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Welcome from CEO Jane Hanna

Dear friend,

I hope you are well.

The Spring is here after the most difficult year in our 25 year charity history. On **Wednesday 5 May** we will be remembering loved ones that we have lost to epilepsy, during our <u>Online Epilepsy Memorial Day</u>. You will be able to access content throughout the day via <u>our Facebook page</u> and encourage you to **dedicate a cherry tree** to your loved one on our online dedication wall – Forever remembered, Forever missed.

We will also hear readings from a number of special guests, and we will close the day with **candle lighting at 7pm**, where we invite you to light a candle in remembrance of your loved one too.

Ahead of our Online Epilepsy Memorial Day, I am sharing the sad news of the death of **Dr Rosey Panelli**, a member of our team, who worked for her life-time changing hearts and minds on epilepsy, epilepsy risk and SUDEP. You can read my tribute to my dear friend and colleague, and can add your own tribute.

Your support is amazing and is helping to keep people safe. During the pandemic, because of your support, we have been able to bring the <u>SUDEP</u> and <u>Seizure Safety Checklist to half of GPs in England</u>. We have also been there for suddenly bereaved families helping them fight for inquests, giving support and involvement.

If you would like to get involved and help keep our work going, either through regular giving or by taking part in a sponsored event in 2021, please click on the links in the newsletter below to find out more.

SUDEP Action gives our thanks to all the supporters and donors who are so vital to our cause, and who have made SUDEP Action what it is today. We continue to be here for you too – as always, you can reach us on **01235 772850** or email us at info@sudep.org.

We are here to help in any way we can.

Jane Hanna OBE CEO SUDEP Action



Help Prevent 21 Challenge

A very big thank you and well done to everyone who took part in <u>SUDEP Action's Help Prevent21 campaign</u> this winter – your creativity and commitment in achieving your goals and remembering the friends and loved ones you have lost to epilepsy is inspiring!

Together you raised vital awareness of the more than 21 epilepsy deaths each week in the UK, and you raised over £3,185 to support others through the Prevent 21 campaign.

If you have been inspired by these brilliant challengers to take on some fundraising for SUDEP Action please email us on fundraising@sudep.org

Saving lives with EpSMon

SUDEP Action has been working hard with partners to develop <u>EpSMon</u>, **a free mobile app** that allows those with epilepsy to monitor their health and provide a comprehensive report to their health care professionals, minimising the number of avoidable deaths caused by epilepsy.

If you know someone with epilepsy, why not tell them about the EpSMon app today. Learn more about the app



SUDEP & Seizure Safety Checklist now downloadable for 50% of GP surgeries

Thanks to a collaboration with Ardens, SUDEP Action is now able to make the SUDEP & Seizure Safety Checklist ('Checklist') instantly downloadable to over 50% of GP surgeries across England.

The award-winning Checklist is a free evidence based tool which supports clinicians in discussing risk with their epilepsy patients.

Read more and spread the word!



Feeling lucky?

Have a look at the <u>SUDEP Action lottery</u>, **for weekly chances to win up to £25k!** Winning numbers are announced each Friday across our social media platforms.



An article by a bereaved mother

Recently featured in **The Guardian** was an article written by one of our supporters Sophie Pierce, a loving mother who sadly lost her son Felix to SUDEP in 2017.

Read about Sophie's experience

A gentle reminder that we are always here to support you, no matter how much time has passed. If you would like to share your story with us you can by emailing support@sudep.org or calling us on 01235 772850.



Raise money for SUDEP Action

Help us continue to bring benefits to those with, or bereaved by, epilepsy.

Take a look at our website for more details on events and how you could take part.



#PurpleHeartsAtHome this Purple Day

Thank you to everyone that took part in Purple Day 2021. On the 26th March 2021 many of our supporters from across the world shared stories of their loved ones and pictures online of something purple, including one or many purple hearts which was the theme of SUDEP Action's Purple Day.

A big thank you to the all the schools whose pupils took part in the Day in many creative ways, here are just a few:

- Dolphin School, Berkshire
- The Downs Primary and Nursery School, Harlow
- · The Kings of Wessex Academy, Cheddar
- Ysgol y Bedol, Garnant

Below are some photos from the day.









Regular giving It all adds up.

Find out more about how you can become part of this team of vital supporters.



Because of your regular gifts each month, quarter or year SUDEP Action is able to continue to provide our valuable support for as long as people need us.

Find out more about how you can become part of this vital team of supporters. Visit our <u>website</u> or contact <u>fundraising@sudep.org</u> for more details.



SUDEP Action led COVID-19 research shows rising epilepsy risks & decreased access to epilepsy services

The COVID-19 pandemic has had a significant impact on the lives of individuals and communities across the globe. People with epilepsy are no exception, with many people experiencing changes in their day-to-day routines, access to healthcare and increased exposure to seizure risks.

Research recently published in <u>Epilepsy & Behavior</u> shows people with epilepsy are at increased risk due to the impact the COVID-19 pandemic has had on epilepsy services and the wider community.

For more information on our findings visit our website.

Key dates

Online Epilepsy Memorial Day: Wednesday 5 May 2021

National Epilepsy Week: 24-30 May 2021











SUDEP Action and SUDEP Action Scotland are the working names of Epilepsy Bereaved Registered Registered charity number 1164250 (England & Wales), SC047223 (Scotland).

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