


SUDEP Action 

Making every epilepsy death count

Winter Newsletter 2022



Jared's
story,
See pages
12-13

Support services integrated
into 70% of GP surgeries,
see page 9



Raising awareness in Senedd

Leader of Plaid Cymru Adam Price (pictured) took time to raise awareness of SUDEP and the work of SUDEP Action in the Welsh Senedd. Adam also learnt more about Hayden Yates, who died from SUDEP, after meeting with his mother Helen.

It's estimated that more than 32,000 people live with epilepsy in Wales. To read Hayden's story go to sudep.org/my-story/stories/hayden



European award for Jennifer

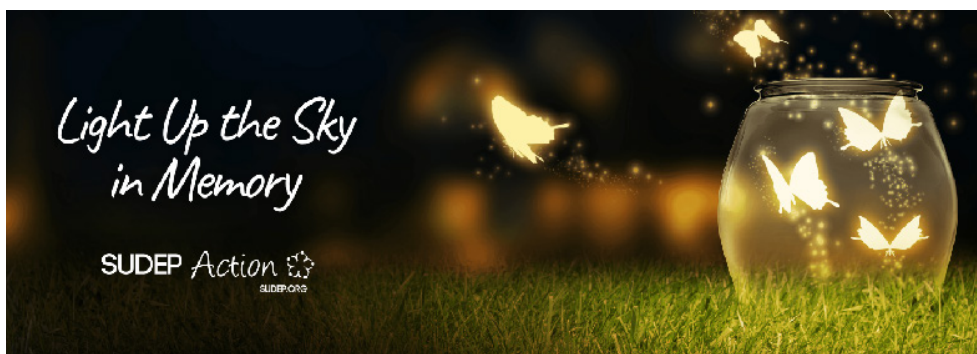
SUDEP Action Research Assistant Jennifer Thorpe was awarded first prize by the International League Against Epilepsy (ILAE) for their Covid-19 research competition – recognising the hard work of researchers worldwide for their work in epilepsy during the pandemic. Jennifer won the 'European prize' for the research project looking into the impact of the pandemic on people living with epilepsy.

Together, we lit up the sky

Thank you to everyone who joined us to Light Up the Sky in November and December, leaving messages, butterflies and photos on our dedicated website page. Thanks also to everyone who left a dedicated message on a butterfly for our office Christmas tree. In total, we received 355 dedications this year.

On Christmas Eve, many also joined together online to light candles in memory of those we have lost.

Pictured right is SUDEP Action CEO Jane Hanna lighting a Christmas Eve candle in our Wantage office.



A letter from the CEO

Jane Hanna



As we enter a New Year I want to begin this letter by thanking all of our wonderful supporters for enabling our work to progress through the pandemic.

Recently, we published our Annual Report which shows that in the last financial year (up to March 2021) we supported 20,493 people, a 25% increase on the previous reporting year.

The report also shows that:

- 9,867 people were helped by personalised services addressing individual need.
- 10,626 people were supported with educational material and training.

The numbers, though revealing, do not tell the full story; that our work with the bereaved is not only highly specialist, personal

and individually meaningful, it is also offered free, for as long as it is needed. We are proud of the fact that we can still make that commitment to people.

Doing what we do on a daily basis has certainly been more challenging in the midst of a pandemic and the uncertainties that brings. However, it's also been apparent that the need for our services right now is greater than ever. Our experiences, in our research and policy work, reinforce this point further.

Looking back on this past year, we have increased

our collaborations and partnerships on the research front, working with the likes of the University of Oxford, Newcastle University, Plymouth University, Exeter University, University College London and Imperial London. We are working behind the scenes on some further exciting projects and collaborations and believe these will emphasise the importance of our services in wider circles as we stand alongside those who need our support during these difficult times. We are looking forward to telling you more about these projects in the coming weeks and months.

We are very hopeful that 2022 will bring increased recognition of the need to be aware of potential risks and, with that, a continued realisation of the usefulness of our tools. However, to return to my opening point, we can only accomplish the many things we are doing with the continued backing of our fabulous, loyal and generous supporters.

To each and every one of you, thank you for standing with us as we stand with you.

Doing what we do on a daily basis has certainly been more challenging in the midst of a pandemic and the uncertainties that brings.

Your efforts change lives



Thank you and well done to Jane Exley and her fabulous team of about 40 fancy dress fundraisers for the brilliant pub crawl event which raised £620 for us, in loving memory of Jane's son Jared Exley (see pages 12-13).

Organising a fundraiser or need help turning an idea into a reality? Give us a ring on 01235 772850 or email fundraising@sudep.org

Thank you for thinking of us

- Aleks Duvnjak completed the Royal Parks Half Marathon in 1:55:34 to raise an incredible £647. And Mike Boardman raised £1,703 for us by running the Manchester Marathon for us in memory of his brother Matt. Thank you!

- Members of the Making Websites Better team tackled the My Way to 5k challenge to raise £625. Business Development Manager Richard Downham also took on the Reading Half Marathon to raise further funds.

- Melissa Biggs's second sponsored haircut, in memory of her best friend Kim, raised over £200.

- Thank you so much to the Leeds University Union Women's Hockey Club for the fantastic race night fundraiser held for SUDEP Action in memory of Emily Sumaria. Emily's mother and SUDEP Action trustee Rachel Shah attended the event.

- Jonjo Warrick organised a concert in memory of his friend Charlie, who tragically died from SUDEP. Live music on the night came from Self Help and Dead Cosmonauts and there were also sets from top DJs.

- Andy Ward raised funds for us in memory of a friend who he lost last year. Andy created two fantastic Christmas tracks and made them available for download.

- Thank you and well done to The Powerbuilding Gym for a lifting event held in memory of Joshua Owen. An incredible £610 was raised.

Anne's Virtual London Marathon raises over £1,300

RIGHT: Thank you so much to Anne O'Neill for taking part in a sponsored 2021 Virtual London Marathon in loving memory of her sister Brigid O'Neill. Including Gift Aid, Anne raised an incredible total of £1,311.25 for SUDEP Action. She said: "I was thinking of my sister Brigid every step of the way, hoping she was looking down on me in my endeavours. I was very pleased to have done the Virtual London Marathon for SUDEP Action, such a very important and personal charity."

BELOW: SUDEP Action has partnered with Run for Charity to offer you charity places at hundreds of different events around the UK. From 5k events to marathons and obstacle challenges, we have a wide range of events on offer. Visit sudep.org/looking-take-part-sponsored-event or contact us via fundraising@sudep.org or 01235 772850 to find out more.



A letter between two brothers

*I carry him everywhere all the time.
Sometimes he's a lead weight and sometimes he's a life
raft. Sometimes he's annoying but oftentimes he's there
to remind me of the finite nature of this life.*

*He is a reflection and daily reminder of my own
mortality and my relationship with the afterlife.*

In memory
of his
brother
Blair, who
died of
SUDEP,
Fraser
Morton
shared
these
beautiful
words.

SUDEP Action expertise supports national review & action to improve care



SUDEP Action was brought in as experts to support a national review looking into a death in care. We were able to support the family's long campaign for justice into Clive Treacey's sudden death.

As a result of our support for the investigation, the fact that SUDEP and the risks of SUDEP had been ignored by professionals through Clive's life, and by the investigators of his death, became central findings of the report that otherwise would have been missed. The report recommends that those

purchasing services for people with epilepsy and learning disability must use a standard risk template for people living with epilepsy that crosses organisational boundaries, such as SUDEP Action's SUDEP and Seizure Safety Checklist. The report also recommends that national agencies make improvements to the investigation of epilepsy-related deaths to ensure pathology guidelines are followed.

SUDEP Action has now been invited by the NHS to help co-design the action plan.

Elaine Clarke says her brother was 'failed in life and failed in death' as the national review found that Clive's death was 'potentially avoidable'.

Clive was 47 when he died on January 31, 2017. His family has campaigned tirelessly since then for his life and death to be properly scrutinised and in July 2020 NHS England commissioned an independent review into the serious matters raised by Clive's family about his experience of care and the

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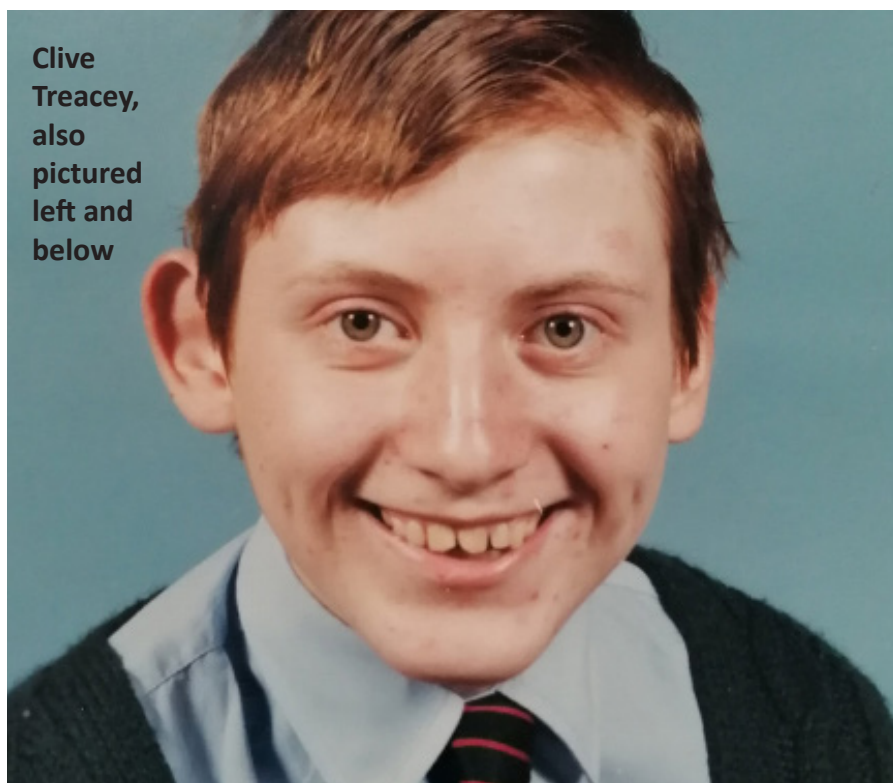
circumstances leading up to his death. At the time of his death, he was living at Cedar Vale in Nottingham, an assessment and treatment unit for men with autism, learning disabilities and complex needs.

The review, which was published in December, found that Clive's death was 'potentially avoidable' and that 'there were multiple, systemwide failures in delivering his care and treatment that together placed him at a higher risk of sudden death'. Clive suffered from epilepsy and the review found that:

- The post-mortem and pathologist's report that followed Clive's death failed to consider epilepsy/SUDEP (Sudden Death in Epilepsy) as the cause of death.
- Clive's epilepsy care fell far short of acceptable practice for someone with complex intractable epilepsy.
- Clive experienced health inequalities throughout his life that had a negative impact on his quality of life, some of which caused him pain and suffering for prolonged periods of time and placed him at greater risk of premature death.

Other findings included:

- Those responsible for commissioning and monitoring Clive's care did not place him in settings that could meet his needs, did not sufficiently monitor the quality of care he received and, on some occasions, this placed him at risk of harm.
- Clive and his family were not listened to and opportunities



Clive Treacey, also pictured left and below



were missed to listen to Clive and engage with his family on how best to meet his needs.

- The emergency response by Cedar Vale staff on the night Clive died was limited, confused and chaotic and may further have reduced his chances of survival.
- The series of investigations and complaints handling that took place after Clive's death were inadequate and may have

resulted in missed opportunities to take action to prevent harm to others.

Elaine said: "We have had to fight so hard to get here. The system should have supported and empowered Clive in his life, but it failed him. We want the failings identified in this review to be addressed so that no one else has to go through what Clive went through or what we have gone through as a family."

Sam's story

Sam was a veteran who served in the British Army until he was medically discharged after sustaining a head injury during an exercise. This resulted in severe epilepsy. Sam had many difficulties after leaving the Army because of the frequent and severe epileptic fits that he suffered.

Sam was a young man in his thirties when he died suddenly. Following a post-mortem, his death was recorded as Sudden Arrhythmic Death Syndrome (SADS). The SADS finding allowed the Veterans Agency to declare that Sam's death was not attributable to his head injury.



I did more research and sought out the specialist support service at SUDEP Action. Our families believed that Sam's epilepsy was too readily overlooked so with SUDEP Action's help we appealed against the findings. SUDEP Action provided us with two documents that became key elements of the appeal and were so convincing that the decision was changed without us having to go through a stressful formal appeal. The Overview of SUDEP document was a concise, but comprehensive, summary of SUDEP and the reasons

why the sudden death of someone with epilepsy should be recorded as SUDEP. The second document was based on the background to Sam's death and highlighted the specific factors that showed that his death should have been recorded as SUDEP, and not as SADS. The documents provided by SUDEP Action were submitted to the Veterans Agency as supporting evidence to the appeal case.

My experience of the SUDEP Action support team has been very positive. Their support had a significant

impact on me, and the two families affected by Sam's death. The unexpected death of a young person will always be distressing, but in this case our distress was increased by the unfair treatment of Sam's widow – my daughter – and the consequent need to challenge the findings of a post-mortem and coroner's inquest. SUDEP Action's support allowed a non-clinician to successfully challenge both findings and helped to secure a young widow's financial situation.

**Stephen,
Sam's father-in-law**

Signposting possible via 70% of GP surgeries in England

Continuing SUDEP Action's ongoing collaboration with Ardens, a letter to contact bereaved next-of-kin with details of support services after a death has now been integrated into over 70% of GP surgeries across England.

Ardens, who provide templates and resources for EMIS and SystmOne patient record systems, have now added extra options in their systems to enable clinicians to contact the next-of-kin when an epilepsy-related death has happened, along with guidance on where they can turn to in order to:

- Arrange a funeral
- Register a death
- Get answers to their questions about a death and what has happened
- Understand the investigations after a death
- Understand the inquest procedure
- Access specialist support and counselling

For health professionals using EMIS patient record systems, there is also an alert available which will prompt clinicians to access the signposting letter, if appropriate. Research involving people bereaved by epilepsy-related death has shown that all-too-often, they are not contacted after the death of a family member and many don't know who they can turn to for help. This alert will help to

“ ”

This addition into many GP record systems is a huge step forward, enabling the bereaved to get to the right place, at the right time, to receive the right help and support

Tracy Cowdry, SUDEP Action Bereavement Support Services Manager



ensure that the next-of-kin will be contacted after a death, and signposted to SUDEP Action as well as other useful services who can provide support and advice.

Ardens templates are used by over 4,500 general practices across England.

Tracy Cowdry, Bereavement Support Services Manager at SUDEP Action, said: "Early help and support for people who have experienced an epilepsy related death is vital. They are often left with many questions, minimal support, as well as

having to navigate unfamiliar and sometimes confusing death investigations. Not knowing where to turn for support can be the painful reality. This addition into many GP record systems is a huge step forward, enabling the bereaved to get to the right place, at the right time, to receive the right help and support."

If you have lost someone to epilepsy or SUDEP and would like to know how we can help, please telephone our support line on 01235 772852 or email: support@sudep.org

BMJ research builds on existing knowledge

Recent research published in the British Medical Journal (BMJ) has shown an increase in epilepsy-related deaths despite the overall number of pre-Covid-19 deaths (from all causes) having decreased.

As advances in diagnosing, condition-management and emergency treatment continue to improve medical practice generally, all-cause mortality rates have decreased in the general population. However, this isn't the case for epilepsy-related deaths, which have actually increased between the 2004-2014 period covered in this latest piece of research led by a team at Kings College London.

With many epilepsy-related deaths known to be potentially preventable, this research, part-funded by SUDEP Action, highlights the importance of raising awareness of epilepsy mortality risk factors in clinical settings and with families.

With a circulation of 80,000+, publication of this research in the BMJ will ensure that the findings from this important research are raised to the attention of clinicians and policy-makers. This research adds to existing knowledge about epilepsy mortality risks and the risks highlighted in this research

Key findings of the recent BMJ Research (part funded by SUDEP Action)

- *While the number of people with epilepsy registered in the GP database decreased by 22% over an 8-year period, the number of deaths in people with epilepsy increased by 69%.*
- *The average age of death increased over time, and the data showed increased risk linked with emergency visits and/or emergency admissions, prescription of more than one anti-epileptic drug (which indicates someone has more complex, tricky to control epilepsy) and status epilepticus.*
- *For the younger group of people with epilepsy included in the research, emergency visit or emergency admissions, number of medications, and injury were linked with higher risk of death.*
- *For all age-groups, seizure freedom was linked to a lower risk of death.*

For the free SUDEP and Seizure Safety Checklist (clinical tool) go to www.sudep.org/checklist (also available as a direct download via Emis Health and SystmOne patient record systems).

are already included in SUDEP Action's SUDEP and Seizure Safety Checklist and EpSMon app to ensure clinicians and people with epilepsy have access to up-to-date risk information. These safety tools have been shown to reduce risk in a local population, and SUDEP Action is working hard to make these available as widely as possible.

SUDEP Action has been

producing free, award-winning risk-monitoring resources since 2015 which are recognised as best practice for tackling epilepsy mortality by NHS Rightcare, and the LeDeR and MBBRACE national mortality inquiries. We will continue to work with research partners to improve knowledge in this area and to push for urgent change required to prevent SUDEP and epilepsy-related deaths.

Understanding healthcare workers' pandemic concerns

As part of ongoing research into Covid-19 and epilepsy, the project team at SUDEP Action and the University of Oxford received 464 survey responses from healthcare workers worldwide, including epileptologists, neurologists, epilepsy-specialist nurses and GPs.

Because of the valuable information shared by healthcare workers, the project team were fortunate to showcase this information in *Epilepsy & Behavior Reports*, where data was published from 79 healthcare workers, based in the UK.

Key findings from healthcare workers

- 43% reported that the pandemic had impacted their mental health.
- Close to half expressed



concerns about becoming infected with Covid-19.

Remote consultations

- 39% of healthcare workers had no face-to-face consultations.
- 19% were significantly less confident diagnosing epilepsy when working remotely.
- Half specified that the pandemic had negatively impacted their ability to deliver care.

Prescribing

- Most healthcare workers did not change their approach to prescribing.
- Three reported an increase in prescribing rescue medication to reduce hospitalisation of people with epilepsy.

Most recently, clinical teams have told us that some epilepsy staff have been moved to work

on vaccines on top of rising waiting lists. SUDEP Action uses our research and stories to campaign for protection and the building back of high quality epilepsy services, supporting healthcare workers' mental and physical health.

It remains vital that healthcare workers are supported to provide services for people with epilepsy both now and in the future, so that risks can be reduced, outcomes improved and deaths prevented.

Jared's story



Jared Grayson Exley was born on 2nd September 2000. An only child, he had a very close relationship with me, his Mum.

Jared had lots of friends, loved life and always looked for the good in everyone. He was the go-to person if anyone had problems. Everyone who knew Jared adored him because he was a laid-back kind of guy with a dry sense of humour. He was hilarious without even trying to be. He loved stand-up comedy

and making people laugh. Jared did very well educationally and achieved all of his GCSEs and a BTEC Level Three in science at college. He wanted to be a radiologist and began studying for a degree in biochemistry.

Jared was 17 when he developed epilepsy, we don't know why. I first noticed the absence seizures, then the complex partial seizures and shortly afterwards he had his first tonic-clonic seizure at

college. He underwent lots of scans and tests but they showed no abnormalities. His epilepsy diagnosis was a shock to us all but, naively, we thought he would be OK with medication. Jared tried all kinds of different medications and different combinations too, but they did not work and his seizures continued. The seizures used to exhaust him and it sometimes took him days to recover. But Jared would always pick himself

continued opposite page

from page 12

up and often said he would not let epilepsy control his life. His amazing friends stuck by him and all learnt what to do if he had a seizure.

We never imagined how epilepsy would affect his life. Every aspect of his life had to be planned, including where he went and who with, and he had to stick to a strict medication regime and consider potential dangers that most people would not even think about, such as drinking alcohol, cooking, crossing roads, and moving furniture with sharp corners.

As the years passed, we

noticed that Jared's short-term memory was slowly declining, he physically suffered with every tonic-clonic seizure and his shoulder and his knee dislocated. Even then he got back up and tried to live the best life he possibly could. We knew about SUDEP but never in a million years did we think it would happen to him.

Jared was found dead in his bed on 24th August 2021 – a week before his 21st birthday. His death devastated many people and family, friends and others from the local community laid flowers under a tree in the local park where he often used to sit with his friends. We did not have a funeral for Jared, we held a

celebration of life event. Over 200 people attended. We played his favourite songs and gave out his favourite sweets and forget-me-not seeds. We made a memory tree and to end the celebration we let off 200 purple balloons. Purple was his favourite colour.

Epilepsy took Jared but we fight on. When Jared died we raised £8,600 for epilepsy research and we will continue to raise money in his memory.

Jane (Jared's mum)

● *Friends and family continue to raise money for others in Jared's memory, see page 4*

Where do they go to, the people who leave?
Are they around us, in the cool evening breeze?
Do they still hear us, and watch us each day?
I'd like you to think of them with us that way.

Where do they go to, when no longer here?
I think that they stay with us, calming our fear
Loving us always, holding our hands
Walking beside us, on grass or on sand.

Where do they go to, well it's my belief
They watch us and help us to cope with our grief
They comfort and stay with us, through each of our days
Guiding us always through life's mortal maze.

~ Anon



Share views, shape futures

The UK Epilepsy Priority Setting Partnership (PSP) is a national survey collating the views of the entire UK epilepsy community. The Partnership is seeking the input of all those working in epilepsy and all those affected by epilepsy, including families, friends, carers and those bereaved by epilepsy. This is a unique opportunity for you to have your say in driving and shaping the future of research.

To find out more, or to complete the survey, go to epilepsyresearch.org.uk/uk-epilepsy-psp-survey/

Leaving a gift for others

Gifts in Wills have been a valuable lifeline to us during the pandemic and have helped us keep our services running and conduct vital new research about the impact of COVID-19 on those living with epilepsy and those bereaved. If you would like to find out more about leaving a gift to SUDEP Action in your Will please contact the fundraising team on 01235 772850 or by email at fundraising@sudep.org

Recycle in the BIG Winter Clear-out



We are encouraging supporters to be eco-friendly this winter as part of our BIG Winter Clear-out!

Old and / or broken mobile phones, games and consoles, sat navs, laptops, tablets, cameras, watches, old or foreign currency, stamps, gold, silver or costume jewellery and used ink cartridges can be recycled to raise much needed funds for SUDEP Action.

Call us on 01235 772850, visit sudep.org/recycling-sudep-action or email fundraising@sudep.org to find out more.

Get in touch, we're here for you

You may have many questions after an epilepsy-related death. It can be very difficult to think about these things in the immediate aftermath of losing someone. Please get in touch with us, we can help you navigate these processes, including contact with the coroner, the inquest and any related investigations (such as NHS Trust investigations).

We can also help with questions about what has happened and why, about SUDEP and other deaths in epilepsy.

We provide specialist bereavement support and casework.

Contact us on 01235 772852 or email: support@sudep.org



The SUDEP Action weekly Lottery has been running for nearly a year and recently we had two cash prize winners. If you would like to take part, and be in with a chance of winning £25,000, while supporting others living with or bereaved by epilepsy, use this link to sign up online: <https://sudep.org/play-sudep-action-lottery>

Our volunteers shape our priorities

Volunteers help us in various ways, for example, by running coffee clubs, carrying out admin tasks or supporting charity days.

You can offer a little or a lot of your time, whatever you can give is greatly appreciated.

Speak to us today to find out more. Call 01235 772850 or email info@sudep.org

SUDEP Action 

Making every epilepsy death count

How to get involved

There are many ways to get involved and help us reduce epilepsy-related deaths.



SHARE YOUR STORY

Our My Story website page can be found at sudep.org/my-story. Sharing your story is a powerful way of supporting our work.

Contact info@sudep.org



FUNDRAISE

If you're thinking of fundraising for us, or would like advice, materials and information please get in touch via fundraising@sudep.org

From bake sales and dress down days to sponsored walks and bike rides, there is a fundraising event to suit you. Get in touch to find out more.



DONATE

To make a donation go to sudep.enthuse.com/donate



VOLUNTEER

Again, there are many ways to get involved with our work if you have time to give. Call us on 01235 772850 or email info@sudep.org

Contact us



BY POST

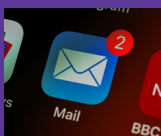
Write to SUDEP Action, 18 Newbury Street, Wantage, Oxfordshire OX12 8DA.



BY PHONE

Support line 01235 772852

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BY EMAIL

General enquiries: info@sudep.org

Support : support@sudep.org

Fundraising: fundraising@sudep.org



BY SOCIAL MEDIA

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