

epilepsy scotland
Scotland's voice for epilepsy



IBE Epilepsy and Society
Conference Malta 2004

Parliamentary activity brings change

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Epilepsy - what changes do we want?

- Good healthcare for 30,000 Scots
- Information and support
- Public understanding

Epilepsy - how can politicians help?

- They influence and change health policy
- They have resources to spend
- They can be champions/opinion leaders

What makes Members of the Scottish Parliament (**MSPs**) care about epilepsy?

- It affects 1 in 200 constituents/voters
- Local epilepsy services may be poor
- Tragedy: misdiagnosis/epilepsy deaths
- **Their support can bring about change**

What can the Scottish Parliament change?

- Responsible: health, education, justice
- Decides on funding, resources, policy
- Hears public petitions to change laws
- Committees take evidence/draft Bills
- MSPs pass laws - Acts of Parliament

How have we contacted 129 MSPs?

- Identified MSPs interested in health
- Sent a briefing paper to **every** MSP
- Our members visited MSP 'surgeries'
- Held information Receptions/Dinners
- Exhibition/events at Party conferences

Does the Scottish Parliament help?

- MSPs^50 **Parliamentary Questions**
- Epilepsy rally/awareness events
- Held 2 Members Debates on epilepsy
- Petition evidence to Health Committee
- Cross-Party Group on Epilepsy formed

Why have a Cross-Party Group?

- To address the needs of ^ 30,000 people with epilepsy on Scotland
- Bring together all those interested in epilepsy issues – MSPs/groups/public
- Provide MSPs **of all parties** with information/access to expert opinion

What parliamentary activity is there?

- Epilepsy Scotland provides Secretariat acting for Joint Epilepsy Council (JEC)
- MSPs meet 4 times a year, hold AGM
- 4 office bearers agree speakers/topics
- MSPs put in PQs, Members Debates, Bills – these get Ministers attention!

Benefits: MSP Mary Scanlon, Inverness

- Constituent said no epilepsy support
- We briefed MSP: gaps in local services
- Public meeting: epilepsy group started
- Health plan: adds epilepsy, ESN post
- Support group on TV, local info displays
- MSP: office bearer for Epilepsy Group

What has Epilepsy Group achieved?

- Research: poor health service provision
- Briefing on epilepsy training in schools
- Raised MSPs epilepsy awareness
- Pushed Government: epilepsy a priority
- Deputy Health Minister at Group – GPs sent Fatal Accident Inquiry findings

Benefits: Findlay Fatal Accident Inquiry

- Deputy Health Minister came to Group
- Questions: lessons from Findlay Inquiry
- Doctors/GPs not sent Inquiry findings
- Epilepsy patients need a care plan
- GPs plan to audit and review services
- Epilepsy trained nurses to run clinics

Where are we now?

- Epilepsy: now largest Cross-Party Group
- 24 MSPs: 20% are members despite Party advice to join only 1-2 Groups
- Scottish Parliament Information Centre produced MSPs epilepsy briefing paper
- Group meetings on Scottish Parliament web site: www.scottish.parliament.uk

What's next for Cross-Party Group?

- Education awareness training for schools
- Launching teachers guidelines on epilepsy
- Comments Education Bill to help pupils with additional learning support needs
- A national public information campaign
- Epilepsy display in Scottish Parliament

Key to parliamentary activity

- Timing - target MSPs at/after elections
- MSPs support - gives cause credibility
- Opportunity - use all parliamentary tools
- Political will – fit epilepsy to top priorities
- Partnerships – JEC/Westminster/Europe
- Commitment - be epilepsy champion 24/7

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- What can happen if you ask the politicians in your country to act for epilepsy?
- Our First Minister Jack McConnell can tell you – he supports epilepsy!