

## How you can help

Each constituency in the UK will have between 500 and 1,000 people living with epilepsy. The JEC encourages you to sign up for regular information so that you can be well informed when asked for help by a constituent.

All you need to do is complete the form (overleaf)

## 5 Epilepsy - making it happen

The table below is an estimate of the funding needed. Historic under-funding means it may take years for this to become a reality, but to implement a quality service for people with epilepsy across the UK financial investment is needed now to bring real progress on the ground.

	Existing resource	Need	Cost per annum
Access to a GP with basic training on epilepsy	Poor knowledge base	One course per year in each PCT/Health Board	£700,000
A seamless patient journey between GP and hospital	Epilepsy Managed Clinical Networks in Scotland and some informal networks in England	An epilepsy 'tsar' in each region	£750,000
Access to an epilepsy specialist nurse	150	600	£12,600,000
Access to a specialist paediatric neurologist with an interest in epilepsy	70 paediatric neurologists	150	£8,000,000
Access to a consultant neurologist	352	1,400	£104,800,000
Access to a clinical neurophysiologist	75	248	£4,325,000
<b>Total</b>			<b>£131,175,000</b>

Footnote: recommended numbers of neurologists, paediatric neurologists and neurophysiologists are taken from the Association of British Neurologists, British Paediatric Neurologists Association and Association of British Clinical Neurophysiologists.

The greatest source of investment identified is to fund a far greater number of neurologists and specialist nurses. The benefit would not be restricted to people with epilepsy, but also to people with Parkinson's disease, multiple sclerosis, cerebral palsy and every other neurological condition.

## 6 JEC - who we are

The Joint Epilepsy Council of the UK and Ireland represents 23 epilepsy organisations operating in England, Wales, Scotland, Northern Ireland and the Republic of Ireland. We present evidence-based views on the need to improve services for people with epilepsy, their families and carers in the UK and Ireland.

Our key aims include:

- 1 To promote improved standards of and access to integrated services in health, education and social care for people with epilepsy and their carers.
- 2 To increase epilepsy awareness amongst politicians, civil servants, service providers and the general public.



The Joint Epilepsy Council

# epilepsy

## The case for investment

Making the choice agenda relevant to people with epilepsy

## 1 Epilepsy - the problem

**Epilepsy is a neurological condition which presents in as many as 50 different types. It is diagnosed when someone has recurrent seizures (also known to many people as fits, grand mal, petit mal, absences). It is caused by excess electrical activity in the brain.**

Over 456,000 people have epilepsy in the UK. It is the most common serious neurological condition and is a major long-term disability with similar numbers of people affected as insulin dependent diabetes.

- Two out of five people experiencing seizures could be seizure free, but are not.
- 50% of children with epilepsy under perform at school.

Many of the world's leading epilepsy specialists work in the UK, but:

- Very few GPs understand epilepsy sufficiently.
- There are too few consultant neurologists specialising in epilepsy in both adult and paediatric care.
- For far too many people it takes far too long to have an EEG or MRI examination. EEG and MRI are scanning techniques used to diagnose and treat epilepsy accurately.

## 3 JEC response

Reports and plans are one thing but the real challenge is whether improved awareness will translate into the chance for people with epilepsy to reduce their seizures, improve their quality of life and live longer.

Annual reviews of patients and community clinics have been common for asthma and diabetes for many years. But epilepsy has suffered historical neglect and lack of investment. (Ref: Chief Medical Officer for England Annual Report 2001)

**To contact the JEC call Sharon Harvey on 01943 871852 or email her at: [sharon.jec@btconnect.com](mailto:sharon.jec@btconnect.com)** JEC is a registered charity (number 1104315).

## 2 Response from Governments

**JEC welcomes significant initiatives that have raised the profile of epilepsy. These include:**

- A UK-wide National Audit on Epilepsy Deaths 2002 finding that up to 400 of 1,000 epilepsy deaths each year are avoidable.
- Epilepsy is in the GP contract.
- National epilepsy guidelines in England, Wales and Scotland.
- Epilepsy managed clinical networks in Scotland, and the new National Service Framework for Long-Term Conditions.

To begin to catch up, epilepsy needs its own fair share of the public investment in health services. Only then will people with epilepsy feel that they have any kind of real choice.

Despite increased funding in the health service, there is growing evidence that, locally, health officials do not feel that they have sufficient money to turn these aspirations into reality. This is deeply worrying.

## Spending funds wisely by cutting waste

**Right now over 80,000 people with epilepsy are having seizures that could be prevented if they received the same level of care as people attending the best epilepsy treatment centres.**

**As well as improving quality of life and saving lives, investment in epilepsy would begin to deliver major savings in public expenditure.**

Footnote: 58,900 people with epilepsy are claiming disability living allowance. This costs £184 million per year (Source: Information and Analysis Directorate, Great Britain estimated expenditure on Disability Living Allowance in each financial year and disability type). The National Institute of Clinical Excellence states that epilepsy misdiagnosis rates in the UK are between 20 to 31%. Based on this evidence the annual cost is estimated to be £160 million.

### Potential Savings

- Reduced disability living allowance  
estimated saving of **£66 million per annum**
- Reducing the costs of misdiagnosis  
estimated saving of **£160 million per annum**
- Reduced medical-legal costs from complaints and claims

Please detach this form and send to  
**Sharon Harvey**  
**General Secretary**  
**JEC**  
**PO Box 186**  
**Leeds LS20 8WY**

**Please complete this form**

Name \_\_\_\_\_

Constituency \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Telephone number \_\_\_\_\_

Email address \_\_\_\_\_

I would like to receive regular epilepsy updates from the JEC

I would like to be told about All Party Epilepsy Group meetings (please tick boxes)

telephone: 01943 871852  
email: [sharon.jec@btconnect.com](mailto:sharon.jec@btconnect.com)

## 4 Epilepsy - the way forward

**The JEC believes this treatment gap would be filled if the following initiatives were implemented. All of these ideas have been identified in approved government policy. However JEC awaits progress in their implementation.**

- ✓ Each Primary Care Trust or Health/ NHS Board should include epilepsy in its local plans. At a minimum, regular epilepsy training for its GPs and an epilepsy register should be mandatory.
- ✓ Accurate diagnosis and rapid referral to specialist consultants is essential. Patients with a possible new diagnosis of epilepsy should be seen by a specialist with training and expertise in epilepsy within two weeks of referral.
- ✓ A new patient should have an EEG examination within four weeks of referral, and an MRI scan, if required, within four weeks of referral.
- ✓ Each person with epilepsy should receive a structured annual review of their condition and have prompt access to a specialist if their epilepsy is not well controlled.
- ✓ Patients should be well informed on important issues such as drug interaction and side-effects, issues for women of child bearing age, the risk of seizures and fatality.
- ✓ An immediate commitment to increase significantly the number of epilepsy specialist nurses.