



Progress through policy

How we're getting our
voices heard

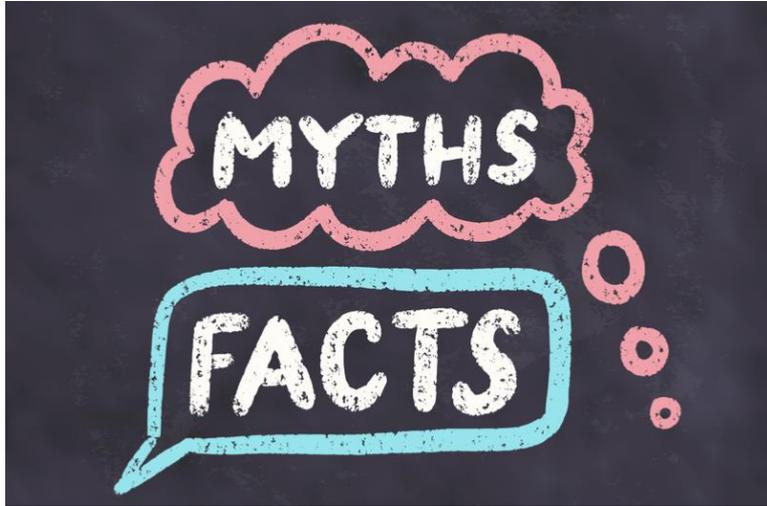
Sammy Ashby

SUDEP Action Deputy Chief Executive

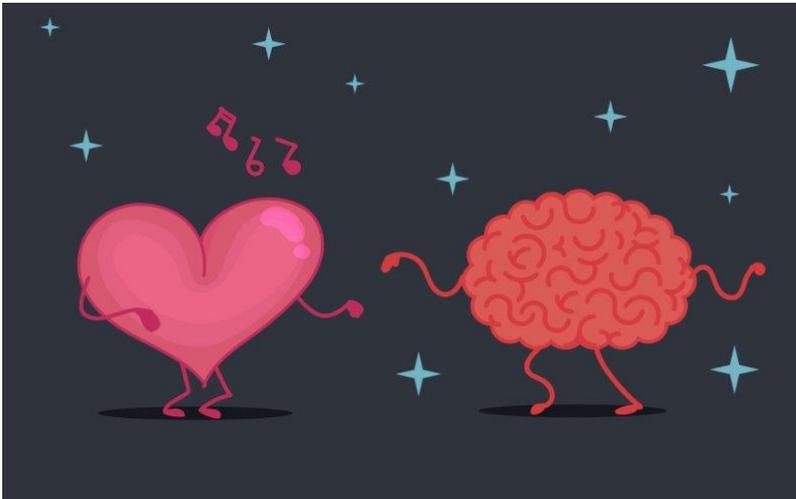




What is 'Policy'?



Debunking myths & sharing facts



Changing hearts
& minds



Empowering
others to create
change

Policy means...

Influencing National & Local policy

- MPs/Government,
- NHS England,
- Ministry of Justice
- National Guidelines
- Local health systems/teams
- Local policy makers eg: councils

Briefing papers eg:
before debates

Building relationships

Showcasing Charity at epilepsy & bereavement meetings



Identifying our key messages on 'hot topics'

Keeping an eye on latest research

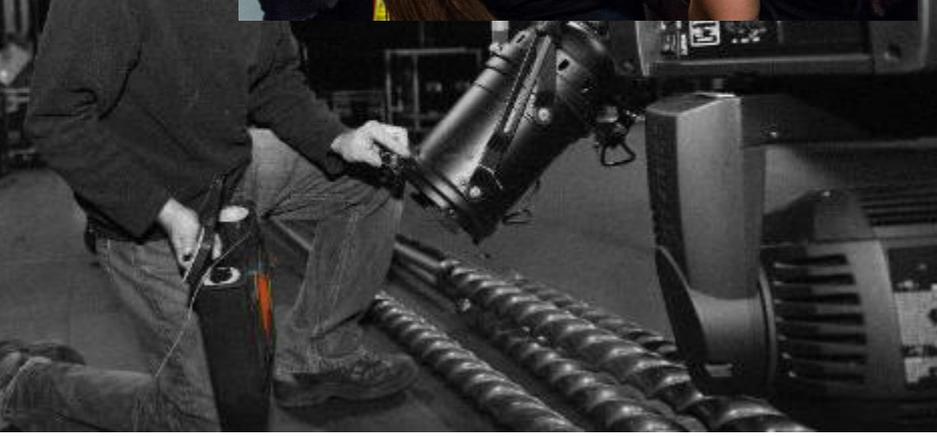
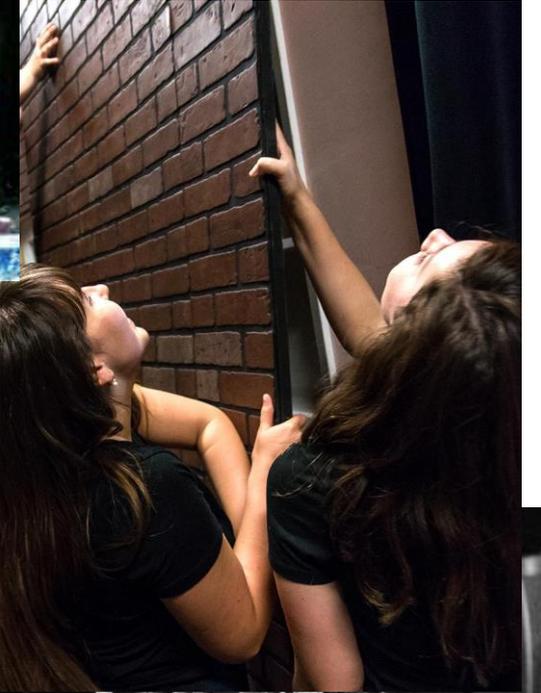
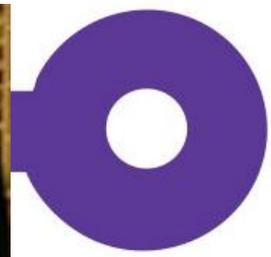
Working with other leading experts

Helping supporters to raise awareness & push for change

Analysing data

Policy work is like a theatre show....





'On Stage'

- Sodium Valproate
- Public Health England Neurology Deaths Report
- Medical Cannabis
- Serious Shortage Protocols for medicines / Brexit

'Behind the Scenes'

- All Party Parliamentary Groups for Epilepsy & Bereavement Support
- Members of the Neurological Alliance
- Stakeholders on NICE and SIGN guidelines – epilepsy & neurology
- Input into public consultations eg: on Sodium valproate, cannabis, national plans
- Campaigning/lobbying MPs
- Influencing NHS England Projects
- Helping supporters to get involved in policy work
- Building relationships to help drive forward in our work
- Sharing key messages through our Comms, media & campaigns eg: SUDEP Action Day, National Epilepsy Week





All Party Parliamentary Groups & Gov. support

Nov 2018 – Prevent21 Summit presented to attendees

Nov 2018 – APPG for Epilepsy endorsed our Prevent21 Summit report

Nov 2018 – Joined the APPG for Bereavement Support



Jan 2019-Now – Parliamentary questions asked, EDMs tabled, MP meetings held

March 2019 – Briefed cross-party MPs on the impact of Serious Shortages on people with epilepsy for a parliamentary debate

Coming soon – SUDEP Action becoming joint Secretariat for the APPG for Epilepsy group



“People respond well to those that are sure of what they want.”

Anna Wintour
Editor-in-Chief, Vogue

SUDEP Action 
SUDEP.ORG



SUDEP Action's Prevent21 Summit - Mes...

Watch later Share



0:01 / 4:00

YouTube



Ed Vaizey January 7

Like Page

Epilepsy medications will be exempt from Brexit Prescription Plans after an #epilepsy coalition led by local charity SUDEP Action intervened. SUDEP Action's letter & article http://ow.ly/VFpb30ncMDi were printed in yesterday's The Times and The Sunday Times – I am proud to support this as their President. http://ow.ly/43Fu30ncMBI



Dr Philippa Whitford @Dr_PhilippaW · May 10

Today is #OnlineEpilepsyMemorialDay when bereaved families across the world stand together to remember loved ones lost to epilepsy. I stand with @SudepAction and those who have been bereaved by epilepsy in memory of all those who have lost their lives too soon to epilepsy & SUDEP



THETIMES.CO.UK

Epileptics exempted from Brexit prescriptions plan

The government yesterday pledged to exempt 600,000 epilepsy patients



Working as part of the Neurological Alliance



Policy group – bringing organisations together to raise the profile of neurological conditions & ‘encourage’ policy makers to improve Neurology care

Chair = helping shape, inform & support the work of the Alliance

Patient experience survey – More data to help us show why action is needed NOW

National Epilepsy Guidelines

SIGN Guidelines – for Children/Young people with epilepsy

NICE Guidelines – on Suspected Neurological Conditions

NICE Guidelines – on Epilepsy (Children & Adult guidelines)



Presented on the role of Guidelines at the Prevent21 Summit





How you can best help our policy work

Can you build a good relationship with your local MP, councillors & health teams?

- Helpful during major campaigns & to support your local awareness/fundraising too

Can you share your story & experiences with us?

- One of the most important parts of our policy documents
- We never know what ‘types’ of story we may need quickly – policy work can be fast paced – being prepared is important
- Helps us make a case for change better than any statistics can
- More stories = more influence, listening & understanding



THANK YOU

*What you do matters,
but **why** you do it
matters so much more.*

@quotes2share211

