



epilepsy.scotland.org.uk

2021

SCOTTISH PARLIAMENT MANIFESTO

6 asks for the 6th Scottish Parliament election



EPILEPSY IS MORE THAN SEIZURES

Epilepsy is the most common chronic neurological condition in the world. It is a condition which affects 1 in 97 people in Scotland, roughly 55,000 people. People with epilepsy are twice as likely to suffer from depression compared to the general population. Additionally, the mortality rate in people with epilepsy is two to five times higher than the national average.

Epilepsy Scotland is Scotland's largest epilepsy charity. We aim to ensure the voices of those with epilepsy and those who care for them are heard. We do this by promoting information across the country to dispel myths and stigma and offer bespoke epilepsy services. We also influence public policy to make sure the interests of people living with epilepsy and their carers are represented.

We are calling on all political parties standing in the 2021 Scottish Parliament Election to support epilepsy in their manifestos. As epilepsy is so common, we are asking political parties and candidates to recognise this by committing to championing epilepsy at the 2021 election.

8 people a day
are diagnosed
with epilepsy in
Scotland

6 ASKS FOR THE 6TH SCOTTISH PARLIAMENT

- ASK 1** Establish a national epilepsy database
- ASK 2** More Epilepsy Specialist Nurses
- ASK 3** Invisible condition training for benefit assessors
- ASK 4** Encourage employment in people with neurological conditions
- ASK 5** Support neurophysiology in Scotland
- ASK 6** Funded PhDs in epilepsy

Ask 1

Establish a national epilepsy database

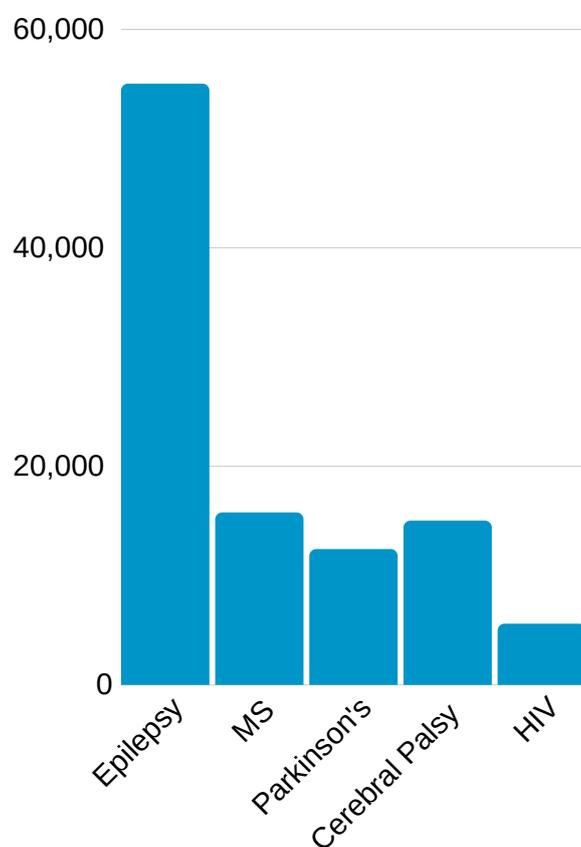
We do not know the exact number of people living with epilepsy in Scotland. This makes it very difficult to plan services on a population basis.

The Multiple Sclerosis (MS) and Diabetes registers have improved knowledge about the conditions, encouraged research and increased nursing provision.

An epilepsy database pilot is already running in NHS Greater Glasgow and Clyde which actively prompts clinicians to make timely decisions about people's epilepsy care. We would like to see this system roll out nationally.

We believe it will increase knowledge about epilepsy and improve clinical outcomes for people with the condition.

Incidence rates Scotland



More people in Scotland have epilepsy than those with a diagnosis of Parkinson's, Multiple Sclerosis, Cerebral Palsy and HIV combined

ASK 2

More Epilepsy Specialist Nurses

There are currently few incentives for students to specialise in epilepsy and so building a strong infrastructure is difficult.

Epilepsy Specialist Nurses (ESNs) are routinely overworked and underfunded – in NHS Tayside there are two adult ESNs managing an active case load of 1,500.

In Lothian, people with epilepsy receive on average 0.4 hours per year with their ESN compared to 42 hours for people with Motor Neurone Disease (MND).

ESNs offer vital medical advice and act as a bridge between a patient and their neurologist, who they may only see once a year or less.

The role of an ESN needs to be better supported with more staff and caseload burden reduced. ESNs are vital to improving clinical outcomes for people with epilepsy.

There should be at least one paediatric and one adult ESN in each mainland health board



No ESN should manage an active caseload of over 300 patients

Ask 3

Invisible condition training for benefit assessors

Under the Department for Work and Pensions (DWP), people with epilepsy are twice as likely to be denied Personal Independence Payment (PIP) compared to other health conditions.

There is a lack of understanding about invisible conditions (like epilepsy and MS) during the benefits process and how it affects people, e.g. medication side effects, fatigue, depression and risk of injury.

We think the new Social Security Scotland Agency should work with third sector organisations to equip assessors with a better understanding of invisible conditions, like epilepsy, to restore trust and reliability in the system. Better training for assessors from the outset will save money in the long run.



Epilepsy has the second highest rejection rate for PIP out of all health conditions, double the national average

ASK 4

Encourage employment in people with neurological conditions

The general disability employment rate in Scotland is 45.4% - for people with epilepsy it is only 34%. People with epilepsy in employment earn 11.8% less on average than their non-disabled colleagues.

People with epilepsy are more than twice as likely to be unemployed compared to those without the condition.

We would like the next administration to encourage employment in people with neurological conditions, through greater investment in schemes and specialist supported employment officers.



Only 34% of people with epilepsy are in employment, they earn on average 11.8% less than their non-disabled colleagues

Ask 5

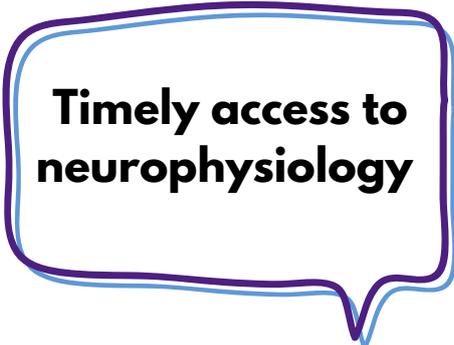
Support neurophysiology in Scotland

Neurophysiologists help measure the electrical activity in the brain to help diagnose whether seizures are epileptic or not. They carry out tests like EEGs and video telemetry (VT) which can be critical in diagnosing epilepsy.

VT is a key step for surgery, which can be curative. Long waits for VT could be delaying someone's chance to live their life free of seizures.

Neurophysiology in Scotland is at a near crisis point with a number of neurophysiologists due to retire over the next five years.

The demand for a career in neurophysiology is high, however training posts are few and far between and permanent posts are very rare. This is dissuading people from specialising in this area. Supporting neurophysiology will have wider benefits than epilepsy, it is used in the treatment and management of comas, MND, Parkinson's, some types of dementia and MS.



Timely access to neurophysiology



accurate epilepsy diagnosis

appropriate treatment started

seizure freedom in some cases

reduced A&E attendances

ASK 6

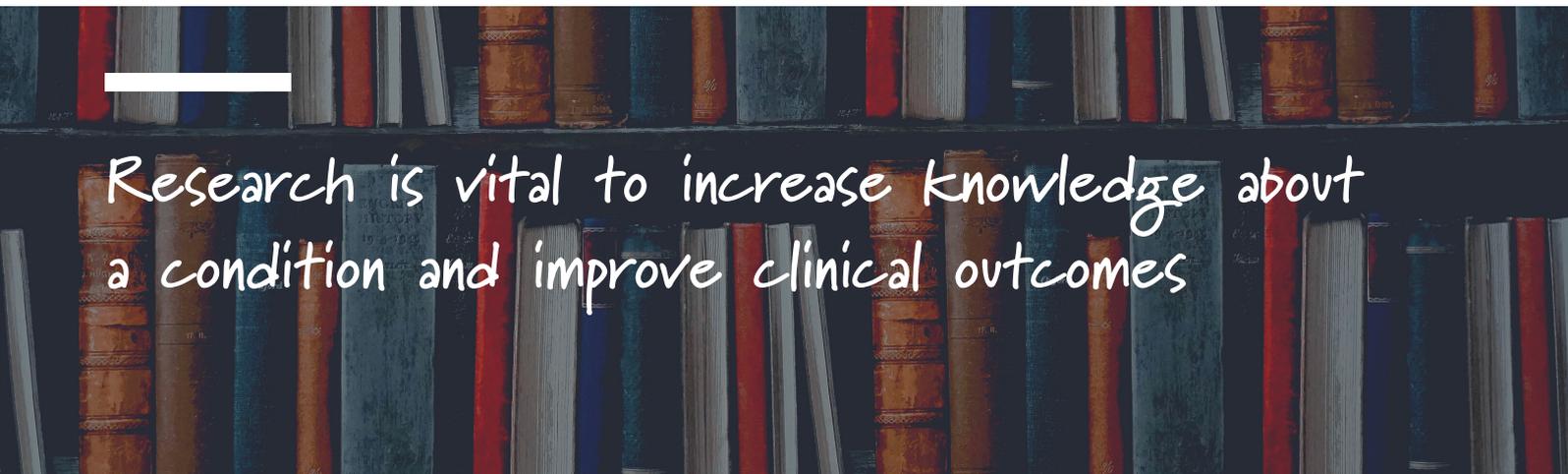
Funded PhDs in epilepsy

For many years the treatment plan for epilepsy has commonly been "two seizures, two drugs, too bad."

Epilepsy is the tendency to have recurrent seizures. If an individual fails to respond to the first two drugs, they are often diagnosed as refractory (drug resistant) and have to live with seizures for the rest of their life.

Research is a key component to broaden knowledge about a condition and encourage new treatment pathways.

Investment in research for other neurological conditions, like MS and MND, has improved knowledge, catalysed interest in the condition and resulted in new drug trials.



Research is vital to increase knowledge about a condition and improve clinical outcomes



#Epilepsy2021

HOW CAN YOU HELP?

Email this manifesto to the political party you support. Ask them to champion epilepsy in their 2021 manifesto.

Email your current MSP a copy of this manifesto asking them to support our asks. The list of current MSPs and their contact details can be found on the Scottish Parliament's website.

Once candidates for the election are decided, contact them and ask them to support our manifesto. This can be done face to face, while they are out campaigning, or you can email a copy of this manifesto over to them.

Vote for the candidate or party who best represents you and is committed to championing epilepsy, if elected.

Political engagement is vital to have your voice heard and encourage change for the better.

If you need help to contact your MSP please do not hesitate to get in touch with Epilepsy Scotland - we are happy to help!



get in touch

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