



**SUDEP Action** 

*Making every epilepsy death count*

**KEEPING IN TOUCH**

**Summer/Autumn 2019**

## HELLO THERE ...

Last month, we invited people to take part in our global **Online Epilepsy Memorial Day** (10 May). A day which can unite us all, in our common cause of remembering and sharing our memories of those who have died suddenly.

Our recent **National Conference** was another opportunity for some of our bereaved families to come together. We shared how your support has helped us with the Prevent21 campaign and why our charity work, to plug gaps in education, needs urgent investment.

SUDEP Action also celebrated winning the **British Medical Journal** award for Education Team of the Year, for the work developing epilepsy safety and risk communication tools. With 21 deaths a week, and huge gaps in recognising and tackling risk, we are focused on putting people and life-saving knowledge and support, first.

Together with help from the epilepsy community, we will continue to help push for the changes we know are needed to prevent future deaths. Take a look through our newsletter for more information, upcoming dates and ways you can get involved.

**Jane Hanna OBE**  
Chief Executive, SUDEP Action

**SUDEP.ORG**

## NATIONAL CONFERENCE 2019

### 17-19 MAY 2019



The National Conference 2019, in Leamington Spa was an emotional and inspiring event.

Allowing for supporters to spend valuable time together, building up new and existing relationships, and to hear the latest research and project updates from the charity.

It started with an informal Q&A session with **Dr Rhys Thomas** and **Dr Arjune Sen**, on the Friday evening. The informal space helped set the scene for the Conference. Questions were asked about hot topics such as: cannabis, epilepsy risks, medications and post mortems.

**If you have any concerns or questions about those topics, please do contact us - [info@sudep.org](mailto:info@sudep.org)**

The Saturday morning was a similar format to last year - short update sessions by SUDEP Action team members and clinicians, followed by an interactive Q & A session.

Here is just a snapshot of what was discussed on the Saturday:

**Jane Hanna OBE**, highlighted the work that SUDEP Action have been doing since the last Conference, including new research, projects and a positive

update on our Prevent21 appeal. Together, we helped **13,040 people** last year via our bereavement services, The Epilepsy Deaths Register, EpSMon self-monitoring app and the SUDEP and Seizure Safety Checklist.

*"Changing and saving lives, putting people first and providing lifesaving knowledge"* - Jane Hanna OBE explaining SUDEP Action's mission and purpose.

**Sammy Ashby, SUDEP Action Deputy CEO** spoke about the ways in which our supporters and volunteers can help us.

*"Debunking myths, sharing facts and empowering others to make change"* - Sammy Ashby, Deputy CEO explaining about the importance of policy work.

**Karen Osland, Epilepsy Deaths Register (EDR) Special Projects Lead** explained the importance of the Register. With nearly 800 reports, it is helping to shape and drive research.

*"It's more than a keeper of stories - it's a catalyst for change"* - Karen Osland

Tracy Cowdry, Bereavement Services Manager and Julia Stirling, Bereavement Case Worker provided a moving presentation about the immediate and enduring impact of

epilepsy deaths for families. Also, how SUDEP Action's support service is a bespoke one - featuring advocacy, advice and emotional support.

**Professor Mike Kerr and Dr Arjune Sen** presented the key findings and outcomes from the Prevent21 Summit in November 2018.

**Rachel and Bharat Sumaria** provided an update following their incredible journey on their **Tuk Tuk to Turkey**, in memory of their daughter Emily, last year.

**Fraser Morton** shared an update video on how the **A Life Electric** project is going and the exciting work that is coming soon.

#### Afternoon Workshops

The afternoon was an opportunity to have space to come together in group discussions around:

- How to help SUDEP Action reach their EDR goals
- Campaigning for change - learning from supporters and charity experiences
- Getting involved in a cause - how supporters have connected with SUDEP Action
- How we can reach fundraising goals together

In the afternoon, we celebrated our wonderful supporters in a video showing just some of the brilliant fundraisers and volunteers who have raised funds and awareness for SUDEP Action in the past 12 months.

Thank you to all of our supporters for all of your support and donations. If you would like to support or get involved in our future work, in any way at all, contact us today on [info@sudep.org](mailto:info@sudep.org) or call 01235 772850.

With your help, we can continue to work to prevent epilepsy deaths.

## SUDEP Action Memorial Service

### Saturday 16 May 2020

Every three years, SUDEP Action organises a Memorial Service in memory of all those who have died from epilepsy. Held at St James's Church, Piccadilly, London, the service is open to people of all faiths or none.

To ensure you receive an invitation (when they are released in January 2020), please ensure you are on our database by contacting our Support team -  
Tel: 01235 772852 or  
email: [support@sudep.org](mailto:support@sudep.org)



SUDEP Action



## PATIENT SAFETY CAMPAIGN RENEWED AS JUDGE UPHOLDS MINISTER PRESCRIPTION POWERS



On Friday 10 May, The Good Law Project lost its case before the Court of Appeal, about whether the Government had acted illegally and outside its powers, when it rushed in Serious Shortage Protocols (SSPs) for the supply of medicines earlier this year.

In the event of medicine shortage, ministers can action the Protocol, allowing pharmacists to dispense a generic equivalent or even ration a medicine, without talking to the original specialist prescriber.

Lawyers for The Good Law Project argued that such a change to the way that medicines are supplied, would **fundamentally alter the way treatments are decided between doctor and patient, and needed careful legislative consideration through Parliament.**

The presiding judge Lord Justice Hickinbottom, agreed to hold an urgent hearing as SSPs are more likely to be issued, whilst a no-deal Brexit remains a possibility. Lord Justice Hickinbottom, found that The Good Law Project's case was unarguable, that these powers were similar to the legal powers for a pandemic; or other powers to supply medicines without prescriptions.

**Jane Hanna OBE, CEO of SUDEP Action,** has been working on highlighting medicines shortages issues for seven months said, *"Thanks to The Good Law Project and the legal team for taking this to Court. The Court recognised that there was an important public interest regarding Serious Shortage Protocols. The case was made about whether Government had the legal power to be able to make legal changes to allow for Serious Shortage Protocols to happen. Unfortunately, they agreed with the Government's arguments.*

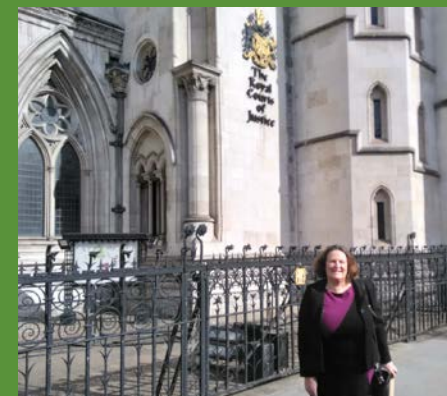
*As an organisation dealing with 21 deaths a week, many of which are avoidable, it is sad to contemplate that powers usually restricted for use during disaster situations, are now available in case of a no-deal Brexit.*

*This new law sidesteps the supply of medications by prescription, by a clinician who knows patient history, and has been rushed in at great speed, bypassing public consultation and any in-depth scrutiny. This is worrying given the potential consequences to people with epilepsy who may already be at an increased risk of death, people who should be kept at the heart of decisions involving their medication and any changes they may face.*

*We will continue to lead a campaign to shine a light on the causes of medicines shortages and why the public interest is to mitigate against increasing risks to the supply of life-saving medicines"*

Maxine Smeaton, CEO of Epilepsy Research UK, which has supported the campaign said, *"Research has shown that establishing the correct dosage and combination of medications to successfully control a persons' epilepsy and associated conditions can take months, or even years, with careful thought and consideration from clinicians in both primary and secondary clinical care teams. Upsetting the careful balancing act of medications and adjunctive treatments may reduce seizure control and increase risk of life-threatening seizures."*

Phil Tittensor, Epilepsy Specialist Nurses Association representing concerned clinicians commented,



*"Epilepsy like many life-threatening conditions, is complex and requires prescribing by specialists who know the patient and have access to their medical record. For some it may take years to establish the best anti-epileptic drug treatment. Changing this treatment without a full consultation between the specialist and the patient will, in many cases, have serious consequences, ranging from the social and psychological impact of further seizures, through to the impact on driving, work and safety, including the increased possibility of SUDEP. At this stage, we have still not had formal guidance whether epilepsy is wholly exempted, partially exempted or not exempted at all from the Serious Shortage Protocols. The circumstances when this new power can be used by a minister to override prescriptions remain dangerously wide"*

If you continue, like us, to be worried about medicines shortages, you could write to your local MP about this issue, expressing your concern. Some MPs hold local surgeries, so you could even arrange to meet them to discuss this with them in person. **Contact us if you need a letter template or more information on how to find out your MP's details.**

## BRITISH MEDICAL JOURNAL (BMJ) AWARDS 2019

We are thrilled to announce that SUDEP Action and its partnership of researchers and clinicians, have won the Education of the Year award at this year's British Medical Journal (BMJ) Awards 2019.

This respected award recognises the success of two epilepsy safety tools; the digital app **EpSMon for people with epilepsy**, and the **clinician tool, the SUDEP & Seizure Safety Checklist**. Since their launch in 2015, these tools have been recognised as having the potential to **transform epilepsy patient safety** and **improve outcomes** for people living with the condition.

The safety tools won a BMJ Award in 2016 for Neurology Team of the Year, and 'Highly Commended' for Innovation in 2017. Also, in 2016, the tools won the Health Service Journal (HSJ) Award for Education and Training in **Patient Safety**. EpSMon was also featured as one of six projects chosen by the NHS to celebrate digital innovation within healthcare, as part of their 70 year anniversary in 2018.

**The award judges commented,**  
*"The Epilepsy Safety Education programme has tackled a major problem in epilepsy – the problem of preventable deaths. The programme has involved a safety checklist for clinicians to help them better manage risk in patients and also a patient-facing app. It is about education of clinicians and patients, and driving shared decision making. The programme is both original and ground-breaking and will have a major impact in improving care for patients and their families. Epilepsy Safety Education is*



(Pictured L to R: **Sammy Ashby** - Deputy CEO, SUDEP Action, **Dr Craig Newman** - Senior Research Fellow, University of Plymouth, **Dr Rohit Shankar MBE** - Clinical Director Cornwall Partnership NHS Trust Hon. & Associate Cl. Professor Exeter Medical School, **Dr Brendan McClean** - Consultant Neurologist, Royal Cornwall Hospitals Trust)

*an outstanding winner of the Education Category of the BMJ Awards."*

With over 600,000 people in the UK with epilepsy, there are a lot of people that are impacted by the success of such a conversation and ongoing education on epilepsy risks.

**Sammy Ashby, SUDEP Action Deputy CEO & Project Manager** for these projects commented

*"We're delighted that these projects have been recognised by this award; many people with epilepsy and their clinicians are not well supported to reduce their risks, yet these simple conversations and checks have the potential to save many lives each year. 21 people die every week in the UK – every one of those is worth fighting for. By reaching even more people with these solutions, we hope that future lives can be saved, in memory of those who have died."*

The **SUDEP & Seizure Safety Checklist** was developed in Cornwall (UK) as a collaboration between SUDEP Action and Cornwall Partnership NHS Foundation Trust. It is supported by a Development Group of leading experts in the field, and is entirely **funded by bereaved families** in memory of their loved ones.

Currently used by over 700 clinicians nationwide, it provides the latest research on epilepsy risks to clinicians, boosting their own professional education. It also aids the monitoring and discussion in appointments about a patient's epilepsy and general wellbeing - informing them of possible health risks. Research findings have already shown that these discussions are potentially lifesaving.

**EpSMon** is an epilepsy self-monitor app, which encourages people with epilepsy to actively monitor and take action against epilepsy risks, in between appointments. Based on the information and research within the Checklist, EpSMon enables users to assess their epilepsy and overall wellbeing periodically, calculating and informing them of when a clinical appointment may be appropriate. This further improves patient safety and knowledge by alerting the individual about any specific risks that may not necessarily be picked up elsewhere. Research on the app has shown that **44% of users hadn't previously had epilepsy risk discussions with their clinician**, despite the app showing they were experiencing known epilepsy mortality risks.

**thebmj**awards  
WINNER 2019

**Dr Craig Newman** said:

*"It's just amazing news. To have won once was fantastic and twice is unheard of within this sector. Winning the prize was only heightened by winning it alongside a team I greatly admire. Hopefully this recognition will help more people become aware of the app because that's the whole point of research and digital innovation – making a positive difference to those who need it most."*

**Dr Rohit Shankar MBE** added,

*"The recurrent and renewed recognition of the updates and developments of the epilepsy safety project is an endorsement of its potential to make a difference in saving lives of all people with epilepsy, particularly those at higher risk i.e. those with ID, mental illness, comorbidity or socially deprived. The project benefits from a diverse range of expertise. The hope is where the NHS Long-term plan has indicated digital technology to be a big driver of change in health care delivery EpSMon and the Checklist are vanguards and templates to it."*

**Dr Brendan McClean** said,

*"The award shows that our programme of empowering patients, and supporting those who are vulnerable, can make a difference. It has been a team effort, not least from the patients, their families and the charity, who have been involved from the outset, and have made it such a success. We would hope that what we have developed will be implemented nationwide, to allow others to benefit from what we have achieved."*

If you would like more information about how to reduce epilepsy risks, visit: [www.sudep.org](http://www.sudep.org) or call 01235 772850.



## VITAL GRANT RECEIVED WILL HELP BETTER SUPPORT EPILEPSY BEREAVED FAMILIES

People who have been bereaved by epilepsy will be given practical and emotional support, from SUDEP Action, thanks to a £4,000 grant from **Oxfordshire and Berkshire Freemasons**.

Epilepsy, one of the most serious neurological disorders, is responsible for 21 UK deaths a week, with 42% of these deaths being identified as avoidable. The most common cause is from Sudden Unexpected Death in Epilepsy (SUDEP). People bereaved by epilepsy are often left traumatised after the sudden and unexpectedness of an epilepsy related death. Traumatic bereavement itself can have a long lasting effect, with many going on to suffer poor mental health for many years.

SUDEP Action, based in Wantage, will be using the grant to help fund a bereavement case worker to support these people. The new case worker will provide a bespoke service in the immediate aftermath of an epilepsy related death, which includes advocacy, information and advice. They can also assist the bereaved with their interactions with the coronial service, and other agencies; this unique service is combined with ongoing support.

Approximately 300 epilepsy related deaths have occurred just in Oxfordshire, since SUDEP Action started in 1995. The grant from Oxfordshire and Berkshire Freemasons comes through the **Masonic Charitable Foundation** (MCF), which is funded by Freemasons, their families and friends, from across England and Wales.



*\*Pictured L-R: Jane Hanna OBE (SUDEP Action CEO), Adrian Barlow (MCF), Mark Phillips (SUDEP Action Trustee)*

**Jane Hanna OBE, CEO at SUDEP Action,** said:

*"We're very grateful to Oxfordshire & Berkshire Freemasons for their generous grant. It will help bereaved people maintain control of their lives, reduce trauma and meet their needs for answers, with a view to preventing future deaths."*

**James Hilditch, Head of Oxfordshire & Berkshire Freemasons,** said:

*"I'm very pleased we've been able to support SUDEP Action. They do truly outstanding work raising awareness of epilepsy risk and supporting people bereaved by epilepsy."*

SUDEP Action work to prevent future deaths and support families who lose a loved one; receiving no Government funding for this work.



## MY STORY - HANNAH

My daughter, Hannah Louise was born 26 May 1992. She weighed just 4lbs 12.6ozs, even though the pregnancy had no problems, she was so tiny. Hannah was my eldest daughter.

Aged six months, Hannah was diagnosed with infantile spasms.

As she grew, she could talk and was toilet trained. Her seizures were around five a month. When Hannah was nine, her speech stopped, and she went back into nappies and her seizures increased. Hannah was diagnosed with Lennox Gastaut Syndrome, a severe, rare form of epilepsy. I was told when she was born, her brain cells went in the wrong place.

When Hannah was in her late teens, her seizures became more frequent and more violent. They would be so bad; her lips would turn blue. She often had one after another, after another, and she would sleep for hours afterwards.

Hannah went to an amazing school, which specialised in epilepsy. She loved to go swimming, watch Barney, rip up catalogues and suck tea towels. She loved her food, would eat anything. The week before it happened, her seizures were so bad and more frequent, sometimes 10 to 20 a day.

The night before, she had come back from respite, and she had been having seizures all day at school. When she came home she had five in a row, she was so sleepy, I put her to bed early and kept watch on the camera. Through the night I looked at the camera and she looked as though she was sleeping.



In the morning, I kept watch through the camera and let her have a lie in. I took her breakfast through to her and pulled the curtains. After her breakfast, I was going to bathe her and watch her favourite Barney DVD together. Then, I went to wake her and get her ready.

Hannah was face down in her pillow, her face had gone a horrible colour. I turned her over and her last breath escaped. They said she had a seizure and had suffocated. It would have happened about 2 or 3am.

Hannah died on 2 March 2018.

The funeral was a month later, everyone wore purple and wrote on her coffin and placed Barney stickers on it.

Hannah's birthday is in May. Last year we went to Southend and threw purple roses in the sea and will do so every year.

I miss Hannah so much, she was my world. It's so hard with her gone. I have her ashes in a purple urn with butterflies on, which I keep in my bedroom. I talk to her throughout the day. My youngest daughter and I had tattoos of a dinosaur and Hannah on our wrists.

It's been over a year now, and I still can't believe she's not here.

**Tracey, Hannah's mother**

## MY STORY - CAROLYN

My mum Carolyn died suddenly due to epilepsy on 23 June 1992, aged 35.

I was at home with her the day it happened. Aged 14. My dad was waiting for us in the car outside, my nan had to come by to help that day. My twin sisters were not home fortunately, they were 11 years old at the time.

My mum used to have a lot of big grand mal (generalised tonic clonic) seizures every day. A few weeks before she died she had a big one and ended up in hospital. She wasn't herself when she came out, and I believe she should have been monitored more closely. A few weeks prior to that, the neurologist took her off one medication and changed her to another, to try to get her seizures under control. But the new medication wasn't working, she was having more seizures, which was distressing.

It was frustrating that she had to wait months to see the neurologist.

The day mum died we were going out to get me some shoes, and mum had a grand mal seizure that didn't stop.

She was a large lady, I helped mum as much as I could. My dad froze.

I frantically tried to get help. The ambulance got lost for an hour, and unfortunately, she died.

My nan (mum's mum) and grandad were heartbroken and grieved until my grandad died after heart problems and my nan died from cancer. My nan used to say, 'your daughter is not meant to go before you.'



The day that mum died, we lost who we were and struggled to cope in life, and every birthday and Christmas, we missed the family unit we had.

Until recently, I felt I had to make things like mum would have, otherwise we would be letting her down.

I felt that I had to look after my dad, and my sisters in a mum role, as she was not here.

Dad and I have struggled mental health wise, and always feel we could have done more maybe. But in the situation at the time, we tried the best we could, and my nan did too.

I wrote to an epilepsy organisation to ask what they would have done in my position on that day. As I still felt I should have done more. The helplessness and despair, and not knowing how to help mum on that day, had broken me.

They replied that I was so young at the time, that there was little I could have done. I realise now that my dad was in shock, which is why he froze.

I tried taking first aid courses in the last few years to try to help someone else in future. Maybe with the progress of defib units in the community, and mobile phones nowadays, help can be sorted quickly now.

Mum worked for a short time as a care assistant. She loved making residents happy. She once dressed up as Santa for them, and us. She used to like making clothes and jewellery and was an active part of the community. She helped and cared about others. I am disabled, and she fought for disability rights and fairness, and tried her best to get me included in society as an able-bodied person.

She liked meeting new people and would give anything a go if she was able to.

She was well liked and loved.

She liked scrabble, monopoly, writing poetry and I found poems after she passed. Some funny, witty ones. Ones which expressed her frustration/depression that her epilepsy had robbed her of life in many ways. She wanted to do other things in life but couldn't due to epilepsy. She had such a passion for life. We will never forget her sense of humour or her sense of fun.

I had to look after my dad and my sisters when we were growing up. My sisters left home as soon as they could, they didn't understand that dad was grieving, and he didn't know how to cope in life without my mum. We all

went through so much individually, and we still don't really talk together as a family about the grief part, too painful. My dad and I don't see my sisters much anymore. The grief and trauma of losing mum changed them. They are still finding their way and building their own lives. Being with dad and I, I think reminds them of mum, and what losing her did to our family.

There's still an anger there from them about losing mum, and they feel anger at me for the closeness dad and I have, but we needed each other to recover. Although we tried to help my sisters, they didn't understand dad had to look after me due to my disability. Emotionally we connected a bit more. My sisters, being twins, always kept their bond together, which helped them through.

One of my sisters, who has epilepsy, decided to become a care assistant at the care home where my mum used to work for a short time. She also decided to do a hairdressing course, as my mum always wanted to do hairdressing. She has three boys, one of which has epilepsy – she makes sure he enjoys life to full, he plays football and is a joker. She didn't think she would make it to 35 years, after mum.

My other sister has my mum's determination, no nonsense attitude and sense of humour. She has four boys. Two of which are disabled, one has epilepsy. But like my mum, she fights for him to get the right treatment, and she home-schools him. She makes sure he enjoys life too, and when times are tough, she will ring me.

My mum will always be within us.



My dad still puts flowers on mum's grave on her birthday, valentines, etc. He still loves my mum, as we all do.

Epilepsy did take mum from us suddenly, and this still hurts.

It has robbed us with years of grief. Maybe if we had more help to deal with the grief and trauma at the time, our life would have been better and maybe our mental health wouldn't have suffered as much.

However, we have learnt so much about each other, and we are grateful for the small things in life, as mum

was. We like helping others, and I hope one day, no one has to lose anyone to epilepsy.

My mum was a loving wife, a caring and devoted mother and a daughter and a sister, who will always be remembered.

I recently found SUDEP Action, just at the right time, to share our story.

It's really only this year that I feel I am starting to see life going forward.

**Donna (daughter) and on behalf of my dad, Tom.**

## Do you want to get involved with SUDEP Action?

There are many ways you can get involved with the charity and help us with our constant fight to reduce deaths from epilepsy.

**My Story** - is an important and powerful way for you to join our campaign by sharing your story. Contact our Communications Manager - [shelly.johnson@sudep.org](mailto:shelly.johnson@sudep.org)

**Awareness and events** - raise awareness by campaigning, volunteering, or attend one of our charity events - [info@sudep.org](mailto:info@sudep.org)

**Fundraise** - Celebrate the life of someone special whilst raising vital funds - [fundraising@sudep.org](mailto:fundraising@sudep.org)

Your efforts, whatever you do, however active and however much you raise - makes a difference to what we can do.

**We would love to hear from you.**



## AIMEE DAWES

**Aimee Dawes and her sister** completed the Olympic Park Half Marathon! Aimee informed us: "I ran the Olympic park half marathon with my sister to raise money for SUDEP Action! I chose to raise money for this charity in memory of a close friend's sister, who sadly died 2 years ago. The run went well, we are planning to do another event in the summer to raise more money and awareness."



## THE LEEDS UNIVERSITY UNION WOMEN'S HOCKEY CLUB

**The Leeds University Union Women's Hockey Club** support SUDEP Action following the loss of team member Emily Sumaria. Community Secretary, Geni Carter informed us: "LUUWHC are now almost half way through this year's fundraising and are so pleased with how much has already been raised for SUDEP Action. We've had someone swim the entire length of the Channel herself, our annual Race Night, a pub quiz and we introduced a Karaoke Night which definitely proved



to be a fun night for all. The Yorkshire Three Peaks Challenge, Leeds Half Marathon and many more fundraisers are still to come, we can't wait to raise even more!"

## MELISSA COOK

**Teresa Cook, Simon Cook, Erin Theobald (RM Manager) and Melissa Cook** raised funds in memory of Megan Cook. Teresa commented "A raffle was held in memory of Megan Cook who passed away to SUDEP August 31st last year. The raffle enabled us to also raise awareness in and around the Lincolnshire area. We miss Megan every minute of every day."



From left to right is Simon, Erin, Teresa and Melissa.

## REBECCA BOULTON

Rebecca Boulton made the most of Purple Day and her hobby by hosting a boxercise event. She detailed "I'm 43 and I was diagnosed with epilepsy six months ago after having two seizures out of the blue (the 2nd was in the car whilst driving home from work). I decided to try and find a positive from this.

Throughout my initial diagnosis when I had to have all the tests etc, going to my local boxercise class was my release. I decided to use this to my advantage and on #purpleday I was sponsored to take over the class for the evening (no easy task for anyone!!!) We've raised



a phenomenal amount of money and awareness for this cause of which I am extremely proud and thankful for having such great family and friends who helped along the way."

## CLUGSTON CONSTRUCTION

We are **Clugston Construction Limited's** charity of the year and in March they held a Purple Day event. Claire Drayton, Marketing Services Officer said "We had a great time on Purple Day raising funds for SUDEP Action, our chosen charity for 2018/19. Team members got into the spirit of things, a couple even dying their hair purple."



## SAORLA KEARNEY

Chatterbox **Saorla Kearney** had a great idea of taking part in a sponsored silence in memory of Shane Corrigan. The silence was for three hours and talking involved consequences such as a cream pie in the face, a bite into a lemon slice, ice cold water poured over her head, an egg smashed on her head or herself wrapped in toilet paper! Donors could also buy consequences!



Saorla commented: "It was really good, I had so much fun. Some of it wasn't that nice and sometimes it was hard to do. My head teacher has asked me

to talk about it at my school assembly next week. I'm really glad I got to make some money that will help people."

## TANYA RUSSELL

**Tanya Russell** hosted her second ball event in loving memory of her daughter Johdi. She informed us "So last year was big but this year was even bigger. I had high hopes of achieving 300 guests (75 more than last) but smashed that vision with just over 400. I remember at one point standing on the stage looking out at everyone laughing, dancing, chatting all having a great time together - and realised they were all there to show their love and support to myself and my family all in memory of my beautiful Johdi."



## MAUREEN SAYER

The **Soroptimist International of Heswall & District Club** ended their year of fundraising, in memory of Caroyln Sandland with a fantastic music event. President **Maureen Sayer** commented "Soroptimist International of Heswall & District Club were supported by the Wirral Singers to produce an event on the 5 April at Heswall United Reform Church raising funds for SUDEP Action, through an evening of music, rhyme and bell ringers, raffles and refreshments.




Donations were made by local florist Hare & Hatter, and pubs Jug & Bottle, and Fox & Hounds, and dress shop, Sue Huntington. It was a delightful musical evening for all. Sandra Sandland informed the audience about SUDEP Action."

Keep Wednesday 23 October 2019 in your diary. We'd love for you to be involved in this year's global event. More details will be released soon.







SUDEP Action

## Speak Their Name



Someone I love has gone away  
and life is not the same,  
the greatest gift that you can give  
is just to speak their name.

I need to hear the stories  
and the tales of days gone past,  
I need for you to understand  
these memories must last.

We'll never make more memories  
since they are no longer here,  
so when you say their name to me  
it's music to my ear.

Anon

SUDEP.ORG

SUDEP Action is dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths, including Sudden Unexpected Death in Epilepsy (SUDEP). We are the only UK charity specialised in supporting and involving people bereaved by epilepsy.

Bereavement support:

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

Getting involved and campaigns:

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

Fundraising:

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

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Oxfordshire OX12 8DA

Call: **01235 772850**  
Email: [info@sudep.org](mailto:info@sudep.org)

SUDEP Action, registered charity 1164250 (England & Wales), SC047223 (Scotland)

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