



# Information and Sponsorship Options Sunflower Ball and Charity Auction

7 April 2018



## CONTENTS

ABOUT CHARLIE .....	2
OUR FUNDRAISING .....	2
THE CHARITY - SUDEP ACTION .....	3
CHARLIE'S STORY – SIMPLE STEPS .....	3
EVENING ITINERY.....	4
YOUR HELP .....	4
SPONSORSHIP PACKAGES .....	5
CONTACT US .....	6

# In Memory of Charlie Burns



04 Oct 2001 ~ 11 Oct 2011

10 Years of Joy

Raising Awareness of SUDEP - Sudden Unexpected Death in Epilepsy



<http://www.justgiving.com/SUDEP-Awareness> or text CHAZ96 £(amount) to 70070

## ABOUT CHARLIE

Until the 07 Oct 11 Charlie was a perfectly fit and healthy 10-year-old boy. Four days later on the 11<sup>th</sup> October 2011, a week after his 10<sup>th</sup> birthday our gorgeous little boy died.

Charlie had his first witnessed seizure on Friday 7<sup>th</sup> October 2011. The Paramedics arrived some 12 minutes later and took over. They incorrectly diagnosed this incident as a Febrile Convulsion and failed to take Charlie to hospital.

Over the weekend Charlie was fine but we were not happy with the diagnosis, on Monday 10 Oct, we took him to see our local GP. Charlie explained that he often woke up during the night gagging and needing a drink and quite often couldn't feel the rest of his body. Our GP suggested that Charlie might be suffering with Nocturnal Epilepsy and referred him for an emergency appointment to see a Neurologist. The earliest available appointment was the on 18<sup>th</sup> November 2011.

On Tuesday 11 Oct 11, Charlie went to school as normal, showing no signs of sickness or temperature throughout the entire day. He played with his mates in the new recreational area in Larkhill after school until we called him in. He was totally himself and we took him to visit his sister at boarding school. We had a lovely evening and Isabella felt much better having seen Charlie, who was his normal self and we had such a happy and funny evening together.

Charlie went to bed that evening at 8:45 pm, an hour later he had died. We were downstairs and heard nothing!

## OUR FUNDRAISING

Due to our constant fundraising events and raising awareness of Sudden Unexpected Death in Epilepsy (SUDEP), over the last 6 years we have managed to raise a staggering £68,000 as a family. Predominantly the funds have been directed to **SUDEP Action**, but also the Stars Appeal, Wiltshire Air Ambulance and FAB (Families Activity Breaks – a Military charity who support bereaved Military Families).

We are fully supported by Claire Perry our local MP, who is working to raise the profile of SUDEP in Parliament and is now a Patron of the charity. We have spoken at the Houses of Parliament during the launch of the **Epilepsy Deaths Register** and last year attended an evening reception at **10 Downing Street** hosted by Samantha Cameron. During this evening, SUDEP Action launched an appeal for research into the Wearable Apnoea Detection Device (**WADD**). This is where our fundraising efforts were directed over the last 2 years. We are extremely pleased to announce that the European Research Council (ERC) has awarded the WADD €2 million for its development over the next 6 years!

We as a family are extremely proud to have been awarded the '**Fundraisers of the Year' 2017** at the Spire FM Local Hero Awards. This is an honour that we can only put down to the support and backing that we receive from all of the public in our quest to raise awareness of SUDEP -The Silent Killer.

## THE CHARITY - SUDEP ACTION

Epilepsy is one of the top-ten causes of early death, 21 people every week in the UK die from epilepsy, that's more than Cot Death or AIDS combined. Sudden Unexpected Death in Epilepsy or SUDEP has no cure. SUDEP Action, focus their efforts on the priorities that are important to bereaved families:

- To prevent deaths
- To be supported
- To be involved

As relatively small and charity, it leads the way across the world in the research and development in technologies that could prevent future deaths. They were recently awarded a Global Impact Award on Epilepsy, one of the highest honours from medical and patient organisations working in the epilepsy field. SUDEP Action was founded 21 years ago by a group of people who had been bereaved themselves due to SUDEP. The charity relies solely on public donations and a significant percentage of those donations are raised by families like us that have lost a loved one to SUDEP.

The charity is committed to preventing SUDEP and other epilepsy deaths through research, awareness and influencing change. They lobby clinicians, health managers and policy makers with the aim of raising awareness and ultimately reducing the risk of epilepsy related death. SUDEP Action currently works in partnership with Kings College Hospital London and University College London and many other specialist organisations.

This year we have been heavily involved in the charities new **#Prevent 21** campaign, which aims to raise £1 million to try and prevent 21 deaths a week to SUDEP. We have pledged to raise a huge £21,000 towards this campaign.

## CHARLIE'S STORY – SIMPLE STEPS

During our Campaign to raise awareness of SUDEP, we have also been on our personal journey to ensure that the medical services are aware that it is one of the top 10 killers of premature deaths in the UK. We found that so many things were wrong and that even most experienced medical staff were not aware of the condition. We have worked very closely with South Western Ambulance Service Ambulance Trust (SWAST) to rectify this as a result of a Parliamentary investigation into the failings identified in Charlies Treatment. In April 2017 **Charlie's Story** – Simple Steps training videos and teaching pack was released. It has now been taken on as a part of the Paramedic annual training in 10 of the 12 ambulance trusts in the entire UK. We are still working on the other 2 areas!!

The Patients Safety Council have an e-learning version of the training and it is now mandated to all paediatric consultants, doctors and specialist nurses.

## EVENING ITINERY

- Date:** Saturday 7 April 2018
- Venue:** The Stones Hotel, High Post, Salisbury, SP4 6AT
- Time:** 1830: Arrival Drinks Reception  
1915: Three Course Dinner  
2030: Entertainment Part 1  
2115: Introduction and Auction  
2230: Entertainment Part 2 and Raffle Draw  
0100: Carriages

The evening entertainment will be packed with a full line up which will include Rock Choir, Viva Las Vegas Fun Casino and the fantastic local band Innervision, Wayne Savage Caricaturist.

Formal photographs as well as a fun photo booth will be provided by **John Rose Photography**, which will be available throughout in order to capture your night.

**Dress Code:** Black Tie and Cocktail Dresses

**Cost:** £50 Per Person or £450 Per Table (10).

The cost includes, Arrival Drinks Reception, 3 Course Dinner and a full night of entertainment.

**Accommodation:** For those that wish to stay overnight the '**Stones Hotel**' are offering a discount for a double or twin room with breakfast, for £90 per room. To take advantage of this offer please book direct with the hotel on 01722 782020. Please quote 'Sunflower Ball', a deposit of £15 will be required.

## **TICKET SALES**

## YOUR HELP

It is through the support of local businesses that we are able to continue to run such large events. As a family, we are extremely pleased to offer you this unique opportunity to promote your local business whilst making a huge difference to thousands of people who suffer from epilepsy or have been bereaved through an epilepsy related death.

There are many ways in which you can help support the Sunflower Ball by attending, sponsoring the event, being there on the evening or by donating prizes to either the auction or raffle, which will take place through the evening. Full details are on the next page, however if you have something particular that you are willing to offer then please do **contact us** to discuss the option.

There are 120 tickets available which are selling very well and it looks like they will sell out. Once again, we are pleased to have Spire FM joining us which always helps to publicise the event. Indeed, they have followed our fundraising from the very start of our campaign.

## SPONSORSHIP PACKAGES

### Headline Sponsorship - £1500

- A Table of 10 on the night in a prime location
- Logo to appear on all advertising 'As Sponsored by' Social Media, Tickets and Emails
- Public Acknowledgement at the opening address
- Full Page advert in the Souvenir Brochure (artwork to be provided by you)
- Logo and Advert to be displayed in the Main Room Screens and Casino
- Self-Promotion of Pop-Up banners in the main rooms and Casino
- Logo on the Fun Casino Money
- Adverts and Links displayed regularly through Social Media

The above is not an exhausted list if we can Thank You in any way possible for your support we will do what we can

Please get in touch if this is of interest to you

### Gold - £750

- 4 x Free Tickets to the Ball
- Full Page advert in the Souvenir Brochure (artwork to be provided by you)
- Logo on the Back-Cover Page of the Souvenir Brochure
- Logo included in the Thank You page of Souvenir Brochure
- Self-Promotion of Pop-Up banners in the Drinks Reception
- Logo on Screens in the Main Room
- Social Media Thanks You's including links

### Silver - £500

- 2 x Free Tickets to The Ball
- Half Page advert in the Souvenir Brochure (artwork to be provided by you)
- Logo included in the Thank You page of the Souvenir Brochure
- Logo on Screens in the Main Room
- Social Media Thank You's

### Auction and Raffle Prize Donation

In order to make the Charity Auction and Raffle work it is essential to have excellent prizes. Donations of prizes for our Auction and Raffle are very gratefully received. Auction and Raffle prizes will be listed on the night as well as acknowledgement of donor.

**\* Raffle prizes are requested to be in excess of £20 in value.**

### Match Funding

Match Funding is a popular way for companies to assist in raising money for charity events. If your company has such a scheme and you want to use it for a great cause then please contact us and we will be more than happy to discuss how you could utilise the offer in this event.

### Purchase Tickets

We welcome local businesses along at our events and this is your opportunity to purchase tickets for a night of fun packed entertainment as well as an evening of awareness and fundraising. Please book your tickets online using the link below.


**[TICKET SALES](#)**

## CONTACT US

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**SUDEP Action**   
*Making every epilepsy death count*

SUDEP Action Registered Charity: 1164250