating a death from epilepsy.

### **2/ Signposting to Epilepsy Bereaved**

Support for the bereaved is being debated during the course of the Coroners & Death Certification Bill and there will be some improvements made in the form of a Charter for the Bereaved.

The charity strongly feels that much more could be done to enable bereaved relatives to access specialised information and support as soon as possible following the death of a loved one.

A new guide for coroners and inquests is being developed and included in the reforms will be the establishment of the post of Chief Coroner.

He/she will provide coroners with an up-to-date list of support organisations for the newly bereaved to access.

Epilepsy Bereaved welcomes this and will contribute to development of the register.

### **3/ Research**

Seven years on from the National Audit of Epilepsy Related Deaths, our understanding of sudden death in epilepsy is greater, but we still need to reduce the number of such deaths. To do this, we must find out why people are dying.

We have called on the government to support research into both the cause and prevention of SUDEP.

### **4/ Communication of risk**

The communicating of risk is under constant professional debate and is inconsistent.

Much of the inconsistency is due to the interpretation of guidelines. However, evidence suggests that by communicating the degree of risk to both newly diagnosed and existing people with epilepsy, risk factors will be reduced.

People who are diagnosed with, for example, diabetes or heart problems, are made aware of the risk of death. We feel epilepsy should also be in this

category and dealt with in the same way.

Work is continuing to improve the communication of risk to people with epilepsy. The charity will be focusing our efforts on the Strategic Health Authorities and Local Health Boards to ensure they are aware of the NICE guidelines on providing information to people with epilepsy about the risks associated with the condition.

From the replies received, and level of support given, it is clear sudden death in epilepsy has a high profile amongst many politicians.

Our next task is to keep up the pressure, to ensure changes are made, to: improve the standards of investigating epilepsy-related deaths, communicate the risk of SUDEP to people with epilepsy, improve the signposting of people bereaved by epilepsy to access support and prevent avoidable deaths from epilepsy.

None of this would be possible without your efforts to raise awareness, so thank you again.

## Bereavement support

**Core to the aims of the charity is providing support and information to those who have experienced an epilepsy-related death.**

**While many of these deaths are SUDEP almost half die from other epilepsy-related causes such as: status epilepticus (prolonged or repeated seizures), suicide or accidents (including drowning following a seizure).**

**Below Vanessa Davidson tells the story of her daughter, Rosa.**

My beautiful daughter Rosa died aged 19 on 22nd July 2008.

She had suffered from epilepsy since the age of five, and, although it had never been totally controlled, she managed to live a full and happy life.

She was particularly optimistic at the time of her death, as she was doing well at university and about to move into a student flat with her boyfriend and some friends.



**Rosa Davidson**

I think she was the happiest she had ever been in her short life.

Her favourite occupation had always been swimming, and in the

summer holidays she would often slope off to the pool at the bottom of the garden to do her lengths.

She hated us supervising her all the time, so we would try to check up on her, pretending to pick up towels or doing some gardening around the pool.

The morning she died she must have had a seizure in the first minute she entered the pool (or maybe at the side of the pool and fell in).

My husband saw her walk down to the pool, followed her two minutes later, and saw her lying at the bottom, in the shallow end.

She was airlifted to our local hospital but they failed to revive her.

I miss her and mourn for her every single day.

The person on the support line that I spoke to could not have been kinder, gentler or more sympathetic. She persevered in trying to follow up our conversations when

I could not bear to answer the telephone.

**I would urge anyone suffering from the terrible loss of bereavement to reach out to Epilepsy Bereaved for help and support.**

## Need to talk?

The sudden death of a loved one can have a devastating effect on the family.

Sharing the way you feel about what has happened can be helpful in understanding your emotions.

Many people worry about upsetting others and feel unable to share their feelings with close family as they are grieving too.

We have a number of volunteers who have experienced the loss of a loved one.

They may have experienced some of the feelings that you are feeling right now and, although no two people grieve the same

way, it may help you to speak to someone who understands a little about the journey you are on.

Please contact us to arrange for one of our volunteers to call you:

Telephone 01235 772852

or e-mail

**karen.osland@**

**epilepsybereaved.org.uk**

**If you would like to become one of our support volunteers – please contact us for an informal chat.**

## Sharing your experience

Our public work involves sharing some of your personal stories of losing a loved one to epilepsy. We appreciate that speaking about your loss publicly can be very difficult.

Many newly bereaved people find out about Epilepsy Bereaved from press reports of your involvement in the charity and efforts to raise awareness.

Knowing others share the same experience makes a huge difference to those who are isolated following the death of a loved one.

We make every effort to publicise the work of the charity and the support we are able to give to bereaved families, friends and carers. However, we are not able to offer our support as promptly to everyone who may need us.

Local newspapers often carry reports about deaths from epilepsy, usually from the coroner's inquest. Epilepsy Bereaved staff are not always in a position to respond to each of these as timely as we would like and would therefore appreciate your help.

If you see such a report in your local newspaper, contact our Education & Awareness Manager, Sally (details on back page) who will help you to write a short letter to the editor, highlighting that you

have lost a loved one through epilepsy and that there is support available from Epilepsy Bereaved.

Be sure to include that they can contact us on 01235 772852 or by email at **contact@epilepsybereaved.org.uk**

Also include our web address: **www.sudep.org**

Please bear in mind such letters are generally very brief. Letters pages are restricted in space and the editor reserves the right to shorten and edit as he/she sees fit.

It would also be helpful for us to know that you have sent a letter and if it was published.

We are currently collating stories about your experiences of losing a loved one to epilepsy. To protect your identity we are only using first names and we have avoided using any details about where the person lived. We plan to upload the stories onto our new website in order to reduce the feelings of isolation for people newly bereaved after a sudden death from epilepsy.

Thank you to those of you who have already shared your story recently with Sally. If you would like to find out more about sharing your story with EB please contact Sally for more information.

## My radio broadcast

by Margaret Birch (Active Member from Nottingham)

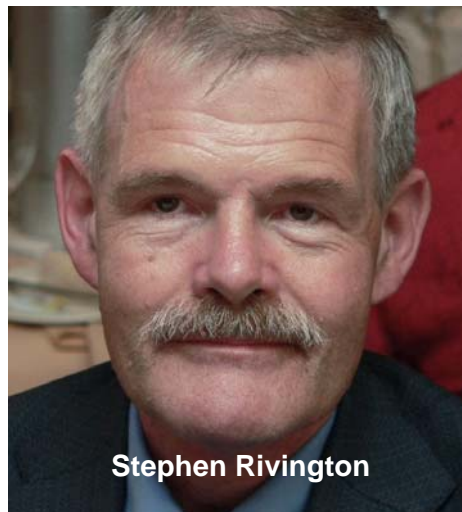
My invitation to speak on BBC Radio Nottingham about the death from epilepsy of my brother Stephen in May 2007 came out of the blue one Monday morning in July this year.

I thought carefully about whether I could cope on air with the inevitable re-visiting of one of the most painful experiences of my life. Having agreed to go ahead, Epilepsy Bereaved gave me every encouragement and e-mailed material I might need.

Local stations are usually keen to share the experiences of local people and handle such broadcasts very sensitively. Certainly that was the case in Nottingham. John Holmes, the presenter, couldn't have been more understanding, assuring me I didn't need to raise issues I wished to keep private and that at all times I remained in control of what was said.

During the programme I touched on the fact not everyone was aware epilepsy could kill, though I and my family had known this since Stephen was a small boy. I also urged people with epilepsy to let family, friends and/or carers know so they would be well supported.

The most difficult part of the broadcast emotionally was talking about Stephen's death but, at a



break in the programme, John assured me he was keeping a careful eye on how I was coping and would break in if it got too hard.

In the event, I managed and feel grateful to have been given this opportunity. Following a death, it can seem there is nothing we can do. We can't bring back our loved one, but we can help raise awareness and this in turn helps us move on with our lives whilst never forgetting the one we've lost.

If you feel you could do something similar, your local radio station would probably be glad to hear from you, and, who knows, you may find your broadcast has helped another family to avoid the grief, anguish, guilt and anger caused by losing someone they love to epilepsy.

## Our new website – coming soon to a PC near you

We have recently appointed a company called Baigent following a formal tendering process to develop Epilepsy Bereaved's new website.

They have an excellent track record of developing websites for a diverse range of charities and are good value for money.

If you are interested in finding out more about them and some examples of their work, you can visit their website:  
**[www.baigent.net](http://www.baigent.net)**

We have agreed a timetable of activity with Baigent's Project Manager. The aim is to officially launch the new site in December.

Part of the process has involved consulting a group of members on the overall design and actual content prior to launch. Thanks to all of you involved – we value your input.

Launching the site will not be the end of the story. We want to ensure the site constantly grows and develops along with the charity and provides our members and other audiences with relevant and up-to-date information about who we are and what we do.

The new site will enable EB staff to constantly update content, so we will be able to highlight upcoming activities including regional and national meetings, but also member events etc.

We want to hear your views about the new site, so please let us know what you think.

## EB members join Living Art Project



Epilepsy Bereaved members Alex Stirling and Debra Hamer participated in Antony Gormley's "One and Other" Living Art Project in London's Trafalgar Square in August.

Alex, (pictured above) from Merseyside, took her place on the plinth at midnight on 10<sup>th</sup> August and dedicated her appearance to her sister, Catherine, who died in 1989 of SUDEP, aged 29.

**Alex said:** *"I decided to apply on a complete whim: I'm not a fan of being in the limelight, and have no talents that I would want to showcase but my mum has always loved Antony Gormley's work. Then I started to think that I could use it to publicise Epilepsy Bereaved."*

*"I was the first person to sign up online to go on the plinth. I happened to have logged on at the day and time the site went 'live'. I put in my details, and it*



**EB members support Debra at the plinth**

*then said that there was one applicant, from the north west of England...that was me!*

*“It is a weird coincidence that when I got my place I was wondering whether I was brave enough to go ahead, and I logged on to the plinth site and saw that Debbie had posted a message saying she was going to do it for Epilepsy Bereaved too!*

*“I couldn't believe the coincidence and that was what tipped it for me. Perhaps we'll be the only cause that has two slots to publicise it, which—for such a small charity—would fantastic.*

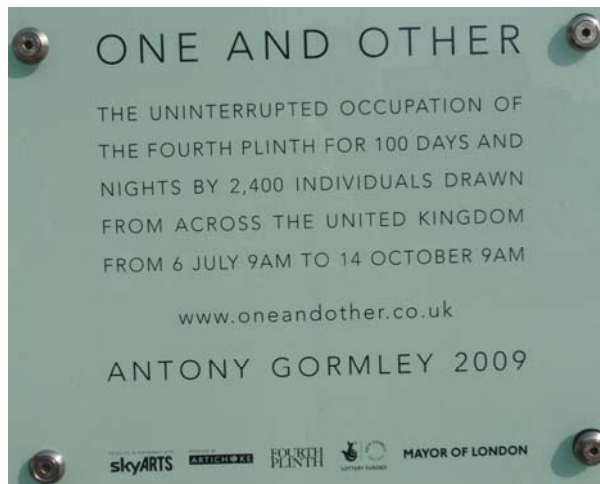
*“Plinths remember and celebrate lives, so this seemed a particularly appropriate way to remember Catherine, Warren and all the other loved ones who die from epilepsy.”*

Debra, an art graduate from Liverpool's John Moores University who lives in Denbighshire, North Wales, exhibited a piece of her own art work and dedicated her appearance on 20<sup>th</sup> August at 9am to her son Warren who died of SUDEP in 2007, aged 23.

**Debra said** *“As a student artist I marvelled at the work of Antony Gormley. I adopted his method of casting the body and*

*incorporated this in many art projects.*

*“In my final year as a degree student I had a conversation with my son Warren regarding the degree show and what I should do when I finished the course. He made me promise I would never give up my art.*



*“Two weeks later he died. I was devastated beyond belief. I was told the cause of death was probably SUDEP. I had never heard of it.*

*“The reverend at Warren’s funeral wanted to donate his fees to an Epilepsy charity so I searched the internet for an address. This is how I came into contact with the Epilepsy Bereaved website and where I also saw the risk factors associated with SUDEP.*

*“I hoped by being a part of this monumental moment I helped to bring SUDEP out into the open so it can be openly discussed. I am not a public speaker so I sat back-to-back with a figure to create a sense of loss and to highlight those quiet moments*

*we have when we can’t speak because there are no words to describe what has happened.*

*“Epilepsy is a common but complicated neurological condition and if this one hour helped people understand that lives are being lost needlessly, then that would be an amazing achievement.”*

Below are the web links for Alex and Debra on the plinth:

**<http://www.oneandother.co.uk/participants/alexs27>**

**<http://www.oneandother.co.uk/participants/DEBBIE>**

## EB joins Neurological Alliance



The charity is joining forces with the Neurological Alliance (NA) across the UK to strengthen our case to prevent avoidable deaths from epilepsy and to improve support to people affected by an epilepsy-related death.

The primary purpose of the Neurological Alliance is to campaign for better services for people with neurological conditions and their carers.

The NA in England has over 65 neurological charities to present a united voice to achieve better

health and support services for people with neurological conditions. It is campaigning for the appointment of a National Director for Neurological Care to implement a strategy for high quality neurological care. The NA also calls on the government to support research investment for neurological conditions.

Epilepsy Bereaved also works actively with other epilepsy organisations as part of the Joint Epilepsy Council in the UK and Ireland, which is also a member of the Neurological Alliance.

To learn more about the Neurological Alliance and Joint Epilepsy Council visit [www.neural.org.uk](http://www.neural.org.uk)

### National Epilepsy Week 2010

Due to the likelihood of a general election in May next year, the Joint Epilepsy Council has decided to hold National Epilepsy Week in June, from Sunday 13th to Saturday 19th June.

Details of events in the next issue of *Epitome*.  
[www.jointepilepsycouncil.org.uk](http://www.jointepilepsycouncil.org.uk)

## New staff team member

### Tracy Cowdry joins us in Family Support



Tracy Cowdry

**Over the past 12 years, I have had various paid and voluntary part-time positions that allowed me the flexibility I needed to fit in with my family life.**

**Volunteering as a citizen advocate for people with learning difficulties, I enjoyed spending time with people on a one-to-one basis and acting as their representative to ensure a fair service was offered to those in need of help.**

**I found a desire to help and understand people more fully and that progressed into my training to become a counsellor.**

**Recently qualifying as a counsellor after five years of study and with my daughter now into her teens I am more able to concentrate on a career that is suited to my training.**

**The role of support worker has allowed me to utilise all I have learned, and to enhance those skills by listening to the powerful and emotional stories that are told by families determined to make a difference.**

**Juggling my studies, part-time work, and volunteering over the past five years I've had little time for hobbies and, although I still volunteer as a counsellor in a generic agency, I am looking forward to finding something new to do with my spare time.**

**I am pleased to have joined the EB team and am finding the position hugely rewarding.**

**Already I have made many friends and I hope that my calls to members have helped in some small way.**

## Heaton Park 10K Walk

This year's 10K Walk took place at Heaton Park on 24th May, during National Epilepsy Week.

Epilepsy Bereaved supporters travelled to Manchester's premier family park to take part. Epilepsy Bereaved Chairman John Lipetz was also in attendance.

Eighty-two participants walked in memory of 23 people who had died from epilepsy.

Twenty helpers, including John Lipetz, gave up their time to be course marshals.

First aid was provided by an independent paramedic arranged by April Mills from Blackpool.

Fortunately the paramedic did not even attend to a blister!

Sandra Sandland, from Liverpool, organised the abundant tombola which took more than £200 on the day.

The glorious weather, a very busy park, and a great position for the charity stand helped enormously to raise funds and awareness.

Avril and Jonny Manson, from Whitefield, invited their MP Ivan Lewis, Minister of State, Foreign and Commonwealth Office.

Ivan kindly gave up his Sunday lunch to join people bereaved by epilepsy, and presented certificates to the first batch of walkers who to complete the 10K course.

Ivan, who is MP for Bury South, said: *"Epilepsy Bereaved is an excellent charity which is making such a difference to preventing*

***avoidable deaths in people with epilepsy.***

***"I am delighted to be involved today in their cause."***

**All the hard work in ensuring the event went ahead safely is accredited to Hilary Baldwin with the support of Alex Stirling and many other members of the North West Group.**



EB Chairman John Lipetz, John Lloyd—the first of the 10K walkers to return back, who was raising money for EB in memory of his good friend Karl Scurry—and Ivan Lewis MP

**Donations in excess of £4,280 were received following the event**

**The following people were remembered and represented on the day.....**

Nick Turner	Leanne Ryan
Melanie Margaret Heath	Christopher Mills
Warren Healy	Robert Baldwin
Rachel Jones	Carolyn Sandland
Philip David Blundell	Audrey Edwards
Neil Richard Warburton	Katie Manson
Damian Aindow	Felicity Farrell
Victoria Hannah	Martin Linney
Karl Scurry	Andrew McDonald
Charlotte Oxley	Scott Crossland
Catherine Stirling	Rose Chavez

## Coming to a coastline near you!

Vaughan Roberts faces a challenge each day but on 20<sup>th</sup> May embarked on another— **to Kayak around the UK coast** to raise awareness and funds for Epilepsy Bereaved, a charity that is very important to him.



Epilepsy has rooted itself into his family. Vaughan was diagnosed with epilepsy last year, his brother, Andrew, also has the condition and his cousin, Natalie, died of SUDEP, aged 22.

His aunt, Sue Kelk, the mother of Natalie, was one of EB's founding members.

Vaughan originally decided to do this trip over three years ago. It was something he was going to do after completing time with the Royal Marines. Unfortunately, however, due to his medical condition, he was unable to join the Marines.

Even for a fit and healthy individual this trip would push them to their limits. But, having epilepsy, it is a lot more challenging.

Due to the mammoth nature of the task, and taking his epilepsy into account, Vaughan will be taking a staged approach to this task. He reached the coast of Cornwall in July and completed the first stage of his journey.

Vaughan's Aunt Sue said: *"I am extremely proud of Vaughan for taking on such an epic journey but, at the same time, I am very concerned for his safety."*

*“EB is close to all our hearts and is embedded in our family. Raising funds and awareness in memory of Natalie is so very special to us. Vaughan carries a photo of her with him. Two days after he left it would have been her 40th birthday. I like to think this trip is marking that milestone.*

*“Vaughan, like Natalie, is living life to the full, perhaps it's in the genes! He has taken on this adventurous challenge for all who have epilepsy but it's also a personal challenge he needs to do.*

*“As he said to me in a recent text, he is doing what makes him happy and if it makes a difference he will be even happier.”*

We will keep you informed of Vaughan's progress on future exploits.

## **Liverpool FC helps to support EB**

**Christine Carter has emailed EB with an exciting opportunity for supporters of Liverpool Football Club and of the charity, as she tells here.....**

***“I sent a letter to Liverpool FC and have been sent Fernando Torres's training shirt. How good's that?***

***“I am going to accept sealed bids for this item so I wondered if you could spread the word around to charity members.***

***“Whoever makes the largest bid gets the shirt. All bids need to be in a sealed envelope and I will open them on the night of the auction.”***

**The auction is on 28<sup>th</sup> November, 2009.**

**Christine is raising funds in memory of her daughter, Samantha Hardcastle, and her unborn son, Regan.**

**You can email your bid to Christine directly at [christinefrog@talktalk.net](mailto:christinefrog@talktalk.net) or post your sealed bid to us, marking the envelope 'Torres shirt' and we will forward it to Christine.**

## News from Wales

### **Epilepsy Aware at the Assembly**

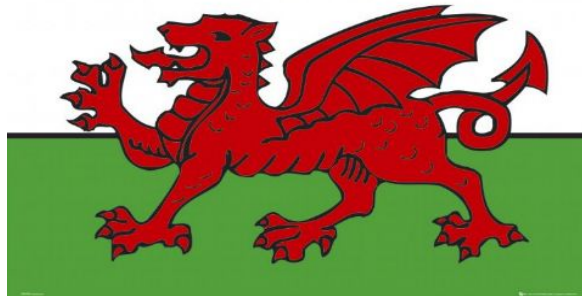
During National Epilepsy Week in May, an unprecedented half the members in the Welsh Assembly Government gathered to meet with their constituents and to hear first hand how epilepsy affects them.

Concern grew throughout the day that we were a potential health and safety risk as there were so many people in the room. An adjoining room had to be opened for us - this was a good problem to have!

Many of the Assembly Members returned to the debating chamber still sporting the *Epilepsy Aware* badges we had made especially for the occasion.

Epilepsy Bereaved member Karen Orsborne, from Neath, spoke at the event about living with epilepsy and losing her 21-year-old brother Michael to SUDEP.

**C Y M R U**



Karen donated copies of a CD she had produced to raise awareness of epilepsy and promote the charities in Wales who support people with the condition. (See last issue of *Epitome* for details. Picture of Karen donating the CDs, right.)

We hope that this strength of support will follow through to the cross-party group on epilepsy which meets on 3rd November.

### **Date for your diary**

The next epilepsy awareness event at the Assembly will take place on Wednesday 16th June 2010 in the Senedd building during National Epilepsy Week (13th -19th June).

More details will be in the next issue of *Epitome*.



**Karen—second from left, back row—donating the CDs**

**Local Health Boards**

Following the launch of the Epilepsy Directive in March, members of the All Wales Epilepsy Forum have been working to keep epilepsy high on the political agenda in Wales.

health boards. The AWEF had intended earlier in the year to embark on an information road show to raise awareness of the epilepsy directive but had to postpone this until the LHBs were reorganised.

The Local Health Boards (LHBs) have undergone a long period of change and from 1st October new chief executive officers have the task of leading the

The road shows will be rescheduled and members in Wales will be notified when and where they will take place.



## Epilepsy Bereaved Meetings 2010

You are warmly invited to our meetings.

Regional meetings, held at venues within specific regions, are informal gatherings of EB members or supporters and welcome any EB supporter wherever they may live.

Regional meetings aim to bring EB members and supporters together in a secure environment for mutual support and information; and provide an opportunity to meet staff and representatives of the Charity and to ask questions of, and/or put ideas to.

National meetings offer a choice of residential or day-only attendance, and are held over two days at Dunchurch Park Hotel near Rugby.

National meetings welcome all EB members and supporters. Besides providing a secure environment for mutual support and time to meet others socially, the national meetings will update and introduce EB campaigns and initiatives and explain the different ways our members and supporters can contribute to our work.

The November meeting also incorporates the Annual General Meeting.

For further information please contact:  
**information@epilepsybereaved.org.uk**  
Tel: 01235 772850

## Charity Meeting Dates 2010

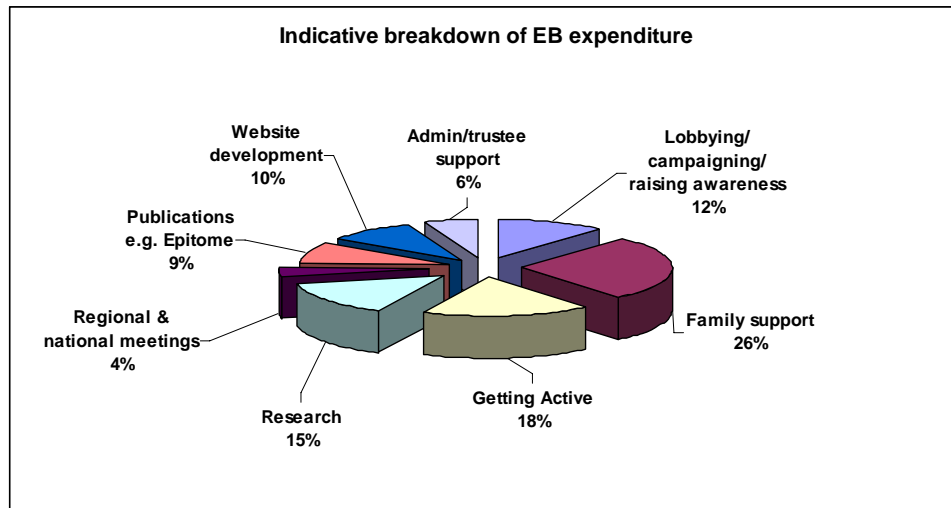
National meeting	20th/21st March (two-day event)	Dunchurch, nr Rugby
South West	27th March	Exeter
Wales	17th April	Denbighshire
North East	22nd May	York
London	12th June	Euston
North West	14th August	Cumbria
East Midlands	11th September	Essex
Scotland	9th October	Glasgow
National Meeting (includes AGM)	6th & 7th November (two-day event)	Dunchurch, nr Rugby
West Midlands	27th November	Central Birmingham

Our meetings generally run from 2pm–5pm and light refreshments are provided. Invitations and details of the venue will be sent out eight weeks prior to each meeting.

*The Charity has agreed to set up a limited financial fund which can be used to provide support to members wishing to apply for some assistance towards the expense of travelling and/or accommodation to EB National and Regional meetings.*

*The scheme will not be means tested; we will consider requests from any members who are experiencing a difficult financial period. Members can apply as individuals, husband/wife/partners, or families.*

## How Epilepsy Bereaved spends its money



Many of you have asked us about how we actually spend our money on our activities.

The percentages above are approximate, but do give you an idea of how our expenditure is split between different activities as a percentage of our total budget during 2009/10 (around £200k). We have tried to include all major costs including salaries and things like venue hire etc, for each area.

As you can see, one of our main investments for this year is in our new website which is currently in development, and therefore is attracting some additional upfront costs.

The website will be key to the development of the charity over the next three years, providing relevant and up-to-date information to our members, supporters and those bereaved by epilepsy.

If you have any questions about these figures, then please give us a call on 01235 772850.

# Commemoration

Due to magazine space constraints we do have to edit contributions submitted. We try to do this sensitively in order to retain the overall message of the story. We have included photographs which were available to us at the time of going to press.

- This section includes donations received up to the end of September 2009. Any donations received after this date will be acknowledged in the next edition.

## Apologies

**We apologise to Rosemary Sherman for listing her name in the 'In Memoriam' Section in the last edition of *Epitome*, issue 26. This should have been in her daughter's name, Alexandra.**

**We apologise to Feroza Leeming for not mentioning the donation of £100 received in memory of her brother Simon.**

## Living Art awareness

Following Alex Stirling and Debra Hamer's plinth appearances donations in excess of £3,000 were received.

Debra and Alex independently decided to take part in Antony Gormley's One and Other Living Art Project in London's Trafalgar Square in August.

Find out more in the article on pages 13-15.

## Just Giving website

Over the last six months donations received via the Just Giving website are in excess of £23,000. This is a fantastic amount of money, for which we are extremely grateful.



We are grateful to the following who took part in the British 10K London Run on Sunday 12th July and raised in excess of £8,000 for Epilepsy Bereaved.

**Lynn Jones** in memory of Felicity Abbott

**David Jones** in memory of Felicity Abbott

**Nigel Fidler** in memory of Felicity Abbott

**Anna Rudd** in memory of Felicity Abbott

**Hayley Mitchell** in memory of Felicity Abbott

**Bernie McDonnell** in memory of Fiona McDonnell

**John McDonnell** in memory of Fiona McDonnell

**David McDonnell** in memory of Fiona McDonnell

**Melissa O'Hare** in memory of Natalie Foulds

**Roger Brown** in memory of Eve Brown

**Marion Brown** in memory of Eve Brown

**Luke Stanton** in memory of Kathryn Treadwell

**Emma Heward** in memory of Tom Heward

**Sean Toole** in memory of Mark Toole

**Chris Haher** in memory of Elizabeth Haher

**Suzanne Haher** in memory of Elizabeth Haher

**Richard Haher** in memory of Elizabeth Haher

**Nordine Bennison** in memory of Elizabeth Haher

**Stephen Smith** in memory of Sam Smith

**Emma Breakspear** in memory of Kyle Breakspear

**Sarah Goodenough** in memory of Kyle Breakspear

**Janice Brady** in memory of Alan Brady

**Colm Brady** in memory of Alan Brady

**Paul Weston** in memory of William Preston

**Mark Bennison** in memory of Elizabeth Haher

The race ended with a charity picnic in St James's Park, hosted by EB Trustee Jennifer Preston. We would like to thank her and all our members who helped on the day.



After the race John and Bernie McDonnell said:

*“We completed our second consecutive British 10K London run on 12th July 2009. It was a lovely day and our son joined us on the run this year. It was also a great experience to run with thousands of runners and enjoy the wonderful atmosphere and the great sights of London.*

*“We support the charity Epilepsy Bereaved because they offer great support to loved ones following an unexpected death*

*from epilepsy. The charity is also helping to fund research into the causes of death, particularly in young people, from epilepsy.*

*“We hope to run again next year and raise more funds for our favourite charity.”*

**Please Note: We have 24 available places for the 2010 British 10K London Run which is due to take place on Sunday 11th July 2010. Please contact the office for registration forms.**



### **Nigel Ash**

Nigel's mum, Francis, ran in the Great West Half Marathon, (see front cover picture) and donations

totalling £500 were received.

### **Jordan Boyce**

On 7<sup>th</sup> April 2009, Ben Wreford, Adam Mirams, Matt Wakefield and Mark Stocker—photo below—set out on a five-day, 500-mile charity bike ride from Land's End in Cornwall to Botany Bay, Broadstairs, Kent.

Donations will be divided between EB and Cancer Research UK.

Donations in excess of £2,100 have been raised via [www.justgiving.com/landsend2botany-sudep](http://www.justgiving.com/landsend2botany-sudep)



We also received £60 via a Charities Aid Foundation cheque and personal cheque.

The group website is at:

**[www.landsend2botany.co.uk](http://www.landsend2botany.co.uk)**

Adam Mirams said: *"The ride went really well. The idea arose after a close colleague of mine lost his 18-year-old son to epilepsy about 18 months ago.*

*"The effect on the family and all of us was devastating.*

*"At the same time my best friend lost his father to cancer, so we decided to do something to raise the profile of both charities.*

*"All of us are fitness addicts so we came up with the Land's End to Botany Bay challenge.*

*"The experience was amazing.*

*"Every day we cycled 100 miles and kept the public informed of our progress through a daily radio slot.*

*"We finished the ride at the home of Jordan, who died in December 2007.*

*We hope to come up with a new cycle challenge next year.*

*"I pledge my support to the charity to continue to raise the profile."*

***‘Don’t worry about doing things you have never done before. If it raises awareness and money—just do it!’***



**Eve Brown**  
David and Denise Brown raised £160 in memory of their daughter, Eve, pulling pints at their local beer

festival and raising awareness.

Denise writes: *“The realisation struck that I had*

*never pulled a pint in my life, but quickly our fears vanished. More and more pints, and happy people asking us about EB, epilepsy, and the beer.*

*“We raised £160 for EB. Best night out for years, cost us nothing. Don’t worry about doing things you have never done before.*

*“If it raises awareness and money—just do it!”*



**Denise, Andrea and Alan**



**Danny Burns**

Thirteen friends took part in the Adidas Women's 5K in Hyde Park on 6th September raising over £2,438 in memory of Danny—picture below.



Running for Danny Burns



**Danny Cowell**

An annual pool tournament—picture below—held at The Welcome Hand, Rainham, raised £305 in memory of Danny.





**Rebecca Davies**  
Debbie Davies, a staff nurse at the Royal Glamorgan Hospital,

Llantrisant held her annual Christmas Raffle on Ward 5. Donations of £200 in memory of her daughter Rebecca were received. Thanks go to all on Ward 5 who were so generous. (Photo above shows Rebecca with her son, Morgan.)



**Martin Doran**  
Following her participation in the Two Castles 10K run on

7th June, Susan Biddle raised £115 in memory of her brother, Martin.

Susan writes: *“On Sunday 7th June, I took part in the Two Castles 10K run (Warwick Castle to Kenilworth Castle) in memory of my brother, Martin Doran, who died from SUDEP on 16th July 2006.*

*“On race day when I woke up it was absolutely pouring with rain, but nothing was going to stop me. I braved the torrential downpours, thunder and lightening and ran amongst 3,000 other competitors. Despite the weather, the atmosphere was still amazing.*

*“When the going got tough on the hills I could hear myself saying, ‘Come on Martin, give me a push up this hill.’ This gave me the incentive to carry on.*

*“I made a sign to wear on my back saying who I was running for and why.*

*“I was tapped on the shoulder towards the end of the*



**Kristen Dandy**  
Donations totalling £145 were received following a bungee Jump by Kristen’s auntie,

Elizabeth Flint and her friend Samantha Knowles.

Kristen’s Mum, Pam writes: *“EB has been inspirational for me in many ways, not least in the early days of bereavement. The work you do is phenomenal – long may it continue.”*



**Susan Biddle, above, running the Two Castles 10K Run for her brother Martin Doran**

*race by a fellow runner who said, 'Well done, fantastic cause, my son has epilepsy'. I suddenly felt a new lease of life and felt very proud of myself.*

*"I know I can't bring Martin back, but I just want to help others with epilepsy and hope that one day there will be a cure.*

*"I know Martin was watching me that day and was with me all the way. I did it for him."*

Susan's Just Giving page is: **[www.justgiving.com/susanbiddle1](http://www.justgiving.com/susanbiddle1)**

A further donation of £23 was received from The Rotary Club of Kenilworth.



**Martin Fewell**

Martin's brother, Peter, and his friend, Vince, completed a sponsored bike ride from Tapestry Cakes, in Watford,

to Avebury Stone Circle, Wiltshire—see picture on next page.

Peter writes: *"At the end of July 2007, Martin passed away at the age of 37 due to SUDEP. At the time I wasn't aware a seizure itself could be fatal. Since then, having been involved with EB, I have met many other families who have lost someone to SUDEP.*

*"In memory of Martin and others who have died from epilepsy, I felt I had to do something.*

*"My friend Vince Groves joined me on the journey, which took us through Reading along the Kennet and Avon Canal.*

*"It was approximately 80 miles in total and required an early start. For a couple of guys in our forties, we hope it inspires others to get on their bikes.*

*"Of course, this event was made possible by Martin not me, and the support given reflects the respect my brother deserves. On his behalf I would like to say*



**Peter Fewell and Vince Groves at Avebury Stone Circle after their 80-mile bike ride**

*thanks to all who have donated, including his work colleagues at Capcon Limited, my parents for their technical support and Vince for enduring the ride with me. Words can't describe the thanks I owe to Denise and Dave of Tapestry Cakes: the barbecue raised a further £150, plus getting up before the birds to send us off was truly fantastic."*



**Ria Garland**

On Saturday 30th May, Annie and Chris Garland held their annual Plant Sale and Cream Tea in their garden in memory of their daughter, Ria.

Annie writes: *"We had another glorious day, and lots of people came. I sent out about 60 leaflets through the post – and handed out another 170-200.*

*"A couple of the local pubs advertise it for us too. It gets bigger every year.*

*"My friends Jackie and Ted Sweet came up from Devon and did the cream teas again – always a favourite.*

*"We had all the usual stalls – tombola, books, bric-a-brac and plants.*

*"The stalls were manned by our friends Carolyn, Sally, Angie, Julie, Sarah, Pete, Claire, Patsie, Tracy, Sue, Ruth and my*

dear dad, Harold, who raffled all his drinks cabinet and raised £146!

*“Harold will be 90 in August and helps a lot with the sale. He made marmalade, apple pies, and sausage rolls, brought rhubarb from his garden and gave us a basket of fresh eggs from his chickens. He made lead weights for fishing lines and, after planting all the seeds, I collected two boot loads of runner bean plants, dahlias and parsley from him.”*

Donations totalling £2,135 were given to EB following the plant sale, of which £1,800 has been allocated to research on the request of Annie and Chris.

The Dexam Trust, a charitable trust, has supported Annie and Chris on several occasions since Ria died. It sponsored Annie on her 100-mile South West Coast Walk in 2004 and helped generously with the Pantomime Horse Day.

Following a sponsored slim by Lester Knight who works at Dexam International Limited, donations of over £543 were received, £250 of which was donated by the Dexam Trust.

Thanks must also go to the staff at Dexam International Limited who held a raffle and raised £72 in memory of Ria.



### **Mike Garrad**

Mike's younger brothers Nick and Chris organised a party and music festival

in the meadow behind their house – nine bands played for the charity over a weekend in early August.

There were locally-brewed Potton ales, a barbeque and an ice-cream van.

There were also one or two craftwork stalls, plus archers demonstrating and instructing.

On the Saturday evening a huge bonfire competed with a beautiful sunset – after the rainbow which accompanied a short sharp shower!

The music went on well into the night, and the next morning saw around 150 campers stumbling into the daylight.

Nick, Chris, and their friends had a splendid time, and raised around £600 for research into SUDEP.



**Elizabeth Haher**  
Elizabeth's uncle, Mark Bennison— pictured with Elizabeth— once again

completed the London to Brighton bike ride and the British London 10K run, in June and July respectively.

Donations in excess of £1,900 have been received in memory of Elizabeth.

#### **Helen Herbert**

At the recent marriage of Andrew Herbert and Sally Forrester donations in lieu of presents were received in memory of Helen (Andrew's first wife) who died in 2006.



**Natalie Kelk**  
A donation of £50 was received from Sue Kelk following Vaughan

Roberts's fundraising— see article on page 20 and 21.



**Kim Larkworthy**  
(Kim is pictured holding her niece, Mollie.) A donation of £84 was received from

donations made via our collection box at Oake Post Office, Taunton.

A further £311 was received following a charity bingo held in the Victoria Rooms, Milverton, and organised by Margaret Parsons who organises the bingo for different charities each month.



**Garry Lathan**  
Graphical and Municipal Workers Union donated £1,119.77 in memory of Garry.

Garry's dad, David, works where the union has a presence.

A further donation of over £230 was received following a charity performance at Prudhoe Community High School.



**Matthew Mawhood**  
Patrick Mawhood completed the gruelling Stockholm Marathon

in May, followed by trekking the Tour du Mont Blanc, in the summer, in memory of his brother Matthew Mawhood.

Patrick said: *"Running the marathon and hiking Mont Blanc was a fabulous experience made all the more rewarding by raising money for SUDEP."*

Despite being based in Stockholm, Patrick raised over £2,700 by making good use of all his contacts and made the most of Epilepsy Bereaved's online Just Giving facility:

**[www.justgiving.com/epilepsybereaved/](http://www.justgiving.com/epilepsybereaved/)**

Matthew attained a degree in psychology. After university he worked as a recruitment consultant in the telecoms industry. His career took him to Denver, Colorado, where he trained the locals in the fine art of recruitment.

Patrick and Matthew's mother, Sheila Mawhood, from Buckinghamshire, said: *"Matthew's health had been excellent. Three weeks before*

*his death he may have had a night-time seizure but this is not certain. The unexplained seizure which took Matthew's life was a complete shock to his family and all of his friends.*

*"We strongly support the research into the prevention of deaths from epilepsy at King's College Hospital in London.*

*"We want to find out why he died and how to prevent other healthy adults with everything to live for from falling victim to SUDEP, 'the thief which comes in the night'."*

**Russ Mayes**

A donation of £450 was received from Kerry Mayes, raised in memory of her husband, Russ, 38. The donations were in lieu of presents for Kerry's 40<sup>th</sup> birthday last year and have been allocated to research, as requested.

Kerry writes: *"Russ wasn't diagnosed with epilepsy until he was in his twenties.*

*"Since I met Russ, two years after he was diagnosed, I am only aware of him having half a dozen or so seizures. At no time at all did a medical expert ever express any reason for us to be concerned.*

*"Russ was on medication and we believed this would*

*control the epilepsy. Never did we think he was high risk. For this reason, I would like the money to go into researching why sudden deaths occur.”*



**Keiran McLoughlan**

A family fun day was held at Whitefield Kindergarten, Moss Lane, Manchester, in memory of Kieran.

Keiran's sister, Charlotte, organised the day to help spread the word about SUDEP and to raise money for Epilepsy Bereaved.

The day included a bouncy castle, face painting, games and homemade snacks.

A donation of £1,275 was received.

Charlotte writes: *“It was fantastic! I never expected so many people and such a big turnout. I didn't think we would raise so much money.*

*“It took a lot of planning and everybody worked really hard.*

*“No one was prepared for Keiran's death and we didn't know how to cope.”*

Kieran died in 2006 in the

middle of the night. He was a pupil at Castlebrook High School and had just completed a vocational course in business studies at Bury College.



**Christopher Mills**

An event at the Burlington Pub, Lytham Road, Blackpool, raised

donations in excess of £1,150.

Mark Kingsley is the owner of the Burlington and he organised an Apprentice Night (as per the BBC programme) in memory of Chris Mills.

Pictured below—the Apprentice Night boys' team.





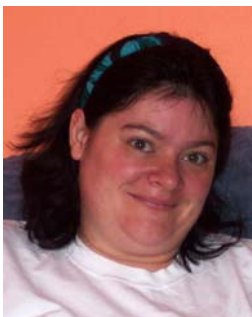
**Selena Milne**

Kelly Greig walked Ben Nevis, she has sent in donations in excess of £3,300.

(See photo, below.)



A quiz night was organised by Ashleigh Carnegie with help from Selena’s sister, Sam Holden. Donations in excess of £1,120 were received.



**Hazel Nicholas**

A donation of £130 was received from Ed Nicholas in memory of his wife, Hazel.

Ed writes: *“Epilepsy Bereaved became our*

*nominated charity following the death of my wife, Hazel, on 16th April 2008.*

*“Karen Osland and I emailed several times which really helped.*

*“I’m now coping better than I was initially and this in turn is making things better for my two small children.*

*“The amount raised was from the donations given at Hazel’s funeral last year. I should have sent the cheque through much sooner but I went through a long stage of severe denial and I didn’t really want to deal with anything that would remind me of what had happened.*

*“I am gradually coming to terms with the situation, though, and learning how to cope.”*

Donations in excess of £172 were also received from the Mudesley Singers and Ed tells us:

*“As my wife was a very active member of their group, they put on a special concert in her memory which was very well attended.*

*“As you can imagine it was very emotional for the family but they did an absolutely fantastic job.”*



**Alan Pring**  
A donation of £556 was received from one of the charity's founder members,

Sheila Pring, in memory of her son Alan.

A garden party was held at a friend's house and various stalls, including books, plants, greeting cards and sports wear were set-up.

Light refreshments were also served.



**Colin, in white T-shirt, with supporters at the Flora London Marathon**

Colin's daughter, Grant's sister Kirsty Cunningham, writes: *"Dad managed all 26.2 miles of the London Marathon in record time.*

*"Sunday was a glorious day and despite the heat he managed to smash his personal best for this marathon by a whopping 12 minutes. In addition, he shaved two minutes off his previous personal best for a marathon distance (set in Palma, Majorca in 2007).*

*"He was cheered on by seven of us all wearing T-shirts in the shade of blue used by Epilepsy Bereaved and with 'Running 4 Grant' printed proudly on the front. The back carried the website of the charity so, although we weren't being quite as energetic as Dad, we still managed to raise some awareness.*



**William James Alexander de Berniere Reed**  
Donations of over £1,000 were collected at the funeral of William in Wiltshire.



**Grant Rothwell**  
Grant's dad, Colin, has so far raised over £3,335 in memory of Grant.

Colin ran in the Flora London Marathon on Sunday 26th April.

*"We saw Dad at Blackfriars (24 miles) and gave him a massive cheer to get him through the last two miles.*

*"There is no doubt Dad owes his time to the determination given to him by Grant. Because of Grant, Dad has so far raised over £3,335 and money is still coming in.*

*"Grant would be incredibly proud of him, as we all are.*

*"Epilepsy Bereaved is thrilled with the money they have received as a result of everyone's generosity and my family and I are touched and inspired that so many people showed their support in memory of Grant.*

*"We can only hope this money, although only a fraction of what is needed, will help the charity to get closer to making sure that other young sons, daughters and siblings don't lose their lives in this way. We hope that the awareness Grant has raised will mean another family will hear of this condition and, as a result, have many more precious years with their loved ones."*

Colin's fundraising page on Just Giving can be found at [www.justgiving.com/running-for-grant/](http://www.justgiving.com/running-for-grant/)

### **Karl Scurry**

Karl's widow and her son, Craig Merridith, raised £300 in memory of Karl.



### **Lloyd Short**

A donation of over £700 was received in memory of Lloyd following an auction and

sponsored walk in the Peak district with family and friends earlier in the year.



### **Jason Tracey**

A £250 cheque was received from Scottish Power Bofa project manager, Alex Scott, in memory of Jason.

(See photo below.)



**Alex Scott, Project Manager, presenting the cheque to Jim Walker, who is married to Jason's mother, Sarah**



**Kathryn Treadwell**

Darren Larder has raised over £500 in memory of Kathryn

following his run in the Flora London Marathon.

Darren, pictured right, writes: *“It was a fantastic day – a little bit warmer than I would have liked, though. I definitely suffered towards the end due to the heat!*

*“I finished in 3 hours 9 minutes 5 seconds, so was really pleased with that.*

*“My wife, Kate, has known Sarah (Kathryn’s sister) and her family pretty much all her life and it meant a lot, to both of us, for me to raise money and awareness of the charity.”*

Donations totalling £830 were received from Mike Padbury following a 100-mile sponsored walk in the South Downs.

Mike writes: *“I completed the walk in memory of Kathryn Treadwell who would have been 21 in June this year. I trust the money will be of some benefit to your charity.”*

A friend of Kathryn’s, Eileen Herron from the M&S store in Shirley, completed a



walk and donations of £200 were received.

Ninestiles School in Birmingham have adopted the charity as one of their charities for the year.

Donations of over £107 were received following a “teacher wax” which was attended by Kathryn’s mum, Christine.

Christine writes: *“This was very amusing, but not for the poor men who had their legs waxed! Tickets were sold for £1 and some of the teachers donated money NOT to participate!”*

This event was organised by teacher Nikki Green.

On Saturday 6th June a celebration was held for Kathryn as she would have been 21 on 3rd June and over £81 was raised on the day.

Christine writes: *"This was a very emotional day for all of us as we had planned a barbeque with a bouncy castle, but it never stopped raining.*

*"Nevertheless, over 90 came to spend the day with us – school, college and university friends, neighbours old and new, and many more.*

*"Later in the evening, six ladies came from M&S store, after work, and the party continued.*

*"It was a day I was dreading, but we all sent off a balloon at 3pm for Kathryn which was an amazing sight and extremely emotional for Pete and me."*

Following all the fundraising in memory of Kathryn, Christine continues: *"I feel really privileged that so many people loved Kathryn and are raising money for the charity in her name."*

### **Jess Turnbull**

On 17th September three directors from CaB Studios (Al, Ben and Kevin) undertook the annual Staples2Naples banger

rally—the original and leading European banger rally—in memory of Jess.

More details in the next edition of *Epitome*.



### **Laura Turner**

Laura's dad, Mike, and five friends went on a four-day golfing break

in Northern France.

Each player donated £100 per net birdie or better scored and also donated their prize money fund.

We would like to thank Ashley Knapp, David Yates, Dick Fuller, John Reeves and Justin Cliffe for their help with this fundraising in memory of Laura, which raised £200.

A musical evening organised by Laura's friend, Katherine Tye, raised £260.

The event was held on 4th September at All Saints' Church, Woodham, Surrey.

The audience were entertained with a range of classical solos and contemporary pieces, including music from Debussy, Beethoven, Bach and Handel

and choral pieces from the Loveday Singers, and guitar composition by the performer.

A total of 15 soloists and 25 singers contributed to an exhibition of musical talent enjoyed by a generous audience.

Katherine was particularly grateful for the support of her friends, her local choir, a fellow student who had travelled from Hereford to accompany the soloists, the church in providing the excellent venue, and family and friends who supported the event.



**Stephen Usher**

A sponsored walk, suggested by Stephen's friend Penny Raines,

raised £1,000 via the Just Giving website.

On the same day, some of the police based at Cheadle Heath Police Station formed a team for the Manchester to Blackpool cycle ride and raised in excess of £370.



**Nicholas (Nicky) Walsh**

We received a donation of £150 raised from the sales of cards and bags in

memory of Nicholas.

This event was organised by his sister, Madeleine, who writes: *"Our family had a very special occasion as it was my son Jack's First Holy Communion on 17th May 2009 – the start of National Epilepsy Week—so we decided to use the event to help raise awareness and funds.*

*"We had a wonderful day and everyone was so generous. The bags were most popular and quickly sold out.*

*"Nicky was 45-years-old when he died at Easter 2007.*

*"He was diagnosed with epilepsy when he was a teenager. He worked all his life for the Post Office. Initially he was a postman, but after he had a seizure at work he was demoted to a cleaner!*

*"He worked hard and never took a day off, even if he had a seizure before work.*



**The above photograph shows some of those who attended Jack's First Holy Communion—which was also a fundraising event in memory of Nicholas Walsh. Jack is front right.**

*He worked his way back up and worked in the sorting office in Greenford.*

*"Nicky was able to live an independent life, despite his epilepsy not being very well controlled.*

*"He loved Star Trek and played hockey for Mill Hill Hockey Club early on in his life.*

*"He was quiet and enjoyed his own company, but would always come to all family gatherings, parties and Christmas.*

*"He was Uncle to two nieces and four nephews.*

*"He used to stay with us at Christmas and was brilliant at assembling toys, making up complicated electronic gadgets and always the best at blowing up balloons for all the parties.*

*"Nicky was one of five brothers and sisters and, being part of a large Irish, Catholic extended family there were always parties of one sort or another."*



### **Sean Watson**

A bikini car wash held on 28th August in Brightlingsea, Essex, raised over £180 in memory of Sean.

Sean's sister, Emma, and four cousins from Colchester put on their bikinis and washed cars at the community centre.

Sean's mother, Amanda Aylwin, said: *"Sean was a martial arts teacher and is greatly missed by all the family."*

*"We are very proud of the girls for their hard work in raising funds for Epilepsy Bereaved."*



### **Jack Webb**

The annual sponsored run in memory of Jack—pictured above—held on 24th May, raised a total of over £1,654 for Epilepsy Bereaved.

### **DONATIONS FROM TRUSTS AND CHARITABLE COMMITTEES**

Following a successful application, the charity received £3,000 from the **Simon Gibson Charitable Trust**.

A donation of £350 was received from the **Pace Charitable Donations Committee** in memory of **Felicity Farrell** following fundraising by her father **Kevin**.

### **DONATIONS FROM UCB PHARMA LIMITED**

Donations totalling £1,500 were received from attendees at a Masterclass in Epilepsy sponsored by UCB Pharma Limited at Madingley Hall, University of Cambridge. The delegates were all specialist nurses involved in the treatment of clients with epilepsy who spent a day attending tutorials on different aspects of the condition run by some of the top opinion leaders in the therapeutic area.

Andrew Williams, Senior Brand Manager – Epilepsy, writes: *"UCB would like to re-affirm our ongoing commitment to your organisation and plan to hold similar events in the future."*

## **DONATIONS RECEIVED VIA LEGACIES**

A legacy of £3,750 has been received from the will of Nellie Rhodes who lost her daughter, Margaret Lawler in 1991.

A legacy of £2,000 was received from the Will of Alfred William Brown. The charity received this legacy from the Executor, Chris Lovell, who described Epilepsy Bereaved as “a worthy charity.”

### **Other Donations:**

We received a donation from The Surgery, Newark, Nottinghamshire following receipt of our Health Professional Resource.

We received a donation of £25 from David and Valerie Cross in memory of their friend Maggie Bird who passed away suddenly.

A donation of £5 was received from Mrs D Penney.

We are very grateful to Lee at ‘Printlogic’ who prints *Epitome* at a reduced cost, in memory of his cousin Tom Lodemore.

## **NEW FRIENDS OF EB**

The following have become a “Friend” of EB by completing Bankers Orders.

Danielle Jenkins in memory of  
Joe Short

Lisa Allen in memory of  
Merryn

## **IN MEMORIUM**

In this section, we have listed the donations received in memory of the following loved ones:

<b>Caris Aparicio</b>	<b>Carl Ian Morgan</b>
<b>Adam Astle</b>	<b>Martin Musgrove</b>
<b>Claire Baker</b>	<b>Lucy Phillips</b>
<b>Jordan Boyce</b>	<b>Paul Phillips</b>
<b>Eve Brown</b>	<b>Alan Pring</b>
<b>Sarah Elizabeth Dobbie</b>	<b>Gary Reeve</b>
<b>Carol Durham</b>	<b>Becky Scrivens</b>
<b>Felicity Farrell</b>	<b>Karl Scurry</b>
<b>Kenneth Fielding</b>	<b>Simon Smith</b>
<b>Jodie Ford</b>	<b>Samuel Smith</b>
<b>Justin Glithro</b>	<b>Kenneth John Swadling</b>
<b>John Harden</b>	<b>Jennifer Sykes</b>
<b>Victoria Louise Hannah</b>	<b>James Taylor</b>
<b>Helen Herbert</b>	<b>Matthew Toates</b>
<b>Graham Hilder</b>	<b>Kathryn Treadwell</b>
<b>Anthony Kibblewhite</b>	<b>Stephen Usher</b>
<b>Tina Larkworthy</b>	<b>Sean Watson</b>
<b>Robert MacDonald</b>	<b>Andrew Wesley</b>
<b>Keiran James McLoughlin</b>	<b>Lynda Wilkie</b>
<b>Magnus Milner</b>	<b>Tyler Anthony Wilkinson</b>

## ***Your poems***



### **Mariner of the Seas**

***By Fern Wormald, in memory of her nephew, Martin Linney, who died aged 23 in July 2008***

Water, water everywhere yet not a drop to drink  
Said Samuel Taylor Coleridge, but of Martin did not think.  
As water, water everywhere was Martin's dream come true  
Traditional seas and rivers, to water butts and fish tanks too.

He'd drink it, touch it, Tactile – that was he  
Mmm, the good old taste of seaweed! So at one with the sea.  
Strange, indeed, in that case, that our Mariner of the seas  
Was blessed beneath the star sign of the horoscope Pisces!

With one. At one, with nature, twas not just H2O  
That Martin loved, and that loved he, the element loved him so.  
Trees and fields, woods and vales, his great beloved firs  
His affinity with all things natural a gift and not a curse.  
A mutual appreciation, twas a tryst between the pair.  
His best friends; water, grass and leaves a comfort everywhere.  
But not just running wild and free, but twice weekly trips to baths  
Encouraged, boosted and fully enhanced that cheeky smile, those  
laughs.

Predictably unpredictable, on this I shall try to expand  
Sometimes a world so far removed, and sometimes clear as your  
right hand.  
If troubled by change or noises, he'd try to calm his head  
His simple solution to a troubled day – Thomas the Tank Engine in  
his bed!

So to some of us Martin's life was unusual and somewhat 'not the  
norm'  
For him was one of nature's little tests – he had to ride the storm.  
His cheeky smile will linger on with each of us each day  
Reflected, echoed by the storms, a reminder of 'his way'.

Good night, God bless our special man, you handsome, loving  
chap,  
Now safely tucked up fast asleep for one final exquisite nap.  
And reach a tender hand out and grasp into the air  
And grab the balloons that are now en-route to your special place  
'up there'.

*By Dionne Ankrah in memory of her friend,  
Carolyn Sandland, who died, aged 29, in October 2005*



***Soundly sleeping without a care  
In the world  
Silently creeping, it's so unheard.  
Without a struggle or a sign  
SUDEP silently takes a life.  
Young and with the world at their feet,  
they didn't have a chance to fight.  
The victims of the illness and  
Families alike,  
Were not told that SUDEP  
could strike.***



# Epilepsy Bereaved

P.O. Box 112  
Wantage  
Oxon OX12 8XT  
Tel: 01235 772850

## BANKER'S ORDER

### 1. Your Details

Name \_\_\_\_\_ Tel No: \_\_\_\_\_  
 Address \_\_\_\_\_ Email: \_\_\_\_\_  
 \_\_\_\_\_  
 Postcode \_\_\_\_\_

### 2. Bank Details

To the Manager (your bank) \_\_\_\_\_ Bank Account \_\_\_\_\_  
 Bank address \_\_\_\_\_ Number   
 \_\_\_\_\_ Sort Code -  
 \_\_\_\_\_ Postcode \_\_\_\_\_

Please pay from my account to Epilepsy Bereaved ac. no. 51139258 sort code. 40-45-36 HSBC, Wantage Branch, Oxon the sum of

### 3. Your Gift

Please pay Epilepsy Bereaved £5  £10  Other £ \_\_\_\_\_ every  
 Month  Quarter  Year  Starting on (date) \_\_\_\_/\_\_\_\_/\_\_\_\_ until further notice.  
 Signature \_\_\_\_\_ Date \_\_\_\_\_

### 4. Gift Aid

I would like to Gift Aid all my donations made to Epilepsy Bereaved since April 6th 2000 and all donations I make in the future until I notify you otherwise

*giftaid it*

\* For Epilepsy Bereaved to reclaim the tax you have paid on your donation (s), you must have paid income/capital gains tax equal to the tax that will be claimed (38p for every pound)

### DO NOT RETURN THIS FORM TO YOUR BANK

Please return your completed form to Epilepsy Bereaved at the address above.

Charity Registration No. 1050459



## Epilepsy Bereaved National Weekends

The next national meeting will be on the 20<sup>th</sup> and 21st March 2010 at the Dunchurch Park Hotel, near Rugby—*Please make a note in your diary.* The main aim is for people to meet. Everyone can come and go as they wish over the weekend. We aim to keep the weekend as informal as possible.

*“I found the setting extremely relaxing”*

*“Lovely to meet others in a safe and caring environment”*

*“The weekend was wonderful. The hotel is helpful and accommodating”*

*“A big thank you to the hotel”*

### **Dunchurch Park Hotel**

Dunchurch Park is a beautiful Grade II listed Manor House, set in 72 acres of magnificent gardens and grounds.

Once again, the Manager and staff of the hotel have chosen EB as their Charity of the Year.



They also continue to offer excellent value and service to us and our members.

Visit [www.signaturegroup.uk/venue-dun.php](http://www.signaturegroup.uk/venue-dun.php) to view the hotel.

The venue is easily accessible from Rugby Railway Station or by car from the M1 (Junction 17 Northbound/18 Southbound) and M6 (Junction 1).



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