

PRESS RELEASE

EMBARGOED UNTIL 8AM, FRIDAY 14TH OCTOBER 2022

ANNOUNCING THE TOP TEN PRIORITIES FOR RESEARCH INTO EPILEPSY

The UK Epilepsy Priority Setting Partnership has today announced the Top Ten priorities for epilepsy research, following a nationwide engagement programme involving patient groups, people affected by epilepsy and healthcare professionals. The full Top Ten will be available to view here on Friday 14th October at 8am.

Inequalities in research funding have meant progress for epilepsy has been slow. In partnership with the James Lind Alliance and National Institute for Health and Care Research (NIHR), the epilepsy community came together to develop evidenced priorities to drive greater investment and guide future innovations that matter most to those impacted by the condition.

The eighteen-month-long project used the James Lind Alliance rigorous methodology to identify and prioritise unanswered questions that are most important to those affected by and working in epilepsy.

The first of two surveys asked the community what they thought were the most important research priorities for epilepsy. The responses were then grouped into overarching research questions and put through a process to check whether the issue had been previously answered by research. The unanswered questions were carried forward into a second shortlisting survey for people to rank their own Top Ten research priorities. The final Top Ten research questions for epilepsy were then reviewed, discussed and agreed at a workshop involving equal numbers of people affected by epilepsy and healthcare professionals working in epilepsy.

Of the 5,000 survey responses, by far the most prominent voice was people living with epilepsy, who made up 55% of responses.

The resulting Top Ten priorities include themes such as epilepsy-related deaths, the mechanisms underlying epilepsy, women's health and epilepsy, and drug-resistant (refractory) epilepsy. The full Top Ten can be viewed here.

Epilepsy Research UK Chief Executive Maxine Smeaton discussed the next steps for the UK Epilepsy PSP: *"Our plan now is to disseminate these priorities with everyone connected with epilepsy – the research community and all those affected by and working in epilepsy – and most importantly to work collaboratively to translate them into action. These Top Ten priorities will provide the evidence needed to influence government and institutional funders to invest more in epilepsy research."*

UK Epilepsy PSP Lead Dr Rhys Thomas said, *"The Top Ten research priorities for epilepsy will help shape the research agenda for the next generation. The outputs from this study will*

benefit people living with epilepsy by providing the evidence of need and priorities to support research development. We know that PSPs can lead to increased funding, which is so urgently needed for epilepsy, given the shocking inequalities in research funding."

The UK Epilepsy PSP Steering Committee comprised people affected by epilepsy, healthcare professionals, epilepsy researchers, JLA and charity representatives.

Abbie Fearon from the steering committee said, *"It has been a real privilege to be involved in the UK Epilepsy Priority Setting Partnership. I have three different hats on; with my charity hat, I will use this as a future example of successful collaboration and action. With my researcher hat on, I am so excited to see the research that will come from these priorities. And finally, with my 'person with epilepsy' hat on, I'm just so happy that all of this work has been done, and some really ground-breaking and life changing research will be done because of it."*

ENDS

CONTACT

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NOTES TO EDITORS

Epilepsy Research UK

Epilepsy Research UK's vision is 'A life free from epilepsy'. Our mission is to drive and enable life changing, life saving research into epilepsy. We are the only UK charity exclusively dedicated to promoting, encouraging and funding research into the causes, diagnosis and treatments of epilepsy. In addition to funding research, we also work to develop the next generation of epilepsy researchers by capacity-building the epilepsy research environment and accelerating innovations that will influence clinical practice and health policy. Our work is entirely funded from voluntary donations. You can find more information here.

Epilepsy

- Epilepsy is one of the most common serious neurological conditions in the world
- There are over 600,000 people nationwide with a diagnosis of epilepsy: that's around 1 in 100
- 32,000 people are newly diagnosed with the condition each year (88 a day)
- 65% of people do not know the cause of their epilepsy
- 35% of people are not able to control their seizures with medication
- Shockingly, there are 21 epilepsy related deaths every week in the UK

Inequalities in research funding

Despite being one of the most prevalent, serious neurological conditions epilepsy research funding is disproportionately less than other neurological conditions. In 2018 the government invested:

- £82.5 million in research into dementia (patient population 850,000)
- £34 million in research into Parkinson's disease (patient population 145,000)
- £12.8 million in research into epilepsy (patient population 600,000)

Terminology

Please do not use the term 'epileptic' (rather: a person with epilepsy) or 'fit' (rather: seizure). Please do not use the phrase 'to suffer from epilepsy' as it may cause offence: epilepsy is referred to as a condition.

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