SUDEP Action



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Feb 2021





Welcome to our February e-news

Dear friend.

As you read in this e-news, you will see how we have increased our impact, continuing to give witness to all lives lost, and presenting how this could be different, if the whole system led the change that is needed, as we move through this pandemic, towards our future.

SUDEP Action worked with MBRRACE on the latest maternal report, and has met with Baroness Cumberlege (Chair of an independent review of families concerns about Sodium Valproate), and other national leaders this month to urge action across all deaths. Specifically on women with epilepsy, who are facing a range of worrying messages about their condition and medications at the moment, we are calling for **rapid access to EpSMon and the Checklist** and urgent changes to national policy and media communications.

Our <u>HelpPrevent21 Challenge</u> is running between 21 Jan to 21 March, helping to raise awareness of epilepsy risks and supporting others.

Also, we've an exciting new **Purple Day (26 March) campaign** launching soon, so look out for how you can take part. In the meantime, you can <u>register your interest</u> to hear more about it when details are release.

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. Without you we would not be able to be here for people right now, when they need us more than ever. Your support is amazing and is helping to keep people safe. We continue to be here for you too

- stay well and pick up the phone or email - we would love to hear from you.

You can reach us on **01235 772852** or email us at <u>info@sudep.org</u>. We are here to help in any way we can.

Jane Hanna OBE CEO SUDEP Action

Charity News & Updates

MBRRACE Report recommends free safety tools to help prevent deaths

A national enquiry revealed a doubling in maternal epilepsy deaths over three years, and recommends SUDEP Action safety tools.....



"It's more than a keeper of stories - it's a catalyst for change" THE EPILEPSY DEATHS REGISTER Making every epilepsy death count

New EDR research identifies risk factors in children

Newly published Epilepsy Deaths
Register data learns lessons from vital
reports of SUDEP in Children.

My Story

This month, we've the beautifully written My Story articles in memory of Felix, Fidan and Isabella.

Sharing your story with us can make a real difference to others.

If you would like to, contact us info@sudep.org or 01235 772850



#HelpPrevent21

From 21st of January till 21 March, you



can join the #HelpPrevent21 Challenge and support the final year of SUDEP Action's Prevent 21 campaign.

Whichever activity you choose to do, you'll be making a difference, raising awareness of #epilepsy risk and helping to support others.

For more info, visit our website or join our Facebook group

Regular Giving

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 us <u>fundraising@sudep.org</u> for more details.



Don't forget that we also have a printed newsletter, just email info@sudep.org to be added to the mailing list

Help our Research

The Epilepsy Deaths
Register helps
researchers &
clinicians to learn
lessons from epilepsy
deaths.

For more info, email support@sudep.org

Fundraising

To get involved in fundraising, our Community Services & Fundraising Coordinator, Katie, can help with advice & materials.

Contact Katie on fundraising@sudep. orq

Key Dates

Purple Day Fri 26 March 2021

Online Epilepsy Memorial Day Wed 05 May 2021

National Epilepsy Week 24 - 28 May 2021

We are here for you if you need us.

Our specialist epilepsy bereavement support service is completely free, confidential &

ongoing.

If you would like to speak to our support team, please contact 01235 772852 or email support@sudep.org



You can also follow us on social media...











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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