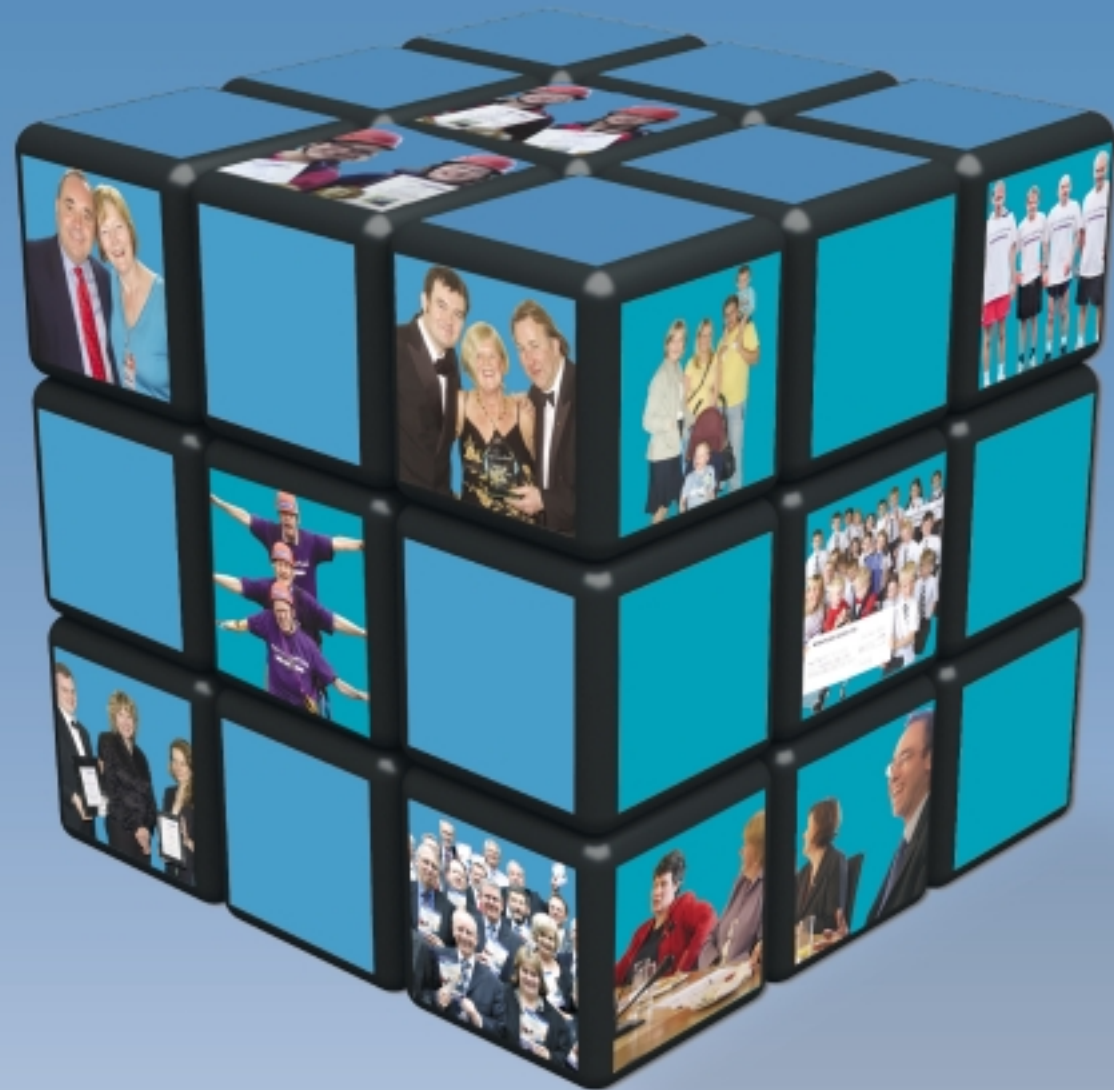


epilepsy scotland

Scotland's voice for epilepsy

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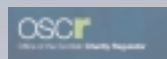


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RNID typetalk



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Side by side

annual review 2006-2007

Who are we and what do we do?

Who we are

We work with people who are affected by epilepsy. We campaign for improved healthcare. We want information that is easy to access. Our aim is to end stigma and discrimination. We are the voice of epilepsy in Scotland and have been since we started in 1954.

Why we exist

One person in 130 has recurring seizures. Local services vary for people with epilepsy. Sadly, health and other public services are not yet meeting their needs. We have a postcode lottery of care across the country. We want to make sure services are available no matter where you live. Our job is to campaign for this. We can provide you with support and information. We want to help with cases of stigma and discrimination. By doing all this we enable carers, families and people living with epilepsy to make the most of their lives.

What we do

We offer a number of different services. There is an accessible website and a freephone Helpline. We send out literature. We give training and we hold information evenings. There is the chance to get involved and people can volunteer to work with us. We have local groups and community based support. We listen to what people with epilepsy need. We also campaign and lobby. We are here to help the 40,000 Scots who have epilepsy.

Where we work

We are based in Glasgow but we work all over Scotland. We help to support a network of local groups from Ayr to Banff and Buchan in the far north. We work with NHS boards and health professionals across the country. Our partners include the Scottish Government and Members of the Scottish Parliament. We join with organisations like the Long Term Conditions Alliance Scotland. We work beside the Joint Epilepsy Council of the UK and Ireland. All of us want to bring epilepsy out of the shadows.

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Our message...

Susan Douglas-Scott, Chief Executive

Partnership working has been this year's theme. We are delighted the Scottish Government gave us funds to produce more information for people with epilepsy. We value our links with all three Managed Clinical Networks for epilepsy. Our combined work helps to improve local services. We campaigned hard for free prescriptions with the Long Term Conditions Alliance Scotland. The government has now agreed with us and millions of people with long term conditions will benefit. Your support is valued. We are proud that we have fostered volunteers. Also, we developed user involvement activities and these are most important.

We found new ways to provide information. The Royal College of Physicians and Surgeons of Edinburgh asked us to prepare on-line information for GPs. We have published a new suite of leaflets in an accessible format. Our website is easy to access and meets set standards. We have expanded our training courses for carers and others who help people with epilepsy.

The theme of National Epilepsy Week was employment. For this we published a new employer's guide to epilepsy. The Scottish Parliament was one of 22 employers we gave a best practice certificate to.

I'd like to praise our Community Support Service (CSS) for their high standard of work. The team has achieved excellent inspection reports from the Care Commission. We are pleased CSS has relocated to our Govan Road office. Next year will be busy. This year we plan to highlight Sudden and Unexpected Death in Epilepsy (SUDEP). We also aim to develop our self management work for people living with epilepsy.

Ian Buchanan, Chairperson

In my two years as Chairperson I have seen the organisation grow. One of many successes is the Epilepsy Cross Party Group which has been the largest in the Scottish Parliament. We continue working closely with the Joint Epilepsy Council of the UK and Ireland to raise awareness among politicians. I am proud that our manifesto which was based on the views of our members met with a positive response from MSPs and election candidates.

It is clear just how much people are getting involved in the running of our services. This year's annual review theme is 'side by side'. We show the different ways epilepsy can affect people and how we help, including our important user involvement work.

Nearly two hundred people have been to our monthly information evenings. This, and our work in supporting more volunteers, has brought two-way benefits. Not only are we getting information out to where it's needed but we are also listening to what people are saying.

I would like to thank our members, supporters, funders and sponsors. Special thanks go to the Big Lottery Fund for helping us to expand our training and Helpline suites. And to part fund our Web Information Officer post.

This coming year, I am most looking forward to our membership drive. We want to raise awareness in new and exciting ways. We also want to give more opportunities for people to feedback through online forums and blogs on the website. Our aim is also to develop a new project that gives information and support for young people with epilepsy and their parents.

Ian Buchanan
Chairperson

Susan Douglas-Scott
Chief Executive



Epilepsy affects people in different ways...

In the past 12 months Epilepsy Scotland has:

- Supported three Managed Clinical Networks (MCNs) for Epilepsy: North of Scotland; West of Scotland, Ayrshire and Arran, Tayside; and the national paediatric network. Each MCN improves services for people with epilepsy
- Held a telemedicine lecture to raise awareness of this service in Scotland
- Ran our biennial conference, "Kerr in the Community: Delivering for Epilepsy?" for over 100 professionals
- Held training courses for GPs and practice nurses
- Supported 50 people with epilepsy and community care needs through our Community Support Service
- Trained over 1,300 people in epilepsy awareness
- Delivered epilepsy talks to 150 school pupils and emailed over 600 schools
- Sent MSPs and election candidates our manifesto with seven key health aims.

Recently diagnosed

Gail Cuthbertson felt her whole world had turned upside down when she had her first witnessed seizure in 2005. She and her husband Michael had a long stressful journey through the health service. They were looking for a diagnosis, support and advice.

Gail finally saw a consultant neurologist. It was only their persistence and support from Epilepsy Scotland's Helpline and the North of Scotland MCN which made it happen. With this help Gail has her epilepsy under control.

She thought her experience was a one off. Since she started an epilepsy support group Gail has met many people and they have had a similar experience. One of the support group's aims is to campaign for improved services for people with epilepsy. She said: "I found Epilepsy Scotland's website invaluable. It helped me when I was looking for answers to my many questions."

Michael and Gail Cuthbertson



"Epilepsy Scotland pushes for change to make services better for everyone. By working together we support people to live their lives."

Consultant paediatric neurologist Sameer Zuberi, Fraser of Allander Neurosciences Unit, Glasgow

Misdiagnosed

Bernard McDevitt was five when he had a seizure. He took epilepsy medication and by the time he was seven his seizures stopped. Aged only 10, he went to live in a special hospital for people with epilepsy until he was 34. Discharged into the community, his seizures started again when he was 39.

"I asked my doctor how my epilepsy had come back and he told me it can happen at anytime. I was put on strong tablets. Two years later I went into hospital for tests. That's when the consultant told me I'd had panic attacks not epilepsy. I was on tablets I did not need. It took me months to cut down gradually."

Bernard uses our Community Support Service (CSS). He's had help to go to college and support to become a charity shop volunteer.



Bernard McDevitt

"You couldn't fault anyone who works here, they are all excellent. All the staff are very kind and they know about epilepsy."

Service User, CSS Annual Review 2006

We are here to help...

Controlled epilepsy

Alasdair Allan MSP admits he has been fairly lucky compared to a lot of people who have epilepsy. Since he was 17 he's only had three or four big seizures a year. He took a languages degree and had various full time jobs before his election to the Scottish Parliament.

"Epilepsy stopped me driving. Between seizures there was nothing wrong with me. I haven't had any for two years and I passed my driving test in December. Believe me it's hard to get around the Western Isles without a car!

"People are confused about what epilepsy is. During one job interview I blacked out and keeled over. My boss thought I'd just died until he found the epilepsy card I carry with me. We could do something about more information for the public."

Alasdair Allan MSP
(Photo courtesy of Alan Millan)



"The most successful thing the Cross-Party Group on Epilepsy has done is to raise awareness of the issue in the Parliament. We have helped to de-stigmatise this condition and that is tremendous."

Health and Sport Committee Convener, Christine Grahame MSP

Uncontrolled epilepsy

Max Reid, aged four, is a twin who laughs a lot. He also takes dozens of seizures daily. His mum Nicola and specialists are trying to find the right combination of drugs to help him lead a full life.

Learning support teacher Nicola commented: "I didn't really know anything about epilepsy when Max had his first seizure. He was just 12 weeks old. Doctors later diagnosed cerebral palsy too. If the seizures aren't controlled, Max could have developmental delays. He's a wonderful boy and people just need to not be afraid of epilepsy."

Nicola believes education is key to wiping out the stigma of epilepsy. She's talked with school pupils, she campaigns for local epilepsy services and she fundraises for us.



Nicola and Max Reid
(Photo courtesy of News of the World)

"Epilepsy Scotland's training is first class. I'm now aware of what to look for if someone has a seizure. I know I'm confident to go ahead and deal with it."

Hansel Alliance carer Siobhan Devlin

In the past 12 months Epilepsy Scotland has:

- Re-launched the Cross Party Group (CPG) on Epilepsy with 19 MSPs
- Provided the CPG secretariat through the Joint Epilepsy Council (JEC) of the UK and Ireland
- Held a JEC/Scottish Parliament event "What would happen if an MSP had a seizure in the debating chamber?"
- Hosted a National Epilepsy Week exhibition and photo call for 40 MSPs
- Pushed 64 Parliamentary Questions
- Taken 1,500 free-phone Helpline calls
- Made our Helpline more accessible with a language line (translation) service and a type talk service for callers with a hearing impairment
- Held monthly information evenings across Scotland
- Helped form an Ayrshire support group
- Started a young people's group
- Supported 7 volunteers to help our training, website, fundraising, PR and Helpline.

Knowing about epilepsy makes a difference...

In the past 12 months Epilepsy Scotland has:

- Raised awareness of epilepsy through our 8th Journalist of the Year Award
- Issued 22 employers with certificates for best practice including Fife Police and the Scottish Parliament
- Printed an employer's guide to epilepsy
- Made our website easier to access
- Had 185,000 web hits
- Produced accessible, plain English leaflets to view online and to print off
- Promoted Sudden and Unexpected Death in Epilepsy (SUDEP) by placing stories in the national media
- Held a SUDEP conference workshop
- Prepared a position statement with Epilepsy Bereaved on the rights of people with epilepsy to be told about SUDEP.

In remission

Kevin Keogh's always had epilepsy. His seizures varied a lot, from one a week to 10 a day. He would wake up confused and disorientated, lose awareness for maybe 15 minutes or sit rubbing his legs, rocking and moaning.

"I still do a bit of moaning right enough! A few years ago I went for tests and decided not to go for brain surgery. But my wife Elaine saw my seizures were getting worse. I felt really low and the prospect of not having this depression made me decide to have surgery. I've a new life without seizures.

"I teach building construction. I can't drive but my college has been flexible and put on taxis to get me to various locations. Another tutor trains students to use scaffolding and dangerous machines. I really value this support."



Kevin Keogh

"How we treat the stigmatized and vulnerable in society is not only a significant matter of public interest, but also a consideration for how we do our jobs in Scottish journalism. Those with epilepsy have important stories to tell."

Tristan Stewart-Robertson, Epilepsy Scotland's Journalist of the Year

A sudden and unexpected death

Graeme and Janet Casey's teenage daughter Erin died in a seizure in her sleep during her first year at university. The death certificate told them SUDEP (Sudden and Unexpected Death in Epilepsy) was the cause. The family had never heard of it.

Mum Janet said: "Erin saw a consultant after her first seizure. He was very positive and told us not to worry. He did not mention seizures could be fatal or stress the importance of taking medication regularly. Information about SUDEP was withheld."

The Casey's are calling for a public inquiry because they want answers. "What happened to Erin needs to be highlighted. No family should be kept in the dark."

Janet and her daughter Shauna



"Sudden and Unexpected Death in Epilepsy (SUDEP) is considered essential information to give patients and carers."

National SIGN (70) guidelines for Diagnosis and Management of Epilepsy in Adults

You can support our work...

Our small fundraising team has to raise almost £500,000 every year. This sum keeps our vital services running. It helps the 40,000 people in Scotland who are affected by epilepsy.

We think of a variety of ways for people to support us:

- Each spring we hold corporate dinners in Edinburgh and Glasgow
- In the autumn we have an Art Sale and auction
- Applications to support our work are made to Charitable Trusts each month
- Energetic individuals are asked to take part in challenge events
- People run marathons, zipslide and abseil for us in a variety of places
- Our inventive supporters create local events and these involve anything from race nights to head shaving
- We recruit new donors and we support existing donors. Many people give by direct debit, payroll donations and fill their home money boxes with small change
- People who wish to remember a loved one send in memorium donations
- Generous adults and children have their friends donate money to us instead of buying presents for special birthdays, anniversaries or other celebrations.

This money is used to support our freephone Helpline. It helps us produce leaflets and information in various formats. It lowers the costs of training courses. It helps us to campaign for better epilepsy services.

Epilepsy is not an easy cause to raise money for and every single penny counts. All monies raised for this cause stay and are used in Scotland. **Thank you for your support.**



Epilepsy Scotland fundraising team

Lianne Woods wants to join our young people's group as it's often hard to meet others of the same age who have epilepsy. Her dad Allan has already raised £4,800 for Epilepsy Scotland by walking the West Highland Way. As a local businessman, Allan supports our work because he knows the impact that epilepsy has on many families.

"We had a really hard time when Lianne was in her teens," he said. "She wanted to be like every other teenager and burn the candle at both ends. We were worried about her taking her medication. Fortunately for us she didn't have major problems and she's been keeping well. We want her to have the opportunities in her life we take for granted. That's why I do what I can to help."



Allan and Lianne Woods

And you do...

Donors and supporters

We want to thank all the individuals, organisations and Trusts who donated funds this year. Here is a selection.

Abbey	Suzanna Harkness	Margaret Noble
Sylvia Aitken Trust	Helen Street Social Club	Northwood Charitable Trust
Albyn School	Henry Smith Charity	PF Charitable Trust
Mary Andrew Trust	Hospital Saturday Fund	A M Pilkington's Trust
Cameron Arnott	Miss Agnes H Hunter's Trust	Irene Pullar
Barr Charitable Trust	James Inglis Trust	Eileen Rae
Big Lottery Fund	The Johnston Family	RAOB Aberdeen
The Binks Trust	JTH Charitable Trust	Red Triangle Snooker Club
Claremont High School	St Katharine's Fund	Nicola Reid
Clyde Marine PLC Trust	Kingfisher Bar	The Robertson Trust
Martin Connell Trust	Geraldine Kirkpatrick Trust	Cecil Rosen Foundation
Cruden Foundation	The Kola's Trust	The Russell Trust
Cumberland Building Society	Lloyds TSB Foundation for Scotland	Walter Scott & Partners
Darroch Charitable Trust	Lochwinnoch Golf Club	Sharegift
Colin Devine	Jane Logan	Paul Sorrie
Ken Dunn	Lorraine MacFarlane	The Souter Charitable Trust
East Fife Male Voice Choir	Maclay, Murray & Spens	Strathaven Academy
East Kilbride Golf Club	Rona MacRitchie	Strathclyde Benevolent Police Fund
Edinburgh Masonic Club	Maersk Oil	Joan Strutt Charitable Trust
Escape Health Club	W M Mann Foundation	Talteg
Myles Fitt & Citigate PR	John McGraddie Butchers	Tay Charitable Trust
Fitton Trust	Janet McQueen	Sir Jules Thorn Charitable Trust
Alice Di Folco	MEB Charitable Trust	Titwood Ladies Bowling Club
Forfar Academy	John Menzies plc	Murray Tyrrell
Alastair Fowler	Miller Foundation	Weatherall Foundation
Hugh Fraser Foundation	Gordon Moffat	James Weir Foundation
The Gannochy Trust	Morrison Foundation	Andrew Whitelaw
Janis Ridley Gemmell	Morton Charitable Trust	Mary Wilson
William Grant & Sons	Margaret Murdoch's Trust	James Wood Bequest Fund
Ann Jane Green Trust	Netherton Primary School	Moira Young
Shirley Gregory	Bill & Margaret Nicol Trust	
Sir Maxwell Harper Gow's Trust	NLR Financial Solutions	
Haggs Castle Golf Club		

Where the money goes...

- The year from 1 April 2006 to 31 March 2007 ended with a deficit of £43,524
- Legacy income was lower than our forecast for the year
- Our Scotland-wide constitution can limit our appeals to UK funding bodies
- We followed good practice and did risk management
- The Big Lottery Fund helped to part fund our Web Information Officer post and to refurbish our Helpline and training suites.

Statement of financial activities for the year ended 31 March 2007

Income	2007 £	2006 £
Donations, legacies, events	410,613	606,000
Grants, training, literature	528,761	429,449
Membership and other income	31,538	31,865
Total	970,912	1,067,314
Expenditure	2007 £	2006 £
Activities to further our work	793,649	831,321
Costs against generating income	196,781	195,608
Governance costs	25,325	23,761
Gain on investments	(1,319)	(4,573)
Total	1,014,436	1,046,117
Funds	2007	2006
Restricted funds	341,526	12,542
Unrestricted funds	629,386	872,104
Capital endowment	-	99,412
Total	970,912	984,058

Statement by the Treasurer

In my opinion the financial statements give a true and fair view, in accordance with United Kingdom Generally Accepted Accounting Practice, of the state of the company's affairs as at 31 March 2007 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended; the financial statements have been properly prepared in accordance with the Companies Act 1985; and the information provided in the Report of the Directors is consistent with the financial statements.

Nellie Buchanan, Treasurer, Director

Statement by the Independent Auditors

In our opinion the summarised accounts on page 9 are consistent with the full annual accounts of the charity for the year ended 31 March 2007.

Hardie Caldwell, Chartered Accountants and Registered Auditors



Working side by side...

Travelling with epilepsy

Many people called our Helpline worried about the Scotland-wide free bus pass scheme. They reported how difficult and complicated the new system is.

Epilepsy Scotland has:

- Listed the many steps disabled people need to go through to apply for a pass
- Put this information on our website
- Partnered with the Joint Epilepsy Council of the UK and Ireland to raise this issue with Transport Scotland
- Met Transport Scotland who administer the scheme, asking them to review it

Transport Scotland have agreed to simplify the application process

Free prescriptions

People with epilepsy qualify for free prescriptions. Last year the Scottish Executive decided to review who was entitled to free medications.

Epilepsy Scotland has:

- Campaigned with the Long Term Conditions Alliance Scotland for free prescriptions for everyone with a long term condition
- Put our evidence before health minister Shona Robison

In June 2007 the Scottish Government confirmed that people with long term conditions will not pay prescription charges

Our Helpline:
0808 800 2200
www.epilepsy
scotland.org.uk

From caller to volunteer

A few years ago **Marilyn Bryce** needed advice. She wanted to talk to someone and called our Helpline. She found the information very useful. She always remembered the difference it made to her life: "More than anything I wanted to talk to an understanding person about what was happening."

After retraining as a medical secretary and with a law degree behind her, Marilyn saw the 'Epilepsy News' magazine appeal for office volunteers. She was in between jobs. She looked at our website then called our User Involvement Officer and offered to become a Helpline volunteer.

She's had epilepsy awareness training, she's written information for our website and she's taken Helpline calls. Marilyn has used her voluntary work to brush up her employment skills.

Marilyn Bryce

Marilyn found a new job but still gives some free time to the Helpline



Fighting stigma

The advert for the London 2012 Olympics logo caused some people with photosensitive epilepsy to have a seizure. The advert was on the television and in the press.

One caller contacted our Helpline to complain about a 'Talksport Radio' jingle. It said their station's logo would 'not trigger epileptic fits'.

Epilepsy Scotland has:

- Contacted the local broadcasting station and explained how their joking advert could be offensive to people with epilepsy

Talksport Radio apologised for their actions. They also stopped playing the jingle

Several members and local groups criticised a cartoon in the 'Edinburgh Evening News'. It showed an MSP foaming at the mouth. He was having a seizure after seeing a logo

- We contacted the cartoonist because people were upset he made fun of seizures

He sincerely apologised. He did not mean to be hurtful to people who have epilepsy

Together we're stronger...

Board member **Alison Guest** took various seizures in primary 7. "I coped well in secondary school because everyone was very understanding. I was lucky in that respect but medication never worked for me. My epilepsy was better controlled then than now. I wish I could drive; I spend three hours a day travelling to work as the buses take so long.

"I know about stigma. A friend I shared a flat with later gave up the tenancy and we went our separate ways. I later discovered she couldn't cope with the epilepsy. I wanted to be involved in raising awareness so I joined the board.

"The Employer of the Year Award has been very good as it enlightens people about epilepsy in the workplace.

I didn't get to put my own employer forward for an epilepsy best practice certificate – someone else already did!"

Alison Guest



Our board

Jean Barclay	Brian Henson
Ross Bennet	Andy Ormes
Ian Buchanan, Chairperson	Chris Ritchie
Nellie Buchanan, Treasurer	Tom Russell, Vice Chairperson
Helen Carmichael, Vice Chairperson	Bill Scott
David Davidson	Arthur Wood
Alison Guest	Sandra Watt

Our services

- A confidential Helpline: **0808 800 2200** with a translation line for different languages and a type talk service for people with hearing impairments
- Interactive, accessible website: **www.epilepsyscotland.org.uk**
- Epilepsy information and fact sheets
- User involvement, information evenings and consultations
- Seminars, forums, conferences and training courses
- Newsletters and policy briefings
- One-to-one community support service
- Network of support groups
- Public awareness campaigns
- Supporting the Scottish Parliament's Cross-Party Group on Epilepsy
- Working with NHS Boards and medical professionals.